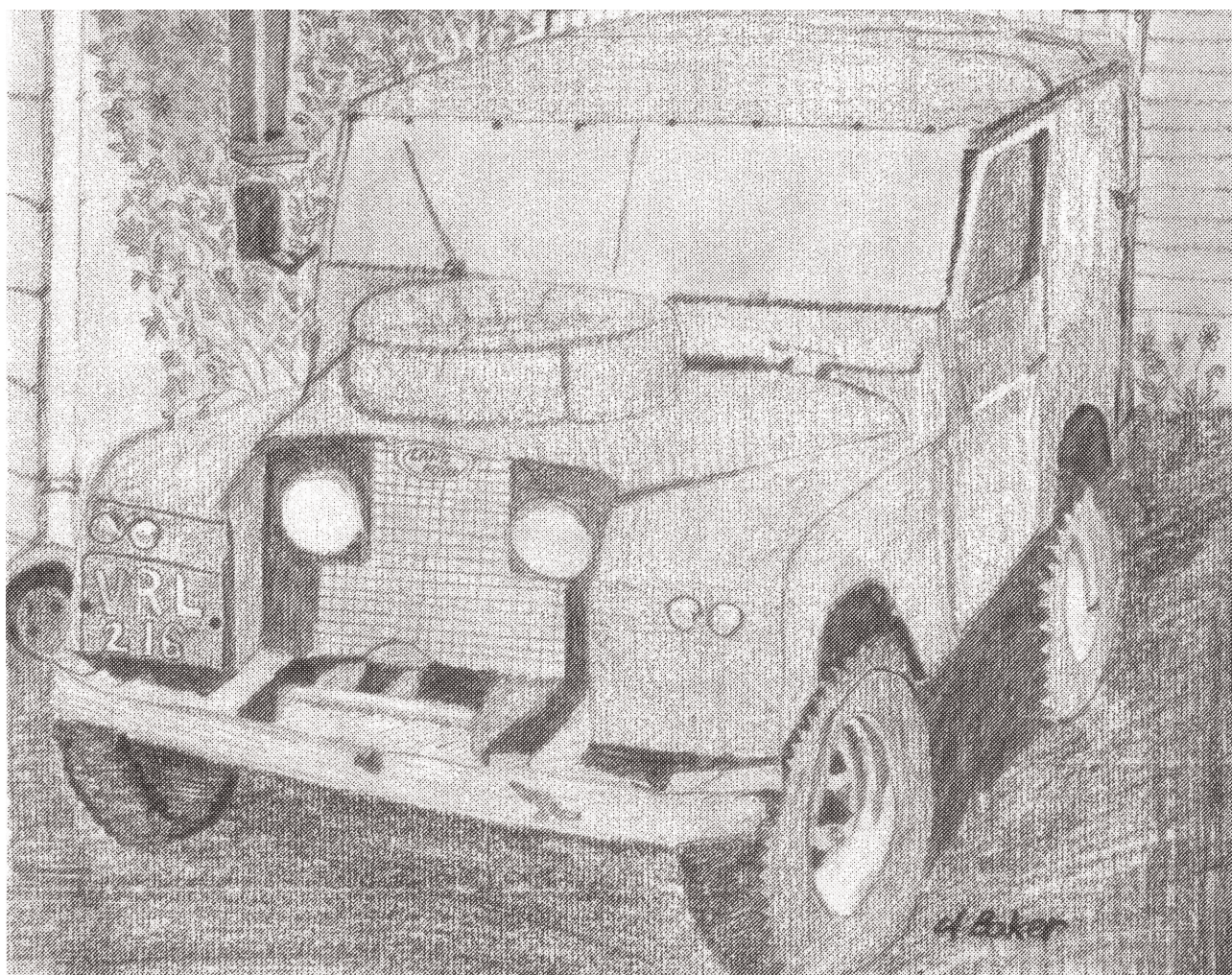


Produced by and for people with autism-spectrum conditions

Asperger *united*

Edition **63** July 2010





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

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

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

Editor the Goth

Telephone and production support The National Autistic Society's Publications Department

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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 magazine.

Contributions for the next issue should reach us by
16 August '10

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

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

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

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

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



Welcome to the July edition, which should be the last edition to look quite like this. In October, I'm hoping technical issues with the new layout will have been sorted and the changes we've discussed for the last few issues will be introduced.

