

Calm, almost too calm Panda Mery

“The diagnosis also helped me to reinterpret some traumatic experiences”

My understanding of how autism is an integral part of myself has been a long journey. I have always been different, eccentric, with very few friends. In primary school I was nicknamed ‘dictionary’ and in secondary school was bullied. I identified as a techie person and spent a lot of time with computers and online. Around 1998, when I was in my thirties, I read a review of the book *Shadow Syndromes*, which made me wonder whether I might be autistic.

The review picked among other things on the incapacity of one ‘patient’ to ‘clap in time to music’. This, in particular, resonated strongly with me. I can only clap in rhythm by visually syncing with another person’s clapping. I had never met or read of anyone with the same difficulty for what is apparently such a simple task. (It is ironic that this is not considered a characteristic autistic symptom.)

Reading more about autism and doing some online tests convinced me I was autistic and I self-diagnosed as having Asperger’s Syndrome. However coming from a medical family I was very aware of the unreliability of self-diagnoses generally and my family did not agree with this self-diagnosis. Tests, especially online ones, didn’t seem to be much more

reliable. This resulted in believing that I was likely autistic, as many of my behaviours and past experiences matched some I had read about as being autistic, but not in the confidence to identify as autistic.

In 2013, in my late forties, I eventually sought a professional diagnosis. The reasons were two-fold.

Having previously worked as a software developer, a technologist and a journalist, I was unemployed, doing voluntary work and had decided to go back to university to do an MA. I thought a diagnosis could help me (as I eventually dropped out, this outcome was not fulfilled).

Also I had been wrongfully arrested. When I attempted to take the tube at Southwark station on 2005-07-28, police officers found my behaviour suspicious and decided to stop and search and subsequently arrest me as a potential terrorist. I thought a diagnosis would help if I was arrested again (this has not happened so far).

To get the diagnosis I went to my GP equipped with a printout of the information page for GPs from the National Autistic Society (NAS) and asked to be referred. My GP did not know anything about autism and asked me for a list of symptoms on one side of an A4 page and for a blood test. I attempted to explain that a blood test was irrelevant (and that I have an aversion to needles) but as I wanted the referral I went along with this request. (This GP also made some derogatory comments about my autism to my wife and we have both since changed surgery.)

In May 2013, a neuropsychologist eventually diagnosed that from information I had given him ‘there are features in social interaction and communication that, in the absence of other diagnoses, places you on the autistic spectrum – of the Asperger’s type.’

The validation from this diagnosis had the effect of enabling me to identify as autistic and to start to explore my autistic identity. Only after this professional diagnosis did I feel a sense of belonging, the confidence to join groups such as the Asperger London Area Group (ALAG) and to attend the Autscope conference; whereas before I felt I was not entitled to do so.

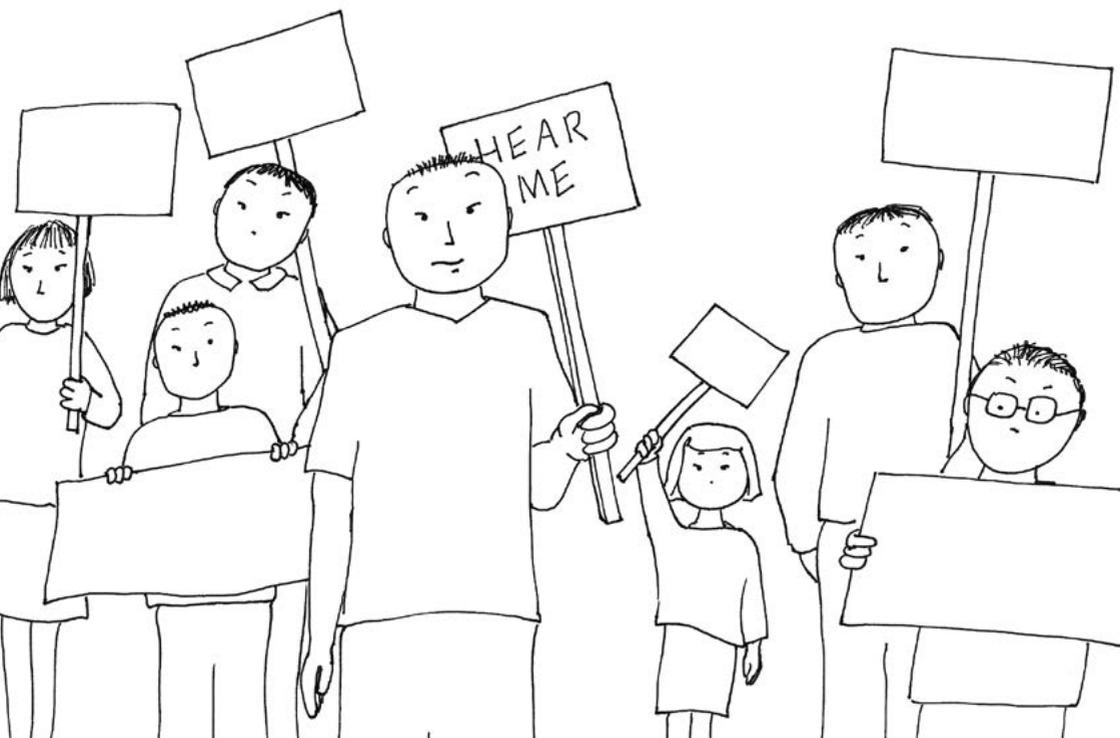
The diagnosis also helped me to reinterpret some traumatic experiences. It has made me realise that when police officers had found my behaviour suspicious, it was because of how they had interpreted some of my typical autistic behaviour, such as a lack of eye contact with them (i.e., I was ‘avoiding them’) and how I was dealing with the sensory-rich environment of the tube station. When I was made to wait in the entrance of the station before being led to a police van, some station’s alarms were ringing; I am hypersensitive to sound, but as my hands were still handcuffed I could not block my ears. When I was eventually processed, the custody sergeant found me ‘calm on arrival [at the police station], almost too calm’ and as a consequence I was ‘placed in a video cell on half hourly checks’. Again, my behaviour was found to be atypical.

