

Produced by and for people who have autism-spectrum conditions

Asperger *United*

Edition 72 October 2012



Asperger United

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. Discussions on editorial choices will not be entered into. *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

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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.

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

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 editor, the National Autistic Society or those involved in the publication of the magazine.

Asperger United is available in **large print** on A3 sheets (double the size of this page). If you need large print, please let us know using the postal or email addresses above.

Contributions for the next issue should reach *AU* by **5 November 2012**

Welcome to the October edition of *Asperger United*, enclosed is a flyer about the new e-mail notification service to let you know when the electronic edition is available for download. Anyone who would like to receive a notification, please follow the instructions on the flyer.

Now, creativity: the wandering mind has been found to be an important factor in creativity, and many of us are prone to getting lost in thought and failing to follow what's going on around us. Do you feel that's important for creativity?

Equally, failure to pay attention to things that need thinking about is a cause of anxiety for many people, so is not knowing what to pay attention to a major cause of anxiety for you? Is anxiety a cause of your insomnia (assuming you have insomnia)? Does anxiety affect your ability to work? Does insomnia affect your ability to work?

Sorry for all the questions, but I hope you understand where I'm heading: the next issue notice on page 5 suggests three possible topics: fear and anxiety, insomnia and work, though they could all be closely related, or, rather, inter-related. So I am looking forward to your letters and articles exploring these topics — remember, you can send things in by post or email, either is fine.

Lastly, I'd like to point out that when my mind "wanders" it is still very focused, just focused on one "random" thing after another. I assume we can take that to be true of everyone on the spectrum, but I don't know. Your thoughts on this would be appreciated.

I hope I have inspired you to send in many letters and emails. Keep up the good work!

the Editor

the creativity edition — next issue notice on page 5

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The creative impairment fallacy

How a picture can paint a thousand words for us too

by Hannah

My childhood artwork was never displayed proudly around the house, and I never thought anything of it until I started visiting friends' houses, which seemed to be littered with clashing-coloured finger-paint drawings and wobbly pieces of pottery. I trotted home and asked my mum why mine just got hidden in unlabelled boxes in the attic, which my dad would sporadically throw away declaring "don't worry, none of the stuff in here is yours, that's still safe in the attic"; my mother's blunt reply was simply that it was rubbish. She had a point, but out of principle I rebelled and insisted she put my half-finished phallic totem pole on the windowsill of our lounge for all to see, and there it stood for almost a whole year until it met its unfortunate "accidental" end. The problem I often had with art was not that I wasn't creative or didn't possess any artistic ability, it was that I could never get things looking exactly how I saw them in my head, and no slight alteration to my initial design could be tolerated. So my totem pole was the result of weeks' worth of effort trying to create a sharp-pointed top, which I couldn't get exactly right so had chipped away at it until hardly anything

was left. I found this to be a recurrent theme with all my art and design work at school; woodwork sanded within an inch of its life brought home unfinished, pottery which had been so smoothed out it was caving in on itself, and paintings half-painted and holey from excessive erasing. Who would have thought in my adult life I would be a freelance photographer and designer? It was not that I wasn't creative, it was just that I needed the time and to find the right medium to express that creativity exactly how I saw it. I think this is why those with autism are often labelled as having no creativity. In fact, when someone with autism turns to creative pursuits, that creativity can be even more intense than a "neurotypical" of the same disposition. So where has this myth come from?

I think the difficulty that may be faced by those with autism, who find it hard to express their creativity, is that it is not their "specialist" subject. As I grew older and more academic pursuits became my central interest, being creative seemed pointless; why did I need to waste time drawing the image in my head just so others could see it also? I

applied my creativity instead to research projects, essay writing and reading. However, in my last year of university I was thrown into art therapy and expected to draw and visualise my emotions on a weekly basis — nightmare! I started off just drawing things I'd seen and planned the night before and making up some elaborate emotional link; the planets and space after watching a documentary, which somehow mirrored my sense of loneliness, the anatomy of the brain during my dissertation finals, which somehow reflected my rigid thoughts. You would have been forgiven for thinking that my creativity was somewhat lacking, I just couldn't connect the two, and until I could the therapy would have no benefit to me whatsoever. Eventually, I managed to just let it all go and let that creativity flow. It was the most useful experience of my life thus far, it made me realise that not everything has to have a point to it, that just in the act of creating something disorganised and irrelevant it would untie a lot of the knots in my head, and that in itself gave it a purpose.

Impairments with creativity, however, are still

feature (continued) and a notice

being recognised as a tell-tale symptom of autism, which no one seems to be questioning. Often, when I tell people I have Asperger's they are surprised by my job as a designer; the myth has become an ingrained stereotype of the condition. It isn't a stereotype without evidence though. In 1999 Craig and Baron-Cohen tested impoverished creativity in autism and Asperger's syndrome and found that the ASD children did show impairments on creativity tests. Furthermore, although such children could create possible novel changes in an object, which required creativity, they made far fewer than the control children, and these tended to be reality-based. For example, the novel changes were all situations they had previously experienced or knew about, not elaborate imaginative fantasy situations. Finally, they found that children with ASD did not seem to have imaginative fluency, in that they generated fewer suggestions involving attribution of animacy to foam shapes. They suggested that this was due to poor executive function, which refers to a set of mental processes that help us connect past experience with present action, thus aiding the production of creative, novel experiences. This evidence added further to a debate started a decade before in 1988 when Shallice found that patients with damaged frontal lobes had deficits in executive function and creativity, and were poor at generating novel responses: the three seemed to go together.