Remember, if you are unhappy about any of the changes, let me know. We can always reverse any change if there are more people who are upset than there are people who are helped by the change.

Now, thank you to the three people who sent in small pieces that I can use to fill little gaps in the magazine — one such piece appears on page 6 — though I haven't filled the deliberately chaotic layout on page 10.

I am sure I will need more in future, so if you have any very short stuff, I would still love to hear from you.

I hope you like the idea of fillers used in this way — please let me know.

Moving on to this quarter's theme, diagnosis, it's clear that a lot of people struggle with both the process and the consequences, though on balance, knowledge of who you are seems to be an advantage. Forewarned is forearmed.

I look forward to hearing from you,

the Editor

the diagnosis edition

If sufficient material is sent in, the theme for October will be **creativity**. After that, it's probably time to revisit the subject of **work**, including unemployment. Writing on any subject is still welcome, as are ideas for new themes, and artwork.

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Diagnosis

by Jacqueline

I have wanted to contribute something to the magazine for a long time now, but not knowing how I could do that Meaning I did not know how I could find words . . . but since reading the last edition I received this week I think I might be able to write something now.

I would like to write about getting a diagnosis as an adult . . . how this has been for me . . . and how I feel about my diagnosis, including how I feel about the proposed changes to the diagnostic manual for psychiatry (DSM-5).

I have had psychiatric help ever since I was a teenager living in New Zealand. (I am now 54 years old.) I did not understand what was wrong with me all those years ago, I was admitted to a psychiatric hospital because I could no longer look after myself, I was very neglected and I did not have a family who loved me. The psychiatrists tried very hard to help me, but they could not reach me. They did help me, though, to leave New Zealand so I could try and have a life of my own far away from my family. I came to England first (I was 21 years old) and a psychiatrist in England was very good to me and wanted to help me, but I did not want to go back with him to hospital. I wanted to be on my own. I came to Holland and I have lived here ever since. All the years I have been here I have only known good psychiatrists who have always helped me any way they could.

In 1989 I was admitted once again to a psychiatric hospital, and from this time I started receiving help from a psychiatrist whom I still see today (I see him now once every six weeks). It is this psychiatrist who has told me that all the psychiatrists who have ever seen me, and tried to help me, have always found it very hard to know what my diagnosis is. He has also not known for many years what my

diagnosis might be. He has thought of autism, and he has consulted a colleague who is a specialist in autism here in Holland. Now after all these years, he says I have an autism-spectrum disorder and I also have a schizotypal personality disorder. He also says that at different times in my life the whole psychiatric diagnostic manual could have been applied to me. (Maybe he was exaggerating a bit? But I have had very many diagnoses.)

I wanted to tell all of this because I have always had a positive experience with psychiatry, even though they did not know until the last few years that I have autism. I have come a very long way since the very traumatized child I once was. There was no help then for me, and it was only when I was able to get help from a psychiatrist in my teenage years that I started feeling there maybe really was a world out there that could help me. I have a home of my own now, with a lovely garden I like to work in almost every day. I have friends I meet at my local athletic club every Saturday morning. We run first and then we drink coffee together afterwards. They have slowly become friends I can be with and I am very glad about that. For years now I also have been able to keep my job doing documentary work at the local university hospital. My boss and the people I work with know I cannot handle a lot of social interactions so they do not pressure me too much and leave me alone to work quietly on my own. I have a room where I can work alone. They know I am happiest like this, and they are very happy and pleased with all the work I do. I get good reports about how hard I work and how extremely accurate my work is.

I do documentary work for several departments. Part of my work is to be very well acquainted with the *DSM*. I am extremely interested in psychiatric diagnoses

and for the longest time I have struggled, myself, to wonder what my diagnosis was. These last years I have not been able to decide whether I have Asperger syndrome or High-Functioning Autism. (My psychiatrist believes it may probably be more the latter.) So I was very pleased when the reports came out about the changes in the new DSM . . . and how they see my diagnosis just as my psychiatrist does: an autism-spectrum disorder.

I would like to add just one last note to tell how so very deeply grateful I am to Lorna Wing for all her work on catatonia in autism-spectrum disorders. I have read the book she wrote on this subject and I have recognized myself so much in the people she has known and described in her book. It is the recognition of these catatonic-like states . . . that I was like this when I was a little girl and how it appeared again later in my teenage years, and again and again in my life whenever I have become overwhelmed and

deeply distressed, and had to go back into hospital, that has made it very clear to my psychiatrist (and the specialist in autism he consulted) that this is autism.