During the police interview, some questions about my laptop, such as ‘has it got anything on there about plans for any terrorism act?’ and ‘has it got anything on there that might be

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construed as causing a public nuisance?', particularly bothered me. The correct answers would have been 'yes' as I have a word processor, an email client, etc. that could all be useful to a terrorist and most likely can be construed to be of use for anything including causing a public nuisance, however, I realised that such answers would not have been helpful to me and challenged the questions when the investigating officer just wanted answers.

Since the arrest I have become alcohol and fructose intolerant and I suspect this was a reaction to the stress. Policing in London and what happens to innocent individuals when they encounter the police became one of my special interests and I have researched, written and campaigned on civil and human rights issues such as the National DNA Database and the stop and search powers.



A year after my diagnosis, I publicly 'outed' myself and started some autism activism: I sent a contribution to a Home Affairs Committee inquiry into policing and mental health calling for police officers to realise that an atypical behaviour can be just different rather than suspicious; to consider hyper- and hypo-sensitivities that individuals may have; and to use clearer interviewing questions.

I am glad I sought out a diagnosis as it has been very helpful, but paradoxically this journey has helped me realise that for what is a neurodivergence,¹ we should not need a medical validation. The medical pathway is not the best one, what we need is more legitimisation of self-diagnoses and acceptance of neurodiversity.

1 See Panda's piece on terminology for further explanation of this term.

Terminology Panda Mery

I am not a person with autism. I am an autistic person.

Receiving a diagnosis or identifying as autistic – can be very empowering and often entails talking and/or writing about autism. There are many words and expressions to choose from. You might have noticed that the contributors to this booklet express different preferences in their writing. To help you navigate your way through this terminology, here are a few of my choices and their implications.

You can choose whether to use identity-first (I am an autistic person) or person-first (I am a person with autism) language. As autism is an integral part of who we are – the way our brains and bodies work – many autistics are keen on the use of identity-first language and refer to themselves as ‘autistics’. I find person-first language (being called ‘a person with autism’) offensive as it implies that we should strive for a state when we are ‘without autism’. A useful way to think about this is that you would say a person with a cold, but not someone with Jewishness, or with left-handedness. Of course I also respect each individual’s choice of the language they use to refer to themselves.

This distinction is linked to how you consider our differences and how we fit in society. I know of two basic models. The medical model, the most common in our society, explains the difficulties we may have as caused by us not fitting in. To improve our lives, we must change (e.g., forcing ourselves to

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look others in the eyes, not stimming,¹ etc.). The social model, which I and many other autistics prefer, considers that if someone has difficulties fitting in that is because there are barriers that should be removed; society must work to eliminate discrimination and accept us as we are in all our diversity. While the medical model finds autism to be a problem that must ideally be cured and suggests interventions, the social model promotes equality, respect and inclusion.

Autism Spectrum Disorder (ASD), on the spectrum, Asperger's Syndrome or type, Aspