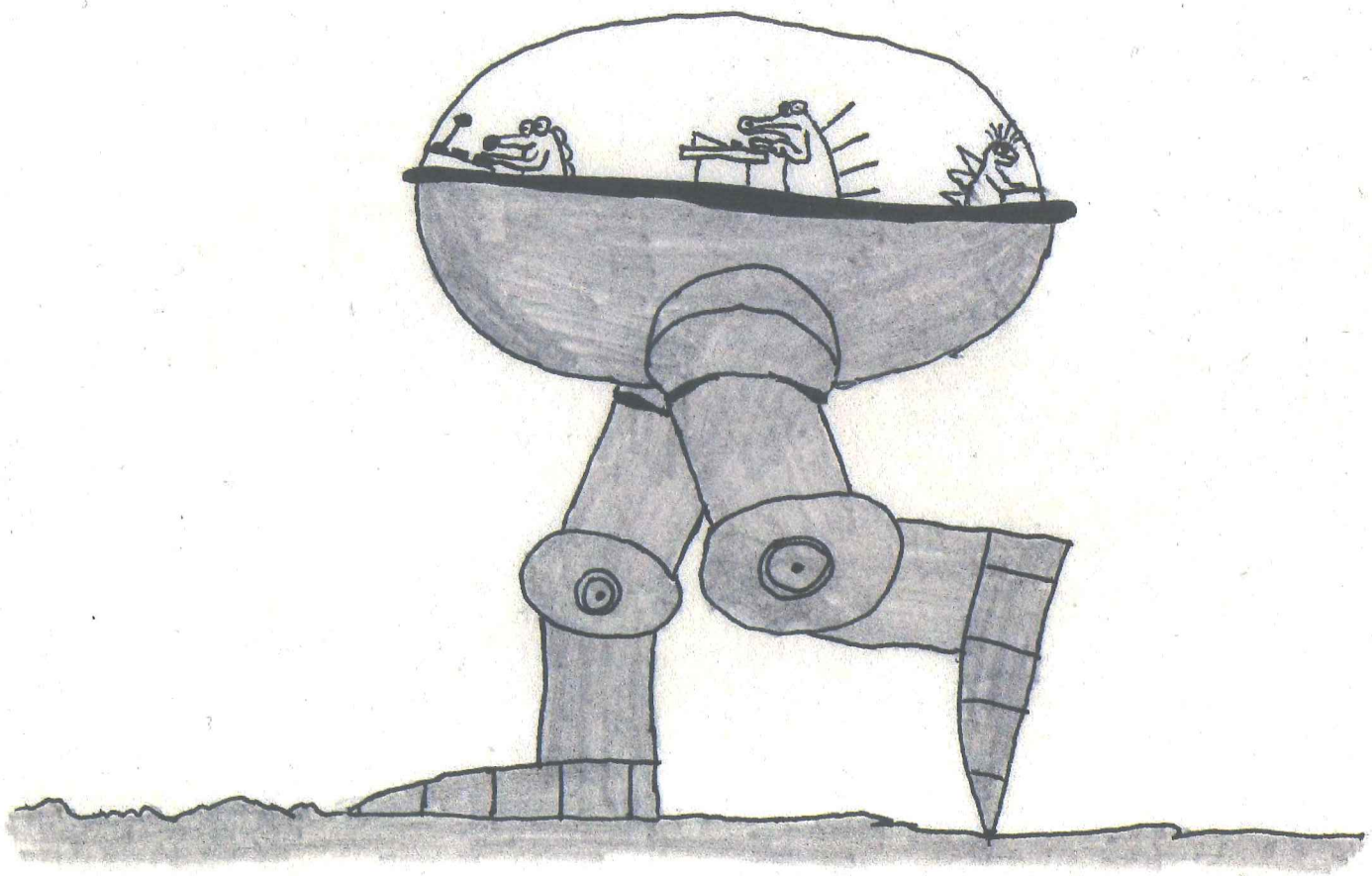
Produced by and for people who have autism-spectrum conditions

Asperger *United*

Edition **79** July 2014



AU

The National Autistic Society

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 who have 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 £9 per year from overseas readers and £15 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

National Autistic Society production support: the Publications Team

NAS phone support: the Supporter Care Team

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 Kaczynski, formerly Cohen.

Please send all correspondence and subscription requests to:

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

Tel: **0808 800 1050** (free from most landlines) or
Tel: **020 7923 5779** (geographical charges apply)
Fax: 020 7833 9666

Email: **asp.utd@nas.org.uk**

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

Thank you to 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 address above.

Contributions for the next issue should reach *AU* by **11 August 2014**

Welcome to the July edition of *Asperger United.*

I am quite surprised that in six months I've only received four submissions about fandoms, so maybe we're not such a bunch of geeks after all. I will publish some of them where they fit in with other topics in future issues. Would anyone care to comment on why there has been so little interest?

One subject I have not been short of submissions for is Edward's article, *Beware the Aspie snob*, which has received so much attention, both originally and since the first responses where published last time, that I have published more this edition, picking out some of those contributions which discuss the use of "Aspie" as a label, to tie in with the theme.

I will look forward to seeing some of you at the Autscape conference in August, which I find one of the most relaxing times of my year.

And I will, of course, look forward to all your contributions for the October edition,

the Editor

the labels edition — the next issue notice is on page 9

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Layout of poems by ST Maddison . . back cover
another layout by ST Maddison is on page 15;
both pieces © ST Maddison 2013

Labels

by Victoria

I recently filled in a survey for the National Autistic Society about the language they use to describe autism. Until I filled it in, I hadn't quite realised what a minefield the issue can be.

There are some labels that I dislike intensely. ASD, or autistic spectrum disorders, is the first. I seriously object to the implication that I am disordered, that there is something wrong with me that needs fixing. A disorder suggests that there is something disordered, or messed up, within the individual. This implies that a "cure" needs to be found, that it isn't okay to be autistic and that we all need to strive to be normal.