I fight now very hard for myself to make sure I do not ever again find myself in situations where people are expecting too much of me. I know others often cannot understand why I need to be alone so much, and why I cannot be among people a lot, interacting the way they do. I need my quiet time alone. And I am happy now in my life, and accept more that I have needed to be far away from a family who have never, ever been able to accept me the way I am.

I do not see myself as autistic. I see myself as Jacqueline, and I have autism.

I do so hope that all I have written will maybe help someone else, the way other people's words have helped me.

Invitation to readers to join the User Representation Group

notice by **Carmel**

The User Representation Group is a group of NAS service users and has been gathering under varying formats for the last ten years or more. We meet with NAS staff to discuss and give our views on services offered by NAS, and to make suggestions. The purpose of this group is to provide interaction and a flow of ideas between the NAS and those who use their services. Usually we are visited by at least one member of NAS staff, who will explain what their department is doing and ask for feedback. We meet in London approximately every three months and work to a tight agenda. Everybody is given a chance to speak, but comments need to be succinct because of time limitations. Of course, this can be stressful, but people can take "time out", that is, leave the room, if things get too much for them. We also have two scheduled

breaks during our three-hour-long meetings. Because there is a level of controversy on some issues, we sometimes take a vote.

At our last meeting, we voted unanimously to invite more people to join our group and take part in our meetings, so that it may be more truly representative of NAS service users. Any *AU* readers who would like to make a contribution to NAS policy, who have views, positive or otherwise, on its services and would like to have a voice would be very welcome to join. We are welcoming new members living within Greater London (zones 1 - 6). If you would like to come to a meeting, please contact **Anna Nicholson**, the NAS staff member responsible for co-ordinating the group, on **020 7704 3804** or email **anna.nicholson@nas.org.uk**



letters to the editor

Hi Goth,

thank you for sending me issue 61 of *Asperger United*. It is good to see your picture.

Sometimes I can flick through *AU* very quickly, and can find little to hold my attention (that is not intended to be a criticism, by the way, just an acknowledgement of the wide-ranging variety of *AU*'s contents). But issue 61 had me engrossed from cover to cover.

Elkie's review of *Lars and the real girl* definitely makes me want to see the film, and I must get to Amazon asap!

And Paolo's article about relationships struck many chords with me — more on that later.

But first I would like to comment on the letters from Sam and Julie, and also on the report from Rachel Blood about her research project.

I think there is a massive problem, both for AS sufferers and for psychologists, and also for the NHS, in deciding whether autism (in all its many guises) is a mental-health condition, or whether it is a "hard-wired" neurological condition. If it is "hard-wired", then there is probably little to be gained from the "talking" therapies, and our only hope lies in drug treatments which would work by modifying our neural pathways.

Previously, I have tried to compare the "Aspie" situation with the situation of a

physically disabled person who is confined to a wheelchair — the sufferer simply has to accept that certain activities are not accessible. The difference, of course, is that a wheelchair is obvious for all to see, and most neurotypicals will make due allowance. Autism is not so obviously recognisable to the casual onlooker, and autistic behaviour sometimes seems simply "weird".

I am currently in communication with a profoundly deaf person who I "met on the net". It occurs to me that deafness is a neurological condition just like autism, but nobody would consider referring a deaf person to a psychiatric unit.

Nevertheless, it seems to me that deafness and autism present similar obstacles to social success — principally the inability to "pick up" on many subtle clues to another person's meaning and intent.

This all brings me to Paolo's article about the "give-and-take" that is required within any animal relationship. My experience is that many Aspies tend to demand more from, and give less to, a relationship than neurotypicals because they simply lack the experience of successful relationships which would have taught them otherwise.

Anyway, I could waffle on like this for ever. If any *AU* reader would like to "take me on", and have a debate about my ideas, then please contact the magazine and the Goth will provide you with my e-mail address,

Kevin

A thought

from **Eric**

We must remember the rest of the world does not think as we do; we might have a very good idea or methods of doing things but we have to explain fully our ideas; the big picture as well as the small things that can be so important to us, we must humour the mere earthlings.