This all sounds like a disaster for our future prospects as artists, and I've not even had time to mention all that theory-of-mind we are lacking!

Fortunately the debate hasn't been completely one-sided. Professor Michael Fitzgerald of Trinity College, Dublin, believes that some of the most brilliant minds have been autistic. He compared the behaviour of his patients with that described in the biographies of the famous. Both Lewis Carroll and Yeats showed signs of autism, two of the most creative minds in literary history. Professor Fitzgerald suggests that Asperger's syndrome actually provides a plus and makes people more creative: they are typically hyper-focused and their attention to detail lends itself well to creative pursuits. Could it simply be the case that those with autism are very tricky to test in a laboratory setting as it isn't realistic? Or just that like the "neurotypical" population, some of us are

incredibly talented with our creativity, some of us absolutely useless, and the rest lying somewhere in the middle?

What I think is important is that those with autism are helped to express the innate creativity they have. What can be better for the jumbled disconnected autistic brain than organising disorganised elements? Clashing colours turned into beautiful drawings, random noise turned into soothing music, muddled ideas turned into comprehensive plans. Being creative involves expressing emotions, so therefore those with emotional problems and/or communication problems can benefit from creative recreational pursuits and therapy — we just need a bit of patience and some help sometimes to make the link! As a fellow "Aspergian" recently commented on my blog, "I believe our lack of obvious creativity comes from our inability to translate inner thoughts to the outer world".

<http://aspertypical.wordpress.com>

#aspertypical

A piece of Hannah's art is on the cover, Ed.

If sufficient material is sent in, the theme for January will be **fear and anxiety** or **insomnia** or **work**. Possibly, a combination of two if, for example, fear and anxiety are a major cause of insomnia. Writing on any subject is still welcome, as are ideas for new themes, fillers (for putting in small spaces like this) and artwork. Remember, if you want to see different content in *AU*, the best way to change it is to send something in!

My first Autscope experience

by the Pea Princess

For as long as I can remember I have felt like an ET (extra-terrestrial) that for some obscure reason has been exiled into living among Earthlings. Now, Earthlings are weird people, if I may indulge in gross generalisations. Most of them are impervious to logic and rational arguments and they usually suffer from a general incapacity to think for themselves. They never say what they mean or mean what they say. They are addicted to gossip and smalltalk, and are unable to gather peacefully without picking some enemy they can all agree to blame and fight. You never know with them; one minute they like you, the next minute they lynch you. They come to you with seemingly good intentions and offer unsolicited help and advice, but if you decline politely they will attack you. I have to admit: I don't trust Earthlings. I don't trust them to know right from wrong; I don't trust them to keep their word. I don't even trust them to know themselves and be able to access their own motivations. This is why I spent so many years on survival mode. My family was unsupportive to say the least, and I grew up in the fear of being either killed or committed — or kicked out of my parents' house.

I read everything I could and did lots of research in my quest to try to understand Earthlings and to find ways of coping. Then one day I discovered that Earthlings were commonly called neurotypicals (NTs) and that mainstream psychiatry would place people like me somewhere on the autism spectrum. The next logical step in my survival/self-help strategy was to gather with fellow ETs/"people on the autism spectrum", which brought me to attend this year's Autscope conference. It's the only conference in Europe — and one of the two conferences in the world — that provides a friendly environment for ETs: people on the spectrum. It's a conference for autistic people, by autistic people. NTs are welcomed guests, but they are not master of the

house, and they are expected to abide by autistic rules, such as: respect the colour badges, refrain from clapping, keep quiet in the quiet dining room, and so on. For the first time in my life, I was in a place where it was Earthlings who had to conform to ET norms and not the other way round. How cool is that! I felt truly at home.

There's an unending debate within the autism community about what it means to be autistic and on-going discussions about all the different labels: ASD, HFA, LFA . . . and this year's Autscope theme was *Similarities and diversities*. But no matter how high- or low-functioning, participants were among the kindest, most benevolent and bluntest people I've ever met. I felt like an ET in ET-land, or like a Martian on Mars. I felt so much gratitude for the organisers and I couldn't help but marvel at the miracle that was unfolding before my eyes: people on the autism spectrum, outsiders, people impervious to social pressure, black sheep, original thinkers, weirdos, call them what you may, all gathered in an environment suitable to them, which is a true miracle when you think of the decades and centuries of isolation, exclusion, slander, locking away, scapegoating, and stoning that people on the spectrum had to endure and are still enduring on some parts of the planet. If there's progress in history, here it is.

Some readers might criticise me for indulging in NT bashing. This might be so. For me the issue is survival in an NT-dominant world; it is a life-and-death issue, and I cannot pretend my heart is wider than it really is. I was born and raised in Lebanon, in a country suffering from chronic civil war, in an area of the world cursed with on-going wars and conflict for countless generations. I have experienced first-hand the collective consequences of NT gregariousness, drama and irrationality. And I cannot help believing that the world would be a better place if NTs were banned from politics.

Pen pals

Pen pal number 131

My name is Becky. I am 28 and I live in a care home for people with Asperger's. I'd like a pen pal who shares one or both of my only two interests, as I only have two interests as my Asperger's causes me to be very limited in what I like doing. My only two interests are the postal system and lyric writing.

I'd love to be a lyricist for chart songs and I'd love to have a pen pal who was interested in lyric-writing and who could send me their lyrics or songs. I'm also highly interested in the postal system as I've sent my lyrics in the post for such a long time trying to get them published. I find it very hard to find friends because I only have two interests and these interests are so niche. I'd need my pen pal to only write to me about these two subjects, as I'm really not interested in anything else and as I feel very alone most of the time because I don't really have any friends. I try to avoid going into town as much as possible as I hate loud crowded places and lots of excitement so I only go into town if I absolutely need to but if anyone shares one or both of my interests I'd love to hear from them so I'd need them to contact me through *Asperger United* and then we could write to each other regularly.

Pen pal number 132

My name is Paul.

I'm a 14-year-old from England. I have Asperger's. I was diagnosed about nine months ago. I can be creative, I like playing on my Xbox and laptop. I find it hard to communicate with people and make friends.

How to place a pen-pal advert

- > All you need to do is send your advert along with your name and address (and email address if you want) to *Asperger United*. You can use the Royal Mail or email. The next pen-pal number will be given to your advert when it arrives.
- > Please note that *AU* does not print dating adverts, as it is unable to provide suitable support.
- > Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*.

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.)
- > Please remember to put your address on your letter.
- > To contact a pen pal, please send your letter to *Asperger United*, c/o The National Autistic Society, 393 City Road, London, EC1V 1NG, or email asp.utd@nas.org.uk
- > 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.

****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 133

Hello, I'm Sarah and I'm 32. I wasn't diagnosed until I was 31 after years of struggling and not understanding why.

I am single and very lonely but obviously struggle with socialising.

I love playing on my Xbox and listening to music. My favourite game is *Fallout 3* and I'm currently enjoying *Skyrim*. I enjoy TV: my favourite ever programmes are *Arrested Development*, *Alias* and *Star Trek DS9*. Currently I'm enjoying *Fringe* and hoping that *Community* isn't cancelled. The only sport I play is goalball which is a paralympic sport for visually impaired people.

I would consider meeting up after we got to know each other. Thank you for taking the time to read about me.

Pen pal number 134

Hello, my name is Emma and I'm 17 years old. I was diagnosed with autism when I was 12; I was also home-schooled. I have three sisters called Nicola, Lauren and Claire. I enjoy listening to music such as JLS, Olly Murs, Jessie J, Bruno Mars, Rihanna. My hobbies are baking and decorating cakes, shopping, going on my computer and surfing the Internet, travelling the world, going to music concerts and spending time with my family. I enjoy watching TV; things such as TV soaps, MTV, *Cake Boss*, and many films, especially the *Twilight Saga*.

I would like to talk to people around my age, mostly females though.

Thank you.

Emma, please write in again and include your address; that would be very helpful, Ed.

Pen pal number 135

Hello, My name is Joshua; I'm 24 years old and I have Asperger's syndrome.

My main interests include creating characters and writing stories. I have been working on creating stories for my new character, Bullseye the Cat, who I aim to create stories for to help non-autistic people understand about Asperger's syndrome.

I am also interested in listening to whale and panpipe music; drawing and reading books (based around the natural environment). I also like walking and keeping fit and I am interested in having a healthy diet.

I live in the Pembrokeshire hills in Wales with my mum, my dad, and my brother who hopes to become a professional actor.

I sometimes get quite lonely, because of where I live. I would like to be able to write (and speak) to other people who share my personal interests and also to hear about other people's interests.

Pen pal number 136

Hello, my name is Jack. I'm 21 years old. I was diagnosed with AS at the age of 14.

I like listening to music and going to concerts. I play the guitar, both acoustic and electric. My genre of music is rock and heavy metal, also my favourite artists are Paul McCartney and Green Day.

I like pets and have a dog. I also like watching films and TV. My favourite sport is football.

I'd love to talk to anyone around my age, who shares my interests or similar.

Twenty-two pen-pal adverts have been held over and will be printed over the next four issues, Ed.

Pen pal number 137

Hi my name is Anthony and I'm diagnosed with Asperger syndrome and I'm 12 years old. I like wrestling and football and having a good

laugh. I'm crazy about my Xbox 360 live and my games. I prefer email to letters. I'm looking for a pen pal who is between the ages of 9 and 14.

Thank you for taking the time to read this.



Big apples by Kevin

letters to the Editor

Frist, two letters in response to discussions at the Autscope conference. Any readers who wish to comment on these, please write or email — I will look forward to your thoughts. A report on the conference appears on page 6, Ed.

Dear Asperger United,

I am writing this letter as an open letter to the NAS, and indeed, to the whole “autism industry”. When I was diagnosed, it was advised that I would be given CBT (cognitive behavioural therapy) and social-skills training, both of which I specifically asked not to have as unhelpful normalising practices. Such things are of no use to me or my son as he develops, yet contact with the autistic community has been. What would be more use is a job. Considering that I am not the only multi-qualified autistic person out of work, and other than *Asperger United* there is no help for autistic-led ventures, who exactly is the “autism industry” supporting?

Regards

**Damian Milton MA, PGCert,
BA (Hons), PGCE, Mifl, MBPsS**

Dear Goth,

as a person with a diagnosis of Asperger's who is past the prime of life I can look back at the years only with regret. Life has been unhappy, lonely and unfulfilled. The NAS and I are both fifty years old but there I feel the similarities end. The former does not truly cater for adults, whilst the latter, having no children, is excluded from the attentions of the organisation. Am I alone in this view or do the children that the NAS concentrates its attention on get cured from their life-long pervasive condition before they reach adulthood?

Yours sincerely,

Steve

Dear Editor,

My name is Andy and I am 28. I have had mental health problems. I take the anti-psychotic Risperidone (6mg) and the anti-depressant Paroxatine (30mg). These help me. Having AS and also being mentally ill cost me my job. My co-workers were unable to tolerate someone different from themselves. I worked with adults with learning disabilities and got on well with them. My colleagues in my opinion did not do the job properly. They washed soiled bedding on a quick wash cycle so I got very angry. I love washing machines and know more about them than they do.

I get visited weekly by Dawn and Mike from the Early Intervention Service. They are great and I like them very much. The psychiatrist from the Early Intervention Service is very clever. He knew first of all that I had AS. I am grateful to Dawn and Mike for getting me into and out of hospital when I needed to.

I am so scared. I feel unable to go out on my own. It's too dangerous, not just for me but anyone who approaches me. I have studied a variety of martial arts including cage fighting to increase my confidence and try to lessen my fear. The forensic psychiatrist says I am unlikely to hurt anyone and I never have before. I am not violent. I am not a bully. In fact, I have been the victim of bullying all through school and I feel I was bullied out of my job.

To finish, I'd like to say I have a dog whom I love and kiss very much and she (Sophie) is beneficial to my mental health.

Andy

Thank you, Andy. This letter and the article on page 14 by Lois touch on fear, which is a subject we haven't addressed in AU before. I will be interested to see what readers have to say, Ed.

All the fruits of my compulsive creativity

by David

As early as age 9 I decorated a scrapbook with a design copied from an illustration on a Neolithic vase. At age 12 I *designed and built* a model plane with the innovative features of swept back wings like the contemporary fastest plane in the world, the Hawker Hunter, and it *flew*. In 1955 model railways became a truly royal rail road to the formation of my character and I am apparently the *only* man in Dunfermline who builds model trains and also builds his models from recycled materials. Emulating the model railway pioneer, the Rev Edward Beal, I could sit down right now and write a comprehensive book on how I build my models, complete with many photographs and scale drawings. I mastered every aspect of photography. I show colour enlargements exposed in reloaded throw-away cameras and many were taken overseas. I have invented and built gadgets for darkroom use including a huge device built of scrap timber that enables me to cut colour paper in a roll one metre wide in *total darkness* to the sizes I use. I invented and made garments I call Gripperbreeks which hold my false leg on painlessly; I even made seven pairs from cloth dumped in a skip and made the brace buttons from bits of broken car numberplate.

However my most important creative achievements are my literary works. At school on my own initiative I produced an ephemeral school magazine which featured a science fiction serial — then a teacher wanted his typewriter back! I had sporadic contributions published when at university including — dare it be said — an illustrated article on shoestring photography! and photographs taken with a *plate camera*. I began to earn a reputation in the 1970s as a contributor to a local magazine but my compulsive creativity began when I was in hospital after an accident where I invested my time writing short stories and poetry. After I left hospital with an empty trouserleg dangling I wrote playlets dealing with the civil strife of 1981.

I had begun to write about a fictional school pal in 1968 but my chronicle of his life, *The Socrates of Charford*, really started in 1981 and continues to burgeon. I have almost completed a novel about his schooldays. When I was diagnosed with Asperger's syndrome I set about writing short stories with Asperger characters and now I have enough for an anthology which illustrates our condition from our point of view and that of close relatives. I have written an ever-burgeoning portfolio of essays on our condition and also many essays and stories about environmental issues, two separate storylines about extraterrestrials depict humanoid ETs and their religions and standards to live by. One storyline written whenever I am aloft in aircraft deals with ETs who colonise Devon after mankind becomes extinct.

In *The Socrates of Charford* I describe a civilisation underpinned by a universal rational code of behaviour, called Contributionism, whose tenets are heresy to mainstream religions. That includes the synergic sense of Masfield's poems *Seekers* and *A creed* to give rise to what amounts to a theology of boundless hope. For if we struggle to improve ourselves and one another we will be reincarnated, as Masfield declares, "with sturdier limbs and brighter brains". The ultimate yardstick of good and evil is *strict consequentialism*. Present society reduces culture to the intellectual level of tiddlywinks; adherents to Contributionism give all of themselves to the common good. Severely emotionally disturbed children redefine themselves by their scholastic achievements and prowess in arts, hobbies, adventure sports, applied sciences and languages. Now aged 70, I have made hardly any progress in my quest to teach the fruits of my self-madness — in fact I am *scorned* by all too many Scots for my compulsive creativity. I plead for people within reach of Dunfermline to contact me in my quest to pass on all the fruits of my compulsive creativity.

“Problems in living” and the mental well-being of people on the autism spectrum

part two

by **Damian Milton**

Another interpretation of such behaviours could be the resultant stress of being an autistic person in society, being hopelessly misunderstood by the psychiatric “gaze”. The article does acknowledge social and environmental factors, but within a narrative of behavioural modification. The two-pronged attack of medical model and (cognitive-behavioural) psychology has done great damage to autistic people, and takes attention away from the social conditions, and the disadvantaged social position such thinking places autistic people in. “Behavioural management” also supports a damaging ideology regarding disability.