Other labels I find horrendous. "Autistics" is one. To me, that indicates seeing nothing other than the disability. The disability becomes more than the individual person themselves. I'm not always sure about the term "Aspie" either, although I use it to describe myself.

Next comes the ongoing debate about whether we should put the label before or after the individual. Entire books have been written about such issues. Are we autistic people, or people with autism? We certainly shouldn't be defined by a label, "autistic people" certainly has a disabling, excluding ring to it. But can a condition such as autism ever be detached from the person? Is it an "add-on"? I am a person with a grey rucksack and with long hair. My Asperger's is, however, so much a part of me and creates my way of viewing the world that it is not a separate entity, not something that can be pushed aside or into a prepositional phrase.

Some people try to avoid using the terms "autism" or "Asperger's" at all. I'm not sure this makes things any better. Being "on the spectrum" is another pet peeve. My aspergic logic (Aspergic! There we go, yet another label!) dislikes this term for a number of reasons. First of all, "on the spectrum". Which spectrum? Is there only one? The electromagnetic spectrum? The visible light spectrum? The political spectrum? Secondly, it just doesn't make linguistic sense. A spectrum can continue infinitely, having no beginning or end. Therefore, every person must be on this spectrum, meaning that to say some people are "on the spectrum" is as illogical as it is irritating.

Even the idea of a spectrum can be contentious! I have Asperger's. I live independently, am employed full-time and believe I have (mostly) exactly the same opportunities and options as any other person. I am closer to "neurotypical" than I am to somebody with severe autism and related learning difficulties. Should we even share the same label? There are people who need lifelong support and cannot function independently in society. In a culture and society more understanding and tolerant of difference, I don't believe many of my differences would even register as "difficulties" in the first place.

Then there is the whole issue of current fashion and trends. Politically correct language comes and goes. It is highly probable that whichever label is deemed "correct" will soon become "incorrect", as it takes longer to change attitudes and opinions than it does to change the words we use. If people have a negative attitude towards individuals with autism (I don't even know which label to use myself now!), then any words used to describe this group will carry negative connotations. It is more important to change hearts and minds, rather than expend so much energy debating semantics. How we say things can convey much more information than what we say; we have all met those who use perfectly correct terminology in such a tone of voice as to imply that we are different, abnormal or just unimportant.

I find that I even manage to argue with myself over this whole issue. It can't be denied

that language plays a huge role in creating our thoughts and opinions. Words are powerful things. We need to get them right. Yet, on the other hand, my aspergic nature means I like to call a spade a spade, not a hand-held digging instrument. Does it actually matter if we say that somebody has autism or Asperger's? Is it not only a word, after all? A word that states a fact.

Yet words can, and do, offend. Whenever somebody tells me I have a "disorder" I am deeply offended. I am even more offended when people ask why does it matter, if I have Asperger's, then I have Asperger's, whatever I call it, why don't I just embrace my individuality and stop splitting hairs over labels? I realise that that person has no idea what it is like to grow up not fitting in, to grow up not connecting with other people, being told that you are not meeting society's expectations. I wouldn't want any person to grow up thinking they are disordered, disabled, or in any way inferior, because of their autism or Asperger's. Embracing your individuality is one thing, embracing your individuality and being led to believe that you are not good enough, is almost impossible.

But having said that, I'm not suggesting that we don't need any labels at all. In fact, labels can be more useful than we may imagine. For me, receiving my "label" of Asperger's was life-changing, in the most positive way imaginable. Being told that I was "officially" different, made me feel, for the very first time in my entire life, very normal indeed! It was only through being given this label that I stopped feeling totally alone and removed from the world and could begin to build the self-identity that I had sought so desperately for almost thirty years. I wish that I had been "labelled" fifteen years early. Being given specialist input as a teenager would have certainly enabled me to enjoy my teenage years, time at university and early twenties, most of which passed in a haze of loneliness, depression and confusion about the world.

So labels have their uses. An accurate label can ensure the most appropriate educational, health and social resources and support is put in place, thus resulting in (ideally) improved outcomes for the individuals in question. A shared terminology also ensures professionals and individuals are talking on the same wavelength. Sharing a label can be inclusive and liberating.

I still haven't come to a conclusion on the matter. I shall avoid the labels I dislike, use the labels I like, and continue to give my opinion should anybody ask (and sometimes I shall give it even when they don't ask).

Labels matter, and yet they don't matter. Have no labels on your cleaning fluid and water bottles and the results may be fatal. However, if you know which is which and mix them with the right things, then you'll get the most out of each one, regardless of the word, symbol or sign you use to describe each one.

Dear *AU*,

I am a transgender Aspie and I am really keen to get LGBT Aspies more support and social opportunities.

I am wanting to set up an LGBT ASD group.

I have started looking into this but I need a number of people to be interested in order to get funding.

I was wondering if any *AU* readers feel they would benefit from such a group.

If so, please get in touch!

If anyone wants to help or has any ideas, please do let me know. It'd be greatly appreciated.

Thank you for your time.

I'll look forward to hearing from you.

(I can be contacted through *AU*.)

Alex

You have rights at work

by **Caroline**

For many years the trade union movement has been fighting for disabled workers and our carers to have rights at work: giving disabled people a voice at conferences, campaigning for legal protection against discrimination, and offering those facing discrimination at work legal support. Even if a disabled person is out of work they can join a union as a community member.

All trade unions work through the Trades Union Congress. The TUC has just (I'm writing this in April) e-published a handbook about autism at work, by Janine Booth. It is on the TUC website.

The union movement is well aware that autistic workers need a voice and the best thing about trade unions is that they are experts on empowering people who aren't getting a fair deal. Janine is an example. She knows from first hand experience what it means to be autistic in the workplace, and have both caring, and management responsibilities (Janine is a parent and a station supervisor). With a background in the union movement, Janine was able to respond to her autism diagnosis as someone empowered to stand up for herself in the workplace, and enable others to stand up, too.

Janine has also written a training course on autism in the workplace. The course covers issues such as using the social model of disability to make workplaces inclusive of autistic workers: instead of seeing autistic people as defective and needing to change to fit their work environment. There are studies of cases where unions have won compensation for autistic people who have been bullied at work, which were discussed by a guest speaker from a firm of solicitors.