How to reply to Pen Pals

- Please remember to let us know the name and number of the person whom your letter is for. (All pen pals are numbered by the editor, not the person who sends in the advert.)
- To contact a pen pal, please send your letter to *Asperger United*, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.
- We will pass your letter on to the person you wish to contact. However, we cannot guarantee the person will reply as that is entirely their decision.
- Please note that all pen-pal letters sent via *Asperger United* are opened before being passed on.
- Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*. Only replies from under-eighteens will be forwarded to under-sixteens.
- The NAS pen-pal website, run and funded by ASSIST, has been taken down, as it was proving too costly to maintain. The NAS is working on an alternative.

****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 75

Hello, my name is Claire. I'm 29 and I was only diagnosed with Asperger's in September 2008. I live on my own in Scotland, north of Edinburgh. I'd like to chat to people aged 20 to 35.

I work part-time. My hobbies include reading, making jewellery, baking, playing games on Facebook and playing the piano and organ. I'm a Catholic and I play the organ at my church.

I have had no help with my Asperger's since I've been diagnosed and want to speak to other adults with Asperger's.

Pen pal number 76

Hi everyone, my name is Geoff. Due to unfortunate circumstances, some replies sent to me (from an earlier publication of my advert) by *Asperger United* never arrived.

I am diagnosed as having Asperger's syndrome only sixteen months ago, I'm 66 and live in Lincolnshire. I am divorced and very lonely and isolated. I enjoy meeting people, home life, DIY, meals/drinks out, short breaks away from home. I'd love to hear from anyone of any age, hopefully to become friends, to spend time with on occasions. Thanks and I hope to hear soon from yourselves.

Pen pal number 77

My name is Eleanor and I am 24 years old with very able Asperger's, but I still need some support on a daily basis. I live in Somerset. My hobbies are: gardening, care of animals, classical music, reading (non-fiction), and country walks. I would like some new pen pals who are of similar age and ability living in the Somerset area only.

I am capable of studying above GCSE level and cooking my own meals.

I would like people to reply who live in supported housing or are living at home only.

Also I get frustrated by my disability and I am in need of some company. If you feel the same please get in touch. I will read all replies. Many thanks for your help and assistance.

Pen pal number 78

Hi, I am a 61-year-old Asperg, who at present (10 years to be precise), is going through hell with the Spectre Smersh (SS) and doctors. Diagnosed at 49 years young.

I would like to be put in the pen-pals spot. I am interested in current affairs, politics, stood for UKIP in 01, was agent for Referendum Party in 97. Am a firm super-sceptic as far as man-made climate change is concerned. Our climate has been changing since the Earth was born. Our ancestors got it right when they worshipped the Sun as the beneficence of our existence. Like listening to music of all kinds, but due to my really bad condition have not been able to listen to radio, CDs, etc., do not watch TV but got a big archive of videos and DVDs. Good sense of humour, in an Asperg way, of course. Would like anyone who has an interest in a suffering being that I am especially the last six years.

Eric

Pen pal number 79

My name is David, I am 34 and was diagnosed with Asperger's two years ago. I live in Northampton with my father, but I'm hoping to move into a place of my own within the not-too-distant future. From what I can gather since getting my diagnosis there is very little in the way of support for adults with AS in Northamptonshire. I have always found socialising and making friends extremely difficult and feel that having a pen pal could be the first step in helping me to build confidence in this area.

I have a deep interest in popular music. I enjoy most styles, particularly indie/alternative, punk and metal. I'd give anything a listen really but most regular top-40 stuff leaves me cold. My other interests are watching films at the cinema or on DVD, reading novels, art history, walking, supporting West Ham United, and my guilty pleasure is watching pro-wrestling.

I'd like to hear from anyone within my age group, male or female, with similar interests.

Pen pal number 80

Hello, my name is Mark and I am 35 years old, live in Canterbury and work as a gardener.

I enjoy outdoor pursuits such as walking in the countryside and swimming in the sea during the summer and visiting places. I have been going to an art class and have produced quite a lot of serial work. I also go to church on Sundays as I am a Christian and have some good friends there. However, I do get lonely at times as I live on my own. I am looking for a friend. I do have high-functioning autism which makes it hard, if not impossible, to interact with people.

AutreachIT

advert by **Dinah Murray**

AutreachIT exists to employ digitally skilled autistic people to bring Information and Communication Technology (ICT) to digitally excluded autistic people.