The differences in theories of mental health in these accounts are deeply entrenched in a wider theoretical and political context. The “treatment” of people experiencing “problems in living” is thus set in a wider conflict of ideas, between those who wish to control “deviance from the norm” and those who question such an analysis. This conflict is perhaps best expressed in the debate between the “medical” and “social” models of disability, where attempts to split “impairment” from “disability” are met with resistance from both sides.

When analysing such debates, I personally take solace from an “unusual” source, that of the “metaphysics of quality” in the novels of Pirsig. Pirsig utilised aspects of “Eastern” and “Western” philosophies to view reality in a way that went beyond the dualistic objective/subjective divide found in Western philosophy. Pirsig argued that the “quality” of something escaped definition as its existence preceded the perceiving of it. The “quality” of anything was thus experienced perceptually, before it could be thought about.

Although Pirsig suggests that such “quality” is essentially indefinable, as a means of making sense of it he splits it into two basic forms: static (patterned) and dynamic (unpatterned). As forms of “dynamic quality” become formalised, they transform into more “static” patterns, for example: “bureaucracy”. A static pattern is anything that can be defined, which for the philosopher Wittgenstein is the basis of what is “knowable” and thus communicable, and for Pirsig, such “patterns of static quality” are the foundations of social knowledge and culture. In this way of seeing reality, though, there is no “duality” between static and dynamic “quality”, but a “spectrum” of “quality”.

Pirsig describes dynamic quality as a process that is pre-intellectual and at the “cutting edge” of reality, which can be immediately “recognised”, yet not “conceptualised”. To illustrate, he gives the example of the dynamic beauty of music being recognisable, before a “static” analysis explaining why the music is beautiful can be constructed. For me, the epitome of Pirsig’s “dynamic quality”, is my son. My son has been variously described as “non-verbal”, “classically autistic”, and “low-functioning”. Yet his world is one of a dynamic connection to his sensory world. Sometimes attempting to force someone such as my son into “static” patterns of being, would make that person “ill”. Sometimes the “dynamic quality” that an autistic person inhabits is so chaotic that they seek out structure and routine to impose upon it, either derived internally or from outsiders. To me, the “inflexibility” and “rigidity” of autistic people is massively over-estimated, and mostly the misperception of those who naturally don’t inhabit such a disposition — the non-autistic

“outsider”. I think that autistic people often seem “rigid”, yet, internally, we are often the opposite.

Pirsig argued that moral progression worked from a dynamic base to increasing forms of intellectualised static quality (for example, the notion of a “civil right”). So, strangely, for someone championed by “alternative culture”, his philosophy takes on the hue of one of civilisation leading to moral advancement. This philosophy then becomes reminiscent of Durkheim’s (the late nineteenth-century sociologist), and the idea that a functional “organic” society needed an element of deviance (or “dynamism”) to provide the “function” of social change. Such changes of society do not always happen peacefully, though. Such changes, however, are like the “transformations” of the individual psyche talked about by Laing and Dabrowski, and the potential for either a stronger new identity or a descent into “dysfunctional” chaos. Something all these writers suggest is the inevitability of change, the need for transformation, and also the negative consequences that such change can bring. The similarity between all of these phenomena is no coincidence, but represents a society dominated by an ideology of “static” and bureaucratic rationalised control, and a subversive multitude of dynamic practices, manifested in psychological diversity.

Historically, sometimes the dominant “static” forms of authority lose their influence. Sometimes they will hold the seeds of their own destruction, and yet with new identities, social practices, and shifts in ways of thinking arriving as a result.

“If we challenge the status quo and choose not to “blend in” but, with respect and dignity, have the courage to be who we are, then maybe we could be involved in saving the human race from one of its worst enemies — itself.”

Wendy Lawson

A slightly longer version of this article (including both parts) and a full list of references is available on request from the usual AU postal and e-mail addresses, Ed.

The passionate mind

by Wendy Lawson

ISBN: 978 1 84905 121 7

£15.99 / \$24.95

Jessica Kingsley Publishers

review by the Goth

Yet another excellent book by the autistic researcher, Wendy Lawson, *The passionate mind* is about psychological theories of autism, not physical, developmental or biochemical theories. Only one psychological explanation of autism can be true, but it can be true at the same time as theories in other categories. For example, a certain thinking style (psychological) could be caused by a gene (developmental) which caused the brain to develop with many more minicolumns than usual (physical), and that gene might only take effect if you are exposed to a certain allergen (biochemical).

She describes and examines all five psychological theories: theory-of-mind, executive functioning, weak central coherence, enhanced perceptual functioning, and single attention and associated cognition in autism (SAACA). If you want to know more about any of these, this is the book you want. She finds all of the theories fall short of being a complete psychological description of autism, but that SAACA, which she herself helped to develop, has the least-troublesome faults and appears to be closest to the truth. As the newest theory, it also has plenty of scope for designing experiments that will allow the nature of autism to be understood. A very intellectual but interesting read.

Racing Thoughts

by Lois

It has been suggested I need to slow down my thinking, and my physical activity. I wasn't aware my thinking was any faster than anyone else's but my racing thoughts, according to information I've read on the Internet, suggest that those with Asperger's seem to have racing minds too. A lot of them talk about not being able to turn their brain off and this can be especially troublesome when trying to get to sleep.

I've suffered with insomnia for years due to a brain that won't switch off. Over recent months I've found a helpful tool — a CD I play when I turn the lights out that makes you focus on your breath, or another one which invites you to go into every part of your body and relax it. It works and my sleep has been much better.