Even better, this course is free! Janine is a member of the RMT Union, which represents tube workers: and if you need one more reason to honour the recent (I'm still writing this in April) passing of Bob Crow, who led the RMT, here it is: he agreed that the RMT would sponsor the course. So you can get your union representative trained to support you, or be trained yourself, for nothing. To book, email **j.booth@rmt.org.uk**

If there are several people from your union who would like to be trained you can invite Janine to speak at your workplace, or book her to deliver the whole two-day course (Janine charges to put on the course at your venue).

In the film *A fish called Wanda* the character Otto makes the mistake of thinking that the London Undergrounds is a political movement. Having met Janine, I'm beginning to have sympathy with his viewpoint. Every time I use my Freedom Pass to travel I remember that autistic workers have brothers and sisters in our unions who stand with us.

NHS SOS

How the NAS was betrayed — and how we can save it

edited by **Jacky Davis** and **Raymond Tallis**

ISBN: 978 1 78074 328 8

£8.99

Oneworld Publications

review by **Annette**

About how current government have passed into law an unprecedented assault on the NHS.

Using facts, references the doctors as authors/contributors, explains the betrayal of the NHS by government. This book also reacts by telling the reader how the NHS can still be saved. It's not too late. The fight to reclaim our NHS will continue as long as there are people who care fro it and what it stands for.

Pen pals

Pen pal number 174

My name is James. I live in Bedfordshire and I am 33. I was diagnosed with Asperger's when I was 26. I'm lucky to have a very creative mind and I love writing short atmospheric stories, making my own websites and films.

I love music with meaningful lyrics and melodies and I like playing my guitar (both electric and acoustic).

I like places like Butlins and Haven, because I love people of all different ages and backgrounds coming together to have a good time, and I love making films of the performances. I also like visiting the North-East of England (where I'm from originally).

I have friends of all ages (I enjoy that wide accessibility) so I would like a pen friend aged 18 upwards. I look forward to hearing from you.

Pen pal number 175

Hi, my name is David, I am 37, live in Northampton and have Asperger's syndrome. I find socialising and making friends very difficult, and would like a pen pal, as I don't know anyone with AS and feel very isolated at times.

I enjoy listening to music particularly Indie, Rock and Heavy Metal, although I do enjoy most styles.

I also enjoy movies, novels and graphic novels, video games, art galleries, West Ham United, walking and my "guilty" pleasure is watching pro wrestling. I would like to hear from anyone with similar interests. Thank you.

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 176

My name is Gareth, I am an Aspie, am 29 years old and live in Suffolk with my dearly beloved parents. I have a lovely sister 2½ years my senior. I have acquaintances but no friends, thus sometimes feeling fragile. I do not have a girlfriend — I often struggle to find the right one. Personally, I do not really like Facebook or rival networks. I lack employment and often ponder what to do about it.

I am doing a "Foundation Degree (FdA) in Travel and Tourism Management". I enrolled in 2011 and have struggled on the course. Fortunately, the college has a very thoughtful amenity for autistic students — the Rugroom — which means a lot to me. Some Rugroom staff members are exceptionally kind, and many of its students are very interesting.

I have a long-term passion for travelling. My favourite counties are Hampshire and Dorset. My favourite overseas country is definitely France. There are many other places I like to visit, such as the rural stretches of Essex; the great lakes of Sweden; Atlanta, Georgia, and Chicago, Illinois, USA. I am waiting to make my debut in places like Denmark and China.

I follow current affairs with the broadsheets. I am obsessed with politics and economics. I love my fiction and creative arts, such as *The Forsyte saga* (John Galsworthy) and *The stranger's child* (Alan Hollinghurst). I love pets — I tend to relate very well to dogs and cats. I like horses, but they seldom have time for affection. I have two brown-and-white mice named Silky and Acorn, of which I think the world! Their "dear little fur coats" are just so uplifting!

I would be delighted to hear anything from anybody. You can use whatever language you feel comfortable with.

Eighteen pen-pal adverts have been held over for publication in the next four issues, Editor.

Pen pal number 177

My name is Thomas. I am 33. I was diagnosed with Asperger's disorder and since the diagnosis my life has improved.

My hobbies include volunteering at a nature reserve, photography and eating out with friends.

I'm thoughtful and caring and make a genuine friend.

I hope to hear from you soon.

Pen pal number 178

Hello, my name is Harry and I am 13 years old. I live in North Yorkshire and I love walking and being out in the countryside.

I have a diagnosis of Asperger syndrome and I would like to hear from anyone of around my age.

Pen pal number 179

Hello, my name is Eddie, I was diagnosed with Asperger's syndrome last year. I am 30.

I am very interested in aircraft especially WW2 planes like the Spitfire and Mustang. I go to various airshows around the country. My local airshow is Southport. I am also interested in total solar eclipses and have several books about them. My intention is to go to the 2017 total solar eclipse in America. I am also interested in classic cars and am a member of the Vauxhall Chevette owners group.

I would like to meet people with similar interests or who would like to learn about them.

Pen pal number 180

In the letter on page 9 Anne asks for pen pals, so please consider writing to her, Editor.

To the Editor.

I have recently subscribed to the newsletter as I found an old copy from 2005 in a drawer and I started reading it. I'm Anne from North Wales and I'm 33. I am totally independant but I do have a social worker, but sadly he's of little help due to the very poor level of service available for adults with Asperger's in my area. I have lived on my own since I was 18 as living with my mum and brother was a nightmare. I rarely see them or speak to them and I get very depressed and lonely. I would very much appreciate it if you would publish my experiences. I'm also looking for a pen friend or email friend.

I was badly bullied in school, college and in the workplace which has made my life a real misery. I tried to learn to drive when I was 18 but I wasnt progressing and cannot multitask, but I did pass my theory test first time in 98, but it's a lot harder now. I dont drive or work due to my Asperger's always getting in the way. I have very few real friends and depend on taking antidepressants which do help a bit. I love socialising but this often ends up with me getting into a fight or heated argument with ignorant people. I have been arrested on a few occassions which was very traumatic. I can remember the exact day and time it happened like it was yesterday.