To be included, empowered, and able to take a real part in decisions about their lives, autistic people need effective ways to communicate.

Legislation supports the right of access to ICT. We want to make that access a reality.

AutreachIT aims to:

- promote access to ICT,
- raise awareness of rights to ICT,
- demonstrate the effectiveness of ICT and
- employ digitally skilled autistic people to develop ICT for hitherto digitally excluded autistic people.

AutreachIT is a not-for-profit group founded in 2008 for the purpose of using autistic skills and knowledge to end the digital exclusion of autistic and other adults receiving funded care. We plan to provide a bank of specialists in varied aspects of ICT and digital inclusion. We have an autistic core team, but do not exclude any willing participant. To learn more, email us at **autreachitaccessproject@googlemail.com**

Our first major project is a research project. The basic idea is to use autistic ICT knowhow to take ICT to adults with autism who cannot meet their needs through speech and are in supported living without digital access, and to find out what the impact of doing

so is. The plan is to distribute personalised iPhones with voice output software installed to twenty service users and paired key staff in an autism specialist service, and assess the impact of doing so on communication, inclusion, and “challenging behaviours”.

We think addressing the basic communication needs of autistic adults may have a profound impact on their levels of participation, inclusion and quality of life. We want to find out if this is true. Targeting the study at people with pervasive unmet communication needs whilst at the same time attempting to meet those needs is intended to fill a yawning research gap. Our research is aimed at getting proof of concept that major benefits may accrue if appropriate investment in ICT is made.

If it goes ahead, the research will need a full-time, or minimum 30 hour week, paid ICT and iPhone specialist for a year, hopefully starting mid-way through next year. This, or any other AutreachIT employment opportunities that arise could possibly be done on a job-share basis. More ICT work will be needed in subsequent years, but probably for fewer hours. A funding application is currently being formulated.

We will also need some part-time autistic trainers since we will use four trainers at each session.

If you think you have or could develop the right skills set either to be an ICT specialist for this, or to be a trainer, or to contribute to future projects, using different platforms, or if you want to know more about the planned research, please let us know on **autreachitaccessproject@googlemail.com**

Asperger's and I

by Chaos

So many things have happened in my life which led me up to this moment. Unexpected twists and turns have shaped me into what I hoped to become and yet never thought I could. I'm 21 years old now and I got recently diagnosed with Asperger's. How it happened is a very interesting tale that I'd love to share with all of you.

I have been a spiritual person for more than eight years now. My journey into deep spirituality started, like almost everything else which shaped my life, by chance. This journey in spirituality is what led me to learn about Amma, the hugging saint. She's my guru and I've seen her hug all kinds of people, including people who have different ailments and who, to me, were very repulsive. I couldn't ever imagine myself even approaching sick or special needs individuals. This was sadder to me than it was repulsive. I've always wanted to be a good spiritual person but this seemed to be a very huge obstacle in my way.

I'm still in university studying pedagogy and, as a course requirement, we have training and observation sessions. It was all okay until I read about a man called Rudolf Steiner who founded a spiritual method of education which

spurred my mental gears into action. I knew that, in Lebanon where I live, such a school could not exist because spirituality wasn't such a big thing here. But I was glad to know that I was wrong. There was only one school which used this method in Lebanon. However, the thing about that school was that it was a school for special needs.

My love for spirituality was big enough to overcome my aversion against individuals with special needs so, I accepted to work there on a trial basis. In a weeks' time, my whole mentality changed and I felt genuine love for the children. They didn't wait for me to approach them, they were the ones who came to give me a hug every once in a while. At first, I started as a shadow teacher. The kid I had was a high functioning autistic 10-year-old whom no one was able to manage. It makes a lot of sense now how I was able to manage him and help him.

I stayed in that school and learned a whole lot, however, I always had more success with autistic children than with other types of special needs. Throughout that time, I was slowly realizing and understanding myself until the beginning of this year when I had a kid with Asperger's in my class. I had more success teaching him than the rest of the class and, the more I observed him, the more I could see things from my past in him. That's when I started wondering that I have it too. Eventually, I got diagnosed and confirmed it.

It's funny how, when you decide to follow the flow, you discover things you never imagine you could discover. Up till three months ago, I thought that I was just somewhat eccentric; who knew that my life's journey would lead me to discover myself in the most unexpected ways?