But occasionally at night, before the CD, my brain races. I get all sorts of weird images, like I'm walking through a hall of mirrors at a fairground or riding a ghost train. Enlarged, gruesome heads sit on top of objects; I see rooms upside down; I see flashing lights and colours and strange people's faces jump out at me through the darkness. It's like a free picture show, or should I say, "freak" picture show, or, like a Dali painting — a mad, mad world which makes no sense.

I can re-live previously unhappy times from my past, over and over and over again, ten times, a hundred times, a thousand times and beg my brain to stop but it won't. My body tenses, my heart races and I feel I'm living a nightmare. No wonder I've dreaded bedtime for years, especially as a kid, and as an adult I learned to use alcohol to dull the senses so I could sleep. But even then, the alcohol would turn against me and cause dreadful nightmares and a mushy brain the next day so I could make even less sense of the world.

So, all that taken into account, it would make sense to try to slow my brain down, wouldn't it?

So I tried meditation and lasted thirty seconds. Wow it was scary! All that silence was deafening. Like I'd entered an alternate universe where nothing was familiar. I don't like unfamiliar so shot out of there pronto, back into my head where I could feel at home again. Won't try that again, I thought.

During the day, when the racing thoughts start, they can turn into an obsession. I often don't realise until it's too late and then I'm on track and can't get off, or at the very least, struggle to get off. This happened last night — I got fearful about something and my thoughts took off like a rocket until I was at the edge of a panic-attack cliff, looking down. Fortunately, I recognised my anxieties rising as a result of my thoughts so knew I needed to take some action to get me off track. A quick talk with a friend and an almighty effort to focus on watering the garden, looking at each plant, talking to myself about that plant and gradually feeling the fearful thoughts ebbing away. Then I focussed on stroking my cat, noticing the tones in her black shiny fur, how it has a chocolate-brown tinge to it, the multitude of greens in her eyes, her soft long belly fur that felt warm and cosy when I kissed it, the tone of her purr, the warmth of her body next to mine, the undeniable sense of unconditional love flowing between us. It all worked to get me off track and resume some sense of normality again. I hope I remember these techniques!

I've now realised that during times of obsessional thinking, my brain is like an almighty firework display. My thoughts can be quick-fired like a rocket, they can go round and round in circles like a Catherine wheel or can be repetitive and boring like those pathetic little green and pink blobs that come to nothing. All this happens simultaneously. I put on quite a show! Once that touch paper is lit, stand back, because I'm off, I'm

fired up, I'm unstoppable. I'm on a mission and I won't stop until I'm done and fall to the ground, spent, burned up.

During the day, for those around me, it's exhausting, they can't keep up. I'm forever lighting another touch paper and I'm all lit up again, firing in all directions. You need to be quick if you're going to keep up and I want you to keep up but you don't seem capable. I've never understood why, until recently when I started to research the difference between those with Asperger's and neurotypicals.

This super-speed firework display can be harnessed for good when I'm working on a project for work, or have to write a project for a college course, or I'm interested in learning something new. I revel in getting stuck into projects, a problem to be solved, some research I need to delve into and make sense of. This is like a game to me and I get all fired up piecing together information to make sense of it all and presenting it in a logical and ordered manner.

I'm an ideas person and can see ideas clearly. It can be a lot of fun but for those watching me, or being near me when I'm in that state, it can be frightening because their neurotypical brain doesn't work at the speed at which mine does, racing from one thought to another, one idea to another, one project to another. I get exasperated with the neurotypicals' inability to keep up. "Bloody incompetents" I hear myself thinking.

So if I can learn to harness my racing mind into a slower, productive, rational thought process, that would be good, right? Sure, sounds great in theory . . . except I don't know how to do that and I'm not sure I want to, even though I can see the benefits. Watch this space.

It takes a long time for good solid friendships to blossom, so rushing at people when you first meet people usually has the opposite effect from what is desired and yearned for: let it take its course, "play it cool."

Eric

Autism all-stars

How we use our autism and Asperger traits to shine in life

edited by Josie Santomauro

ISBN: 978 1 84310 188 8

£12.99 / \$19.95

Jessica Kingsley Publishers

review by the Goth

A book made of chapters, each written by a different, successful autistic person is a tricky thing. On the one hand, it's inspiring to read about how people overcame difficulties and prejudice, and on the other, it's depressing to read about how several of these people have spent tens of thousands on education or therapies in order to achieve what they have — money the vast majority of us can only dream of. Luckily, such people are in the minority in this book, and even some of these were able to give me a tip as to how to deal with a difficult situation I experience. On balance, a book worth reading, especially if you are interested in reading about Temple Grandin, Wendy Lawson, Donna Williams or any of the other autists whom you have heard of.

This book and the one on page 13 are available from all good bookshops and through Amazon's charitable scheme at

www.autism.org.uk/amazon

and if you use this address instead of the usual Amazon one, the NAS gets a donation from Amazon.