I worked in a meat factory for nine years on Sundays only but due to bullying in the workplace (as I didn't fit in) I resigned in 2006 due to being suicidal. I have not worked since but have tried very hard to get voluntary work. This has also failed due to communication problems and lots of misunderstandings. I'm a hard worker and would love to work part-time but I would lose all my benefits and I dont mix well with certain types of people who can be very cruel and laugh at me. I also have bad IBS at times. I also have OCD. I have had many obsessions all my life including balloons, fish tanks, walking sticks, gas cookers, hi-fis, photocopiers, musical instruments, guinea pigs, sewing machines, sunbeds, MRI scanners, saxophones, aeroplanes and snake skin! Sorry if this is too long but I would really appreciate it if you can take the time to read it.

At the moment I have fifteen pet snakes which are nonvenomous. They're very gentle and friendly as I handle them every day. I also have three hairless guinea pigs which I used to breed. I can read music but I'm not professional. I play the baritone horn in a brass band. I started learning to play when I was 25 after watching the film *Brassed off*. I also attend a two-hour maths class once per week in term time as I only got a D in my GCSE. I find it easy to make new friends but when things become too intense or I say something they don't like they disappear and no longer want to be my friend, which really hurts me. I hope other people who read this will understand how I feel. I'm very down to earth and easy to talk to but people always judge me. I currently get no help whatsoever from anyone because of where I live. I spend all afternoon in the library on the Internet on Tuesday afternoons and some days I dont go out of my flat for two or three days for fear of getting into a confrontation with someone, as I have been threatened by people in the street. I don't know who these people are but they obviously know me. I have spoken to the police about it a number of times but as I dont have the names or addresses of these idiots they can't help me. I feel so alone and vulnerable. It would be great if you could publish my letter in *AU*. Many thanks for taking the time to read this.

Kind regards,

Anne

If sufficient material is sent in, the theme for October will be **relationships**. That's all relationships, not just personal ones. But as ever, if lots of contributions on another subject are sent in, then that will be the theme. 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!

Sexuality? Well I've known about my sexuality since I was 15 or 16, but it's been hard and confusing. I wonder at times if I am bisexual because of the abuse I suffered when I was a child. I find it hard being autistic and an Aspy coping with my sexuality, I find it very hard to trust men, I am a very tactile person myself but I am very edgy and nervous when I'm touched by others.

But I don't think that sexuality can be linked to Asperger's. Although at times I do feel lonely and isolated, it is hard to make friends or partners, because of the insecurities with trust. It can be a catch-22 situation, but I fully embrace my diagnosis and try not to let it hinder my chances; I live for today.

Being autistic I feel I don't really emotionally connect with issues and this helps when it comes to my constant questioning of my sexuality. I don't' really think anything more than "I am what I am: if you don't like me for me, then you know where the door is." There are a lot of judgments about us Asperger's sufferers, and instead of buckling under the pressure, we should all come as one and join together in this fight for the judgments.

Well, my Aspy brothers and sisters,

take care,

keep strong,

Elvis

Dear Goth,

I'm not sure if this would be considered to state the obvious but I have prosopagnosia, also called faceblindness, and below are some things I have learnt to do to help me.

1 I find memorising shoes helpful (people get new shoes but with some of the other things below it can be helpful)

2 Clothing style —

for men: do they wear suits? If so, how tight. Do they wear ironed shirts? do they wear a tie? Do they wear a ring?

for women: as above, do they wear dresses or skirts and do they wear earrings or other jewellery?

I use style as opposed to individual garments.

3 Voice recognition is unimpaired for me, so when I meet someone and Im unsure who they are I just need to get them talking for long enough to go through voices I know. They can give me clues in what they say if I ask questions such as

— so when did I see you last? or

— what have you been up to recently? or

— what have you been working on?

My experience is the questions above do not seem unusual or have any negatives attached to them, so asking them doesn't make you look rude.

There is also nothing wrong with telling people, explaining that you don't recognise faces (unless you don't want to disclose this).

Sometimes if I'm arranging a meeting I will ask the person when I e-mail them, text them, or call them on the day, what they are wearing? Or, if in advance, could they wear something distinctive?

I understand these strategies may not be helpful to everyone and may seem obvious. I'm just sharing what I have found useful in the hope it helps others, surely that isn't a bad thing?

Robyn

Horizon: Living with autism

by **Cos Michael**

"People's brains are different and that's how the world is." Psychologist Uta Frith has been working with autistic children and adults for fifty years and, in this programme, introduces viewers to a broadly balanced view of what autism actually is.

From the complex problems faced by Joe Allison to the highly articulate Sarah Hendrickx, the impact of autistic traits on different lives and personalities is well illustrated. Individuals are depicted in a positive manner and the programme steers clear of the recent documentary trends towards voyeurism and disparagement, and actually seeks to inform.

The strength of the programme is in the range of personalities featured. Its main weakness is that although women and girls are included in the programme, the particular problems faced by women on the spectrum both getting diagnosed and having their traits recognised, is overlooked. There is also a lack of discussion around the possible effects of sensory issues on stress levels.

The contested belief that people with autism lack empathy is challenged by the evidence: autistic people are filmed in both caring relationships and being creative within a group. Watching autistic drama student Jules improvising with his fellow students is an excellent example of how well one autistic person can interact. Having so successfully hidden his difficulties, Jules describes the problems he has engaging with others out of class.

Frith talks about the difficulties autistic people have in navigating the world and asks whether there might be an extra "social" sense, which she calls "mentalising", which autistic people lack. This seems to be an inability to see things from other viewpoints, which affects their ability to adapt and be flexible in social situations. I wonder how this accounts for the difficulty many people with autism have with small talk, or their frequent literalness? Mentalising is certainly an interesting concept and worth exploring.