Diagnosis

by **Barrey**

My circumstances are mid-60s male, in retirement zone, just diagnosed last June, coming to terms with parts of the assessment, but reluctant to accept the totality.

What's in it for you by being diagnosed — use NAS checklist to see if there are tangible benefits for you. Statistically, older men will find it harder because they're more likely to be affected and their education, training and experience will have emphasised their systemising skills and brutalised their empathetic side; be as clear as you can about your aim — I did it to validate my wife's (medical) intuition (and have regretted it).

Is your GP aware and onside? Be prepared to accept and work with the result — I thought I could but it takes a long time to let go of the old you.

Who will supply the “evidence” (against) you — your partner? Consider the consequences/implications, eg., for your relationship — are you both really committed to it, in sickness and health?

I found the assessment very hard to accept because of the process and her use or misuse of the evidence to categorise me as being

affected by AS. I've come to terms with aspects like the theory of mind, and can accept that, but I see AS as very different for each individual — heavily influenced by our genes, education, training and experience, and generation.

Who will fund it? PCT or you? Who do you go to? NHS has more credibility than private. Can you self-diagnose using the materials on the web? Who will really support you through it? Do they know enough about AS? Is there a couples counsellor with enough knowledge of AS locally you can both get on with? Are you prepared for the weekly battle as you work through issues?

Attwood suggests there are three steps:

1. Acknowledgement (not acceptance) of the result;
2. Motivation and willingness to change on all sides;
3. Access to CBT counselling that works for the Aspie.

Are there any next steps for you? Or do you agree with the bleak view that AS can't be cured and can't sustain the relationship in the long term, so the Aspie can't change and why should the non-Aspie partner do so?

Personal development courses from Prospects

Throughout September Prospects will be running one-day personal-development courses that enable employed people who have an ASC to develop their workplace skills. The courses are held in London and are open to all. They

offer a unique opportunity to explore work-related issues such as communication skills, dealing with anxiety, and personal management, alongside other employed people with an ASC. For more information, please contact:

Daniel Aherne

Prospects

The National Autistic Society

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020 7704 7450

daniel.aherne@nas.org.uk

A letter of encouragement

I write this to you, the reader, to share my experiences of Asperger's syndrome.

I would like to start by saying that it is sad to read of people with Asperger's syndrome or anyone with a mental-health condition having problems in churches.

It is sometimes to do with a lack of knowledge and understanding yet I accept that some churches can be difficult places because the leadership or congregation can be inflexible in meeting the needs of those with Asperger's syndrome or other mental health conditions.

Yet not all churches are so bad and there are gems out there. I myself am a Christian and attend church in Wrexham, North-East Wales.

I am regularly blessed by the church who have shown me care and warmth. I have been fortunate to find people within this church who accept me and want to move me on.

The leader of the church is energetic and passionate yet flexible enough to accommodate the needs and difficulties of somebody like myself with Asperger's syndrome.

Other help that I get during the mid-week meetings are from two house-group leaders who are witty and fun and they are trained in dealing with those who have mental-health needs and again help with the difficulties of praying in groups, yet I can be left alone to worship without feeling pressured.

Within church meetings I am allowed to sit and sketch my thoughts and prayers without feeling the need to conform to a set way of doing things. I even use photographs with short captions to help me worship.

People within the church want to spend time with me and I have spent time after a Sunday service eating in homes or local restaurants.

I accept that with Asperger's and my own personality I am not always the easiest of people to be around, yet it is possible to find a church that can accommodate Aspergic people.

You may say that I am lucky to have found such a place. I would say that I am blessed with such a church. Yet ultimately it comes down to understanding and love as well as an acceptance by the church that we are all different and unique.

Asperger's syndrome has many ups and downs. It is a condition that causes problems and frustration, yet I say that it is a gift. We are able to see things in a unique way which can help others around us.

I wasn't diagnosed with Asperger's syndrome until 2005 by a local NHS psychiatrist. I had difficulties in school with group work and routinely misbehaved. I have lost jobs because of the inability to work in groups or deviate from a set routine.

Yet despite these knockbacks we should not give up hope, nor despair. I have in my short 27-year lifespan accomplished much.

From getting, in 2004, a HND in photography, I have, despite forgetting to photograph a sports match that got me kicked out, photographed at the Commonwealth Games in Manchester in 2002.