Our day to remember

review by **Cara Dovecott**, the Shadow Queen

Skallagrigg by William Horwood, Penguin, 1987

One of my aims as Shadow Queen is to encourage autistic people to participate in national life; our involvement becoming part of the national consciousness. This edition of *AU* precedes Holocaust Memorial Day (HMD), 27 January, 2013: a day on which disabled people need a louder voice. But I'm going to start this article in the here and now. At this time of year various members of the royal family lay wreaths to the war dead, but my focus as Shadow Queen is the living: those who live through war and are left mentally or physically disabled. Here's the irony: while Hitler was shoving disabled people into gas chambers as fast as he could find them, more people were becoming disabled in the fight against Hitler. There are two remembrance events: HMD if you were disabled before war broke out, and Remembrance Sunday if it was war that brought you your disability. So I've disabled my wreath by slicing it in two.

HMD is itself fragmented. It's in January here but in April in Israel. Like all days in Israel, Israeli HMD begins at dusk. As the light of one day dims the new day begins in darkness and it is the darker side of human nature that HMD asks us to remember. One person who is not afraid of such darkness is Esther, the hero of the novel *Skallagrigg*, whose spiritual enlightenment depends on confronting prejudice. She has cerebral palsy (CP). I read *Skallagrigg* at my book group. The group is for autistic people. *Skallagrigg* had a lot to say to us. It reminds us of the journey of the disability rights movement and asks us to make our own stand within the movement. Furthermore it asks disabled readers to make peace with who we are.

The disability rights movement takes inspiration from both world wars. After World War One, society was ill-prepared to include

disabled veterans. Then there was World War Two: a new generation were disabled as they fought the man who was creating a physically perfect master race. World War Two occurs off stage in *Skallagrigg*, where the disabled inmates of a long-stay hospital know only that a war is being fought beyond their walls. The hospital, which is their involuntary home, is little better than a death camp. Ordinary and sometimes well-meaning people had created a hellish environment. In one incident electroconvulsive therapy is given to a man unable to communicate that he has a broken pelvis. He had been injured by a violent nurse; his cries of pain were assumed to be utterances of madness.

For autistic people World War Two is also why the discoveries Hans Asperger made in Austria, and published in German, where not known in the UK until the 1980s. By this time other disabled groups here were establishing the disability rights movement. We owe so much to people like Esther who laid the foundations. Esther is one of the younger characters in *Skallagrigg*. She is inspired by Arthur to confront attitudes which are slow to change. Arthur, born with CP in 1920, need not have been what Hitler called a "useless eater". He had untapped talent because non-disabled people assumed he was incapable. That prejudice was his disability. Now, twenty-six years since *Skallagrigg* was published, disabled people are still struggling to be valued. Today we have the genetics of Hitler's dreams. The world doesn't know it needs autism: the light of progress casts a long shadow.

By the 1980s, hospitals like the one Arthur lived in were being phased out. Esther celebrates one such demolition. Care for disabled people was handed back to their families: troubled families. Esther's father locked in grief for his wife, killed in a car crash while pregnant, is

unable to bond with baby Esther. In turn Esther becomes a mother. We see her fear that her son will also be disabled, her frustration when she cannot hold him, her joy and despair as he learns to do what she cannot. In each generation love is slow to take root.

Throughout her life Esther needs people to wash, dress and feed her. She is dependent on the society that does not include her, so there is no escaping prejudice in a promised land for the children of a lesser god. Interwoven into Esther's relationships, both with disabled and non-disabled people, is her spirituality. It's part struggle to survive, part fight for justice, part journey to emotional wholeness. It centres on stories about Arthur and someone called the Skallagrigg. The stories have been passed down through generations of people with CP who have formed their own culture, history and identity. This spirituality needs its own language because it expresses what it is to be the one who is less fortunate and be done to, but it also overlaps with the spirituality of wider society.

Autism mirrors CP. People with CP find it physically hard to speak and are assumed to be stupid. Autistic people have trouble knowing what to say but look normal. Yet we share the experience of struggling to communicate and being misunderstood. Autistic people have our own "voice" to raise, our own way of drawing people into our experience. Please send your ideas for autistic participation in HMD to aspergerunited@nas.org.uk January's edition of *AU* should reach you before HMD and will include readers' suggestions. We can take inspiration from Esther. Scope, the organisation which supports people with CP currently uses the slogan, "time to get equal". I smile each time I see it, but I suspect Esther would have insisted that non-disabled people had some way to go to equal her. Few had the courage to complete the computer game she based on her journey to find Arthur. It meant facing one's own weaknesses.

Like Esther's game, *Skallagrigg* is a book that could only have been written by experiencing

disability. At book group we discussed how the author having a daughter with CP influenced the book. The experience of prejudice rang true. We saw that the old brutality was still with us in scandals about care for the elderly. The master race excluded many people. But disability is different. It is the door to the gas chambers that opens to everyone. We all grow old and become disabled. I'm shadowing a woman in her eighties, she stands by the cenotaph unafraid. These are the words the Queen's father used in the first Christmas speech of World War Two: "I said to the man who stood at the gate of the year, 'Give me a light that I may tread safely into the unknown.' And he replied, 'Go out into the darkness, and put your hand into the Hand of God. That shall be better than light, and safer than a known way.'"

— I tried not to have Asperger's
But it didn't work out
Even though I cried
And had a pout

— I told everyone I knew
I was not too pleased
Because before
I used to get teased

— I wrote down my thoughts
That was all I could do
What I'm feeling
Shown to you

— It has gone some way
To improving my life
And reducing my intake
Of pain and strife!