The controversial point was the discussion with Simon Baron Cohen about whether all people with autistic traits need a diagnosis. He believes that it is up to clinicians to judge whether a diagnosis ought to be given or withheld, based on their assessment of how autistic traits affect the "everyday functioning". of the individual. This seems to be a contradictory argument: if a person is having sufficient difficulties that they are seeking a clinical diagnosis, it clearly is affecting their life. Unless the clinician is dismissive of the patient's perspective, there is no case to consider.

However, the bigger question in what he says, which really requires a follow up, is whether it is ethical for a diagnostician to withhold a diagnosis from a patient who is seeking one?

Dear Goth,

I felt I had to comment on Simon Baron-Cohen's point in the *Horizon* documentary: he says that if someone is coping with life then they shouldn't receive a diagnosis of ASD. Logically, then, if someone with a broken leg has made their own crutch and adapted their life to cope, then they should not receive treatment. In other words, we need to move on from highly subjective diagnostic criteria, not have a senior expert in the field promoting the status quo,

yours,

Jay

The nuances of empathy

by **Damian E M Milton**

Baron-Cohen (2011) suggests that empathy can be defined by: ". . . our ability to identify what someone else is thinking or feeling, and to respond to their thoughts and feelings with an appropriate emotion."

The influential study by Attwood (1988), said abnormalities in modulating one's voice, a lack of facial expression, poverty in bodily gestures, and "an often curious impression of woodenness", characterised the autistic difference. This difference was seen as stemming from an inability to appreciate the expressive gestures of others, rather than a difficulty (for whatever reason) in the performance of those gestures (such as how performances might become compromised by sensory overload and stress): ". . . no autistic adolescent ever used expressive gestures."

Much research regarding the recognition of emotions in others, including that of Attwood (1988) and Baron-Cohen (2011), is based on the idea that basic emotions are a universally expressed and understood phenomenon across cultures. However, in recent years this notion has come under more scrutiny, particularly from Barrett (2012). She suggests that how one interprets emotional expressions is far more socially conditioned and situated, than had been recognised. The false-belief tasks utilised by Baron-Cohen and followers has also been widely criticised, most recently by Peterson (2013) who compared the awareness of other minds demonstrated in a competitive game scenario to that of the Sally-Anne test. They found that only 13% of their autistic participants passed the latter test, whilst 74% of the same participants passed the former: "This finding demonstrates that many children with autism who fail motivationally barren standard false-belief tests can spontaneously use theory of mind to track their social partners' beliefs in the context of a competitive game."

In her blog, autistic writer Rachel Cohen-Rottenburg (2012) suggests that autistics lacking empathy is a myth. She suggests that much of what is considered a lack of empathy is based on the performance of expressed empathy, with non-normative expressions being deemed as a deficit in the individual. She suggests that she is rather more sensitive and reflexive regarding her own expressions toward others: "I am sensitive to the fact that a response that might work for one person might not work for another."

She struggles with the reading of non-verbal cues, yet not when with other autistics, nor with people she had got to know over a period of time, suggesting an intuitive understanding of the communication preferences of people of similar disposition. Similarly, Smukler (2005) pointed out that failures in social communication between autistic and non-autistic people are seen as located within the autistic person, rather than in an interactive breakdown between the two parties, which would be assumed in relationships non-autistic people have with one another.

Cameron (2012) uses the term "dyspathy" to highlight how empathy is often blocked or resisted. She suggests that when looking at social interaction, one also has to take into account "dyspathic" instances, which inhibit emotional connections. Cameron cites a number of studies that have demonstrated bias towards in-group members in "automatic" empathy. Such findings support the theories of Billig (1985) and Tajfel (1981), in which people felt increasing connection to those deemed within their social "in-group", whilst stereotyping "outsiders": "If we were to be continually tuning in to other people's emotions, we would be perpetually anxious or exhilarated, and quickly exhausted. We must therefore have very efficient inhibitory mechanisms that screen out most of the emotional empathy being carried out by our brains, without us even noticing." (Cameron, 2012)

Whilst working on this article I happened upon a post on the Internet regarding "interview tips" and how to "master non-verbal communication" (Turner, 2013). Among the suggestions were to: not over-think questions posed, not become distracted, demonstrate confidence, have excellent body posture, keep eye contact and a calm demeanour, avoid fidgeting, and at the same time as all of this, pay attention to the non-verbal signals of the interviewer: "These nervous movements and fidgets may be a sign of anything from uncertainty in your qualifications to lying about something."

If this is how such expressions and bodily gestures can be interpreted by NTs, then can the lack of empathy really be located in the autistic mind alone? I seriously doubt it, which is why I have previously proposed that there is a "double empathy problem" (Milton, 2012) between the two parties, that both parties struggle to interpret the expressions of people with divergent dispositions from their own: "I think they are just as bad at reading us as we are at reading them: it's just that because they're the majority, their failure to understand us is not as disabling as our failure to understand them." (Lindsay, 2012)

Please contact AU *if you would like the list of references for this article, Editor.*

Turning Japanese

by **Cathy Yardley**

ISBN: 978 0 31237 880 6

£11.79 / $19.99

Thomas Dunne Books

review by **Natalie**

I bought this book on holiday in Florida but you can get it in Britain. If you're, like me, a big fan of anything to do with manga or anime, then you won't be disappointed. It follows Lisa Falloya on her journey from winning an internship at the San Diego comic com to work for a manga publishing company for one year in Tokyo.

Although it's a dream come true, to become an established artist, it will also mean trying to face a new country, a new job and, of course, new people.

I did feel really sorry for the main character, Lisa, who while in Tokyo stayed with a family where their son, Ichiro, plays video games very loudly in the might and their daughter, Yukari, goes out partying.

If you know the world of Japanese pop culture, and so on, you may recognise some of the words in this book. This is not a graphic novel, but it is fiction. Definitely a great read from start to finish.

This book and the one on page 6 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.

Aspie — and proud!

by **Neil**

When I read Edward's article, *Beware the Asperger snob*, I choked on my coffee and had to check my calendar to make sure it wasn't April the first! Then I thought this must be an attempt at irony (something we Aspies don't do very well). Finally — and with sadness — I realised he was serious.