I have written numerous stories and poems and had photographic work exhibited in London 2009 as part of a photography competition run by the NAS where I came in the top ten.

I live independently and cook great food from lasagne to cottage pie. I also write stories and help my friend at the library with community work who helps me out greatly by being understanding of my Aspergic condition.

So, dear readers, let me finish by saying that you should not give up. You are unique and life has so many opportunities and it is important to see beyond the difficulties of Asperger's syndrome, even though at times it can feel like you have handcuffs on your wrists.

But you have a lot to offer the world with the way you see things and your own experiences.

Here is a poem that I hope will encourage you.

Chris

It matters

The road of life you are on.
Is unique to you and you alone.
Your background and experience are yours and yours alone.
Time and the world cannot take them from you.
Whether your experiences are good or bad.
Making who you are by the fires of time and thought.
It matters because you matter.
You are important to the world and those around you.
Whether friend, family or stranger.
Who you are matters.
It matters, because we all matter.

Asperger syndrome and anxiety

a guide to successful stress management

by **Nick Dubin**

ISBN: 978 1 84310 895 5

£13.99 / \$19.95

Jessica Kingsley Publishers

review by **the Goth**

It is hard to judge how good a book is when it is the only book of its sort in existence; any day a new book about Asperger's and anxiety could be published — then we could compare it to this book. As more and more books are published it becomes possible to pick out the best books and to have some idea of the standard a book needs to reach to make it worth reading.

Nevertheless, I think this is a very good book — I'm going to stick my neck out and say that I think it will still be seen as one of

the best books on AS and anxiety in ten years time, despite the rapid progress in the field.

The author has Asperger's and many years' experience of anxiety in situations that lots of us are familiar with. He writes with considerable insight into the causes of anxiety and those things that make it worse once it's there. And no sooner has he discussed anxiety in all its complexity but he is telling you how to conquer it, before — almost coincidentally — going on to examine coping with anxiety in various aspects of your life.

Dear AU,

I wish to contribute to the magazine on the topic “getting a diagnosis as an adult”.

I was a soldier for 16 years 196 days, Chief Engineer for two years, a Military Instructor for six years and struggling secondary teacher for eight years, 18 months of which I’ve been laid off with work-related stress and depression.

I received a formal diagnosis of Asperger’s syndrome on 23rd July 2008, having just turned 53. That diagnosis was a three-year ordeal.

I first became aware of being on the autistic spectrum when I read Temple Grandin’s *Animals in translation*. I got the book because I was interested in animals and at the time had no idea I was on the spectrum. As I read of Grandin’s experiences I realised something familiar in that hers seemed to mirror my own.

I started to investigate AS on the Internet and was bewildered to find that according to various sites I fitted the condition of Asperger’s syndrome including a score of 43 on the AS quotient. At the time I was a schoolteacher

struggling with classroom management of teenagers with little support from my seniors. I was transported to my childhood memories by the continuous ridicule and mickey-taking of current pupils.

As an Aspy I now realised that the classroom was probably the worst situation I could be in and explained all the difficulties I found being there. Not long after, I was laid off with work-related stress and depression for the second time in four years.

I took the time of recovery to build a case for early retirement from teaching. I needed a diagnosis. The first phone call I made engaged a medical practitioner in North Wales. After explaining my case she replied, “It has become very trendy to be labelled Aspy these days and I can tell by listening to you over the phone that you do not have Asperger’s syndrome.” I was really upset and it caused me to doubt all the evidence for self-diagnosis I had gathered in the previous year.

A while later my next avenue was to contact a private psychiatry practice in Newport in South Wales. With the reply came the cost

of several visits amounting to hundreds of pounds with no guaranteed outcome. In 2008 I decided to finish teaching on mental-health grounds regardless. I then went to my GP and asked him to refer me to a consultant on AS at a psychiatric hospital in Cardiff. I went along with my wife and through the evidence we presented and diagnostic testing he conducted at the time I received a formal diagnosis.

Believing I had grounds to take early retirement from teaching I then sought help from the National Union of Teachers. Their conclusion was that although my case was sound it was unlikely that it would be successful as one has to prove to the Teachers’ Pension agency that I could never work in the classroom again.