Thomas

Group notices

Dear *Asperger United* readers,

My name is Anna Lansley and I have Asperger's syndrome. I work for a charity called Impact Initiatives as a facilitator for a new AS self-advocacy group in the Chichester, Bognor, Littlehampton and Worthing area of West Sussex. The group meets once a month and will be run by and for people with AS. People with AS will be supported to speak up for their rights, develop links with the West Sussex Autism Planning Group, autism professionals and local services, develop friendship, mutual support networks and workplace skills. The time, place and day of the monthly meetings will vary in order to make the group as accessible as possible for all members. For the date, time and place of the next meeting, or if you have any questions, please email:

anna.lansley@impact-initiatives.org.uk

or phone 07554 333 183 or write to:

Anna Lansley
Dove Lodge
49 Beach Road
Littlehampton
West Sussex
BN17 5JG

I look forward to hearing from you.

Hi and how do you do *Asperger United* readers?

I am a member of **Tameside Autism Group** that's been around for a number of years, initially starting as only two or three members taking part in the social club drop-in at:

Union Street Learn Centre
Union Street
Hyde
Cheshire
SK14 1NF

Today we have around ten members that attend and countless people clicking on the member video track and checking our new website:

www.tameside-autism.org.uk

and for those people surfing via a mobile phone:

www.tameside-autism.mobi

At present what is provided is somewhat basic. Because there is only a social club drop-in that's held on the first Thursday of the month from 3pm to 5pm. At this event there are sometimes free refreshments and activity games (cards, chess, draughts, etc.). Though some of the members do sit around and talk.

I look after the website, the video channel on YouTube and the audio channel on Podbean. Plus I try and provide some advertising with inclusions on various local websites and send posters to nearby hospitals and volunteer health groups and deliver cards provided in waiting rooms at hospital Mental Health units.

A few members have said it'd be great if we could have some grant support or funding: this would help with providing a greater range of activities on a free basis and in the long term provide free refreshments. *Though* at the moment there is no committee and thus *no funds*.

If any one has ideas on how this group could be moved on and make some constructive progress, please do reach me:

gary-website-tech@tameside-autism.org.uk

0800 988 7367 (free to call from landlines)

Thankyou!

Gary

Tameside Autism Group member and
technical website-support volunteer

The rules of Asperger United

(contact information for AU is on page 2 and again on page 20)

- 1) *Asperger United* is funded by the NAS and readers' donations, and is independent of the NAS. Although it is called "*Asperger United*" it aims to cover the whole of the (reading) autism spectrum. That is, the concerns and joys of any subscriber on the spectrum can be printed, not just Asperger's.
- 2) Pieces that appear in *Asperger United* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
- 3) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.
- 4) *Asperger United* does not use your contact details for anything other than administering *AU*. Your details are not passed on to NAS Marketing, NAS Fundraising or any other organisation without your written permission.
- 5) If you move house, please inform *Asperger United* and include your old address as well as your new address.
- 6) Even if you've paid for the Royal Mail forwarding service (or another forwarding service if you live outside Great Britain and Northern Ireland), you still need to inform *Asperger United* that you have moved address.
- 7) If you want to unsubscribe, inform *Asperger United* and include your address.
- 8) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address.
- 9) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as sometimes the line isn't very clear. Please give any phone number you leave twice for the same reason. Remember to give your postal address so that we can find you in our records.
- 10) The current edition of *AU* is available at www.autism.org.uk/aspergerunited
You need to scroll down to near the bottom of the page, where there is a link to the PDF.
- 11) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 12) Book reviews are the most popular thing in *Asperger United*, please consider submitting one. They can be about any book, not just books about autism. Also, they do not have to be short (the Goth keeps most of his reviews short to leave more space for other writers). If you do not want your review to appear in the NAS section of the Amazon website, please make this clear.
- 13) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.



With love from 3am

by Rufus

Three hours until daylight. And it feels good to know that, and to write it. There's an end to this feeling, to the darkness outside the window and the watchful reflection of me upon it, and to being stuck in a glowing ambient bubble of my inner world.

I'm listening to Olive. This is familiar. It's good actually. It's somewhere between the abstract ambient that leaves me to fixate on something else, and intensities of most other genres, and stimulates the more basic pleasant melodic paths in my brain that keep me going.

I can sing or hum along with my simple harmonies. There are musical highlights I can look forward to.

Inside I'm not so good. I guess that's the real problem. I have a feeling that staying up at these times and worrying about how long yet to be up wreaks havoc on the blood pressure, and that this state I'm experiencing is not what life is like for most people, nor have I felt it much the last two months or so. But it's back, it's hauntingly familiar, and I worry that I'll just have to ride it out.

I got up at about 2pm today. Strangely, I managed to get up without the usual self-loathing that accompanies such a late awakening. I spent a short but pleasant burst of time talking to Adrek in the kitchen, and proceeded to cut my hair. First thing on the to-do list done.

Now it feels like when I've eaten too many Jaffa Cakes. A dread of the uncontrollable future (more Jaffa Cakes to shun), and an inability to work out what to do next, with a lingering sense that nothing I do will be fulfilling, that nothing I eat can be refreshing or enjoyable. Especially not the Jaffa Cake, with its moreish blend of orange, subtle chocolate, and soft soft cake.

This is the down in the bipolar journey of oversleeping. And later, maybe about 6am, comes the intense up, where my brain dances through the fog as my body prances to simple melodies with wonderful solar radiance. Or maybe the whole process is one and the same, but for the sunlight and stimulation of the outside world causing the two phases.

Either way, 3am sucks.

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