As with all disabilities/conditions/differences, there are three ways of handling AS. The first is denial: "I can't have this terrible condition because I'm nothing like [insert stereotype here, eg., Dustin Hoffman as Rain Man]. For many people who had hoped that with diagnosis would come a sure for their "difference", the realisation that this is how they will be for the rest of their lives is devastating.

Denial also often comes from families and partners who feel guilty that they are somehow to blame for "making" the person an Aspie. Early researchers used the term "refrigerator mothers" to describe the lack of "warmheartedness" they saw in the parents of children on the spectrum, not appreciating that as a genetic disorder parents would display similar behaviour.

The second group tend to feel deep resentment at the way they have been treated by life for the difficulties they have experienced throughout their lives which they now realise were caused by AS. They can see nothing positive in having AS and many will search for environmental or medical factors to blame for their behaviours (after all, where there's blame there's a claim!) rather than accepting AS as an explanation rather than an excuse. They revel in a sense of being hard-done-by and unfulfilled entitlement.

Parents of children with AS who fit into this category tend to be seekers after what they perceive to be the holy grail: a cure for autism. All too often, however, these "cures" cause considerable harm and/or distress to their offspring.

The third group are those who accept their diagnosis with gratitude because finally they have an explanation for problems they have experienced throughout their lives. They are proactive, learning as much as they can about both AS and its effect upon them in order to make the most of their strengths and mitigate the effect of their weaknesses.

Frequently, members of this group will become advocates for other Aspies, using their own experiences to emphasise and provide possible explanation for strange behaviours and give hope to them and their families for a positive outcome. Perhaps most importantly, they also often take the very courageous stop of "putting their heads above the parapet" by providing information and feedback to NTs about our condition, how it affects us, the difficulties we encounter in our interactions with them, and how they can help us to do things better.

Like Edward, I have been profoundly affected by AS, starting with problems at school and culminating in being on the wrong side of the criminal justice system. I grieve deeply for what might have been and for the damaging effect my actions had on family, friends and others. I received my first (of three) formal diagnoses of AS when I was in my mid forties.

As Aspies, our brains are "wired" differently to those of NTs, and clearly we do think differently to them. It's not being patronising or boastful to state this: it's fact. Sure, the media have a fascination with Aspies — Susan Boyle's recent disclosure of her diagnosis is an example of this. However, it can also help us: without the Daily Mail's campaign, Gary McKinnon would no doubt be in an American prison by now.

I have experienced first-hand the unreasonable and obdurate denial by forensic

psychologists who — lacking any specialist training, let alone expertise or experience in working with people with AS — refuse to accept I have AS, despite two of the secure diagnoses being provided by leading authorities in the field. Instead, I have been labelled as having schizoid, antisocial, narcissistic and obsessive-compulsive personality disorders, despite the fact that the identified traits collectively add up to AS!

In his report, the psychiatrist stated that mine was "not a classic case" of AS despite admitting he had only worked with one other Aspie and assessed four other people for the condition. Basic knowledge of AS would have taught him that not only are all Aspies very different, albeit with distinct sub-groups: those who are "withdrawn and aloof", those who are "active and odd" and those who are "passive".

Since diagnosis, I have made it my responsibility to learn as much as I can about AS and how it has affected my in order to ensure I do not repeat those mistakes. I am hugely grateful for the strengths that AS has bestowed upon me: in particular perseverance, attention to detail, perfectionism, the ability to hyper focus when I need to and my intelligence. My "turned down" emotions — supposedly a deficit — have enabled me to act decisively when others around me are panicking in times of high stress, and to make decisions others have found emotionally too difficult.

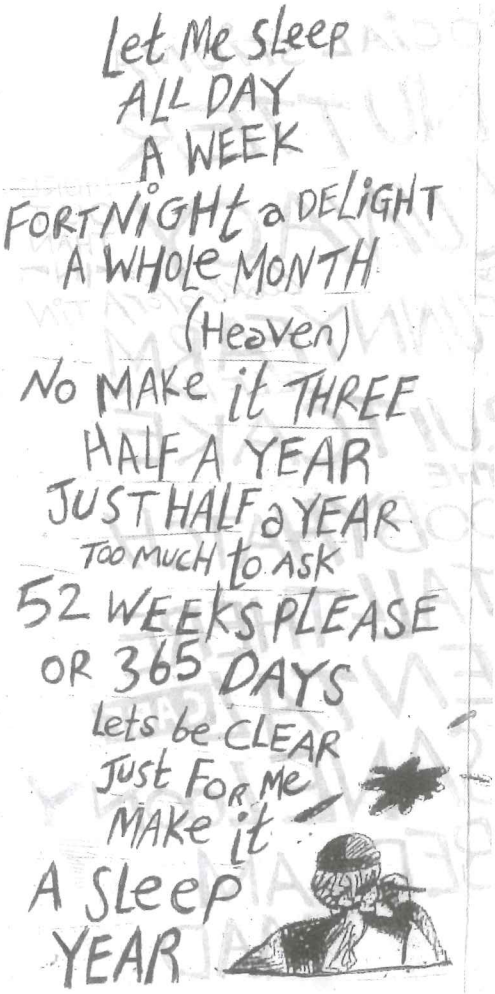
As I continue along this journey that is life, I embrace my inner Aspie and am hugely optimistic about my future — some may say unreasonably so, given my present circumstances. I don't mind. I'm here, and I have AS.

Biting the hand that feeds us

by **Caroline**

If there's one thing that really bugs me as a disabled person, it is being offered a support service only to find that the service is staffed by people who are being exploited. Often people running services for disabled people are poorly paid and overworked, by employers who treat their desire to support people with cynicism. If I am supported by those who are being used I am left feeling that my dignity as a disabled person has been undermined. I am, in effect, being told by the support service that I have no right to participate in society as an equal, only as a charity case. I also end up feeling sorry for the person supporting me and that gets in the way of being supported.