I spent a year on Jobseekers’ Allowance under a disability employment adviser. I didn’t get an interview let alone a job. I now work four hours a week teaching people with learning disabilities and the rest of the week self-employed as a handyman. Life continues to be a struggle but that’s life in an NT world.

Christopher

The Neurodiversity Network

a new self-help organisation for people on the spectrum

advert by **Rob**

As local authorities (including NHS trusts) begin the process of planning new services under the provisions of the Autism Act, they are often acutely aware of how little they know about autism, or what we need as a community. One of the great things about the new act is that it requires authorities to involve autistic people in the planning and delivery of new services. A group of us in Devon have decided to take advantage of this, and have formed the Neurodiversity Network, which is a project run entirely by autistic people.

The idea of the network is to connect people with autism who may have skills or knowledge in certain areas, to provide help to the autism community as a whole. Two of us are training to be counsellors, so this is one service we want to offer. Another member has a lot of knowledge about benefit law, and could help people with applications. I used to manage an employment agency, so that's something I'd be interested to be involved with. These are just some examples. People with programming knowledge could help build an internet site, for instance. People with mathematical skills could help manage finances, and so on.

Within just a few weeks of being set up we were invited to meet the NHS commissioner for mental-health services in Devon. As a result of that meeting, we will be helping to define the job description of the new leader of autism services in Devon. We will also be helping to plan the new service, and will be

able to apply to run parts of the service when it is set up. We have also met with someone from the development committee for the whole of South West England.

We didn't expect to start getting results so quickly, but it's now clear to us that local authorities are very keen to meet with the autism community and involve us in these new services. So I'm writing this article today to ask if there is anyone out there, not only in Devon, but anywhere in the UK, that might be interested in being involved with this kind of project.

If you have any skills that you think might be put to use for the benefit of the autism community as a whole, or maybe just that you would like to share your opinions about services with your local authorities, please get in contact with us at **neuronetuk@googlemail.com** — we'd really like to hear from you. We are still a fairly small operation, but we'd like to help others around the country to take up the opportunities that the Autism Act provides us with.

The next year is a crucial period in making sure that the act works for us how we want it to. We have to be at the centre of discussions about how the new money is spent to improve quality of life. We may have had a hard time being heard before, but things can be different now if we get ourselves organised and push for our own agenda, not one that someone else decides for us.

An item for publication?

by Paul

Twenty years ago, in 1989, I became a “Christian”. I did this because life was difficult and I needed help; also a deep-seated fear of hell pushed me forward at one of the Billy Graham meetings back then. I cannot say the promptings of a loving God encouraged for I had no conviction of the presence of this Being. And this issue of the non-awareness of the existence of God has tormented me these past twenty years.

After my “conversion” I went to and became a member of a lively church; but during the time I went — 1989 to 1995 — I never came to experience a conviction that could have encouraged me to believe God was with me. This made for a painful time amongst “normal” believers, and the experienced sense of difference and alienation forced me to stop attending.

Early on in my “Christian” life I began an interest in philosophy, and found an area called epistemology, which is associated with certainty of knowledge, and whether it is achievable. After many years of searching for the certainty that I thought would make me feel more safe in the world I reached the assessment that limited creatures like ourselves cannot attain this certainty because our limited knowledge would always result in the possibility that any conclusion which we may have come to may actually be incorrect. This wasn’t what I wanted to hear. Now the distressing unpredictability of life would continue: nothing was certain; everything was open to

doubt; a totally secure footing in life cannot be found. All our existence is based on faith!!

The secure footing above could have been attained to a considerable degree in childhood, from the love and acceptance of one’s parents. Unfortunately for me, my folks never got on, and any care in the household would have been given to my mentally handicapped sister, who would also regularly fight with my mother.

All this meant I didn’t have a close attachment to my parents. I was just too frightened of them.

Anyway, here’s the major point of this note: I have considered for some time now that because I didn’t have a close connection with my parents as I grew up and, another major aspect, because I have never had a close relationship with a woman, could this lack of human connection, which has resulted in a very deep distrust and fear of human beings be the reason why I cannot make an intuitive connection with God? Assuming it does exist.

I write the above for I think it would be interesting to know whether others reading this have had a similar religious/spiritual experience, especially in the area on making a connection with God. For if we can connect with this Being, then believing in help from an omnipotent, omniscient, omni-present, wholly good God would understandably be of major benefit for the anxiety-prone.