It will not therefore surprise you that I wish to offer my congratulations to the staff at the NAS's Sybil Elgar School who have taken industrial action to make the point that they, as teachers of autistic children, deserve to be paid at least as much as other teachers. Quite possibly they feel guilty about taking action as it will impact on vulnerable students. But I say there is no need for guilt, if the teachers stand up for themselves they can show their students what it means to stand up for themselves.



Throwing down one's locks

by **Mark**

I refer to Edward's article in edition 77 (*Beware the Asperger snob*). Whereas I may beg to differ with some of the views, I do sympathise with his criticism of the stereotypical media portrayal of Asperger syndrome, as well as his concern that some "Aspies" may be doing more harm than good by unintentionally trivialising the condition.

Twenty years ago, I worked in a bookshop. One morning, the manager was giving me some constructive criticism, including pointing out to me that I did not always look customers in the eyes, instead sometimes looking away from them. Involuntarily, I averted my own eyes for a second or two as he told me this, which proved his point.

About three years ago, I was attending psychotherapy sessions due to severe anxiety. At the start of the first session, so as not to appear rude, I told the psychotherapist that I often prefer to look away when I am talking to someone.

Little did I realise on both occasions that little eye contact is one of the signs and symptoms of autistic spectrum disorder (ASD). In fact, I knew little of the signs, symptoms and varying degrees of severity of ASD until fairly recently. Like many, I knew only of the stereotypical media portrayal, as depicted in films such as *Rain man* and *Mercury rising*. Not only that, I had never heard of Asperger syndrome and other terms associated with autism.

It therefore came as a surprise when I was formally diagnosed by a NHS psychiatrist as having Asperger syndrome. (I prefer the term autism, or ASD, as arguably autism and Asperger are the same, but of varying degrees of severity.)

I liken psychiatric diagnosis to a jigsaw puzzle. One selects pieces (psychological traits) that seem to match the individual. A diagnosis emerges when the matching pieces are slotted together.

Whereas I am convinced the diagnosis is correct, based on what I've been told, read, and my personal history and psychological traits, I also feel guilty as having been diagnosed with ASD because I feel I do not fit the stereotypical media and popular culture portrayal of autism. However, I do fit the diagnostic category and I have many of the stereotypical traits (I won't list them all, except to say that my own psychological jigsaw pieces fit the slots in the ASD puzzle).

Furthermore, some in the media do not help one's assurance. Asperger is at risk of becoming the new ADHD, which has been dismissed by some in the media as an excuse for naughtiness. The counter-argument is that we have a better understanding of ASD and thus more people are being diagnosed. Indeed, I believe a spectrum diagnosis (as in the DSM-5) to be more encompassing than using different labels for differing severities.

One of the advantages of my diagnosis is that others have a better understanding of me and my personality and psychological traits, and can better sympathise when I may inadvertently do or say the wrong thing, despite my best intentions of not wanting to upset or offend anybody. However, I am also mindful of the fact that I cannot misuse my diagnosis to excuse all negative behaviour on my part.

As a regular Internet forum user, I have started mentioning my ASD diagnosis in my signatures and profiles. Attention-seeking is not my motive for doing so; I merely wish to remind others that my social communication and awareness skills are dysfunctional, and thus to treat me sympathetically and not too harshly.

Whereas I sympathise with Edward in his concerns that we can risk trivialising ASD, I also feel that we can help generate a greater

understanding of the condition and its severities by being open and honest about ASD, especially how it can adversely affect our lives and those around us, and our it differs in severity from person to person.

I'll end this article with a quote from *The garbage pail kids movie*, lines as spoken by the late Anthony Newley. They are rather poignant:

"Perhaps it would have been safer to lock them away from the world. But as you have taught me, Dodger, you cannot change the world by locking yourself away from it!"

Hello,

I just thought that I would reply to this article.

The word "Aspie" in my neck of the woods is used widely, and not to describe what Edward says, namely a vain person. Indeed, apart from "Aspie" which abbreviations of the word "Asperger" are used commonly?

However, I am not claiming that I have never come across the type of Asperger whom Edward describes. In response to Edward's plea, what helps me to live with my Asperger's is to know that *all* on the autistic spectrum will drop some sort of social clanger from time to time. The "perverse celebrity" in which these people wallow, as Edward says, can be translated as a comfort zone — which all on the spectrum revisit regularly in one form or another — but let's be clear how this celebrity has come about. Aspergers are so outspoken, so focussed on their ideas, so systematic in their thinking and so clinical when pouncing on the mistakes of others, that, unless some strong-minded individual intervenes in a social situation where this Asperger has been observed, and defends that Asperger, then yes, indeed that Asperger *will* be observed as a "quirky genius". But I am not so sure about the "endearing" part, since my experience shows that we Aspergers upset people so much that we hardly endear them to us. The opposite usually.

As for the Radio 4 programme, and as indeed for any radio programme that employs Aspergers at the microphone, the point is very rarely made that Aspergers *do* have empathy, and this gives the person on that programme, the ammunition to be boastful, and then to set up his own animosity towards the neurotypicals, fired at point blank range with the salvo "we think differently from you". Edward, I am once again in total agreement.

As a long-term committee member in a well-known Essex adult Asperger support group, I have no opportunity to self-aggrandize, you will be glad to learn, Edward. Objective people like you and I have only to look at the alarming statistic, namely 90% of all Aspergers of working age are unemployed, and any lurking smugness dissolves instantly. If there were more diagnostic centres, and lower diagnosis fees, not to mention uniformity in the diagnostic structure and a statement of any condition that the person definitely has *not* got, then we could keep self- and speculative diagnosis to a minimum. And how long *should* it take to train a person to diagnose ASCs? It seems to me that we should re-assess the duration and content of training towards this goal.

What I am trying to promote is the view that Asperger's *must* surely be employed in some of the more dangerous occupations not merely because of our strength in numbers, but also because, as Edward rightly points out, brave and courageous Aspergers are actually here anyway, and the straightforward, and often truthful nature that typifies Aspergers will reveal this. And if more Aspergers are shown to be courageous and brave, as well as defying other odds, then they would, given sufficient publicity, grab the public's attention.

Finally, I do not believe that Asperger's syndrome is something to be proud of. It has severely frustrated my life and curtailed my happiness. But I will continue to fight for what we Aspergers are entitled to enjoy in their lives.

Tim

Hi Goth,

I think like many people will have been, I was disturbed by the claims made by Edward in his letter and would like to respond.

I am Sarah and I am an Aspie. I'm proud to be who I am even though I suffer in a world that doesn't seem to want me. I fail to see why I am considered a narcissist by Edward when I do nothing more than recognise who I am and that there is a community of people like me out in the world most of whom are doing nothing more than making the best of their talents and abilities while minimising their difficulties.

My diagnosis also came too late, my hopes of a career gone as the depression and social anxiety I developed took away my teens and twenties. I'm trying hard to progress but it's taking a huge chunk of my thirties too. However, were I to have an Aspie child, an impossible hope as I have only had one relationship in my life, that child would have opportunities that I never had. My child would know their strengths, I would be able to educate my child in a way that meant they learned, that the environment they were in didn't hurt them and that they had the confidence to act if it did, to use earplugs, headphones, sunglasses and, if they were challenged, to confidently say that they were Aspie, that they had the right to exist, to be happy, to access the world, have a career that they find fulfilling. I wouldn't want my child to be a narcissist just to be comfortable in themselves in a way that I am only just learning to be. This wouldn't be trivialising the difficulties that will always exist, it would however be managing them in order to minimise the negative aspects of them while enhancing the positive aspects. I hope that in time Asperger's will be routinely identified at an early stage and that every one will be an Aspie, who is confident and proud and yes happy to be Aspie.

I have nothing to do with the media, I have no control over how we are portrayed, there are terrible programmes out there, such as *The undateables*, where our difficulties are shown, we are used as freaks for the amusement of NTs, they are left with no doubt however that we struggle, any with empathy would recognise how lonely we must be. There must also be good fictional portrayals of people with Asperger's: the one which stands out for me is Abed in *Community*. It may be tragically hidden away on Sony TV but *Community* has the bonus of being an outstanding sitcom and is well worth buying on DVD and watching from the beginning if you can.

I hope you are having a good week, thanks if you have read this far,

Sarah

by **Tony**

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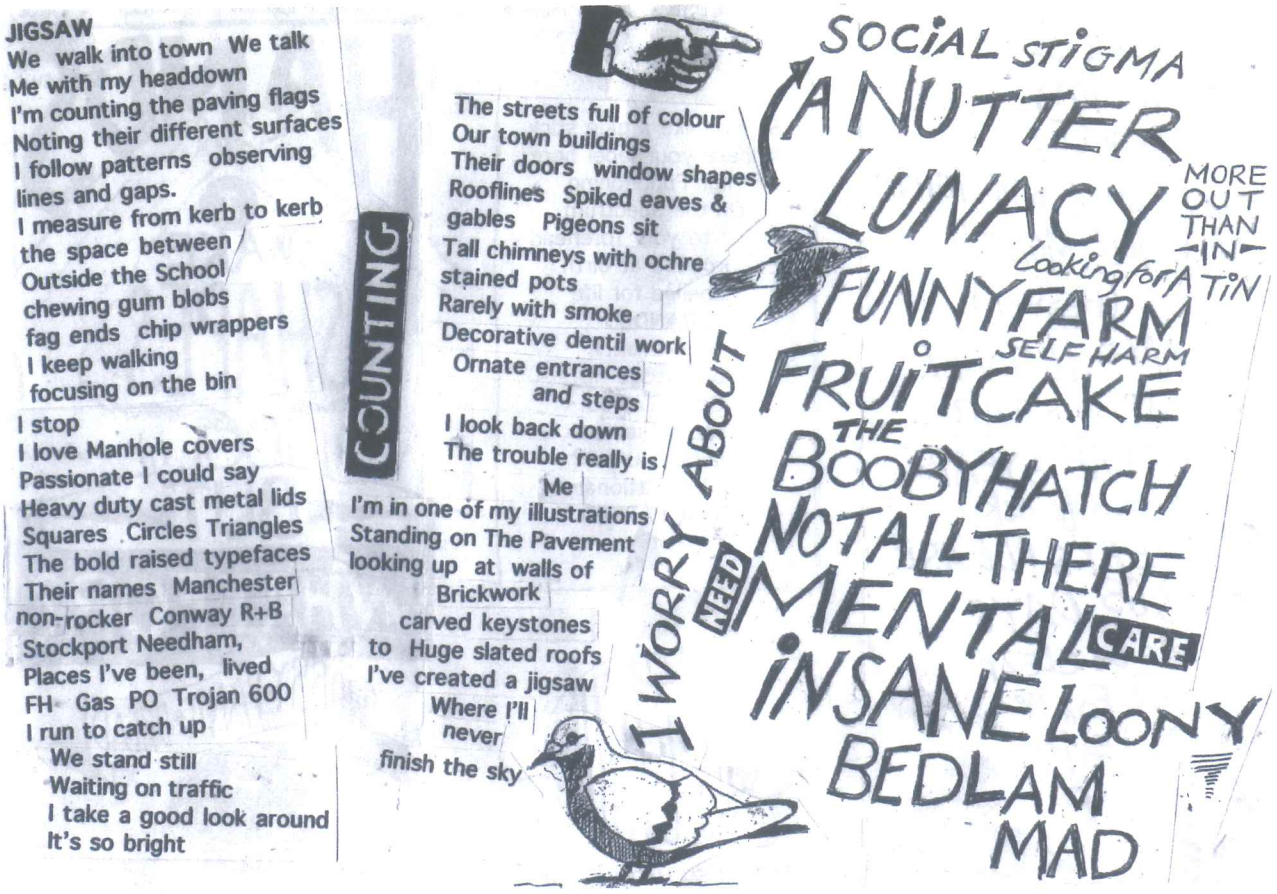

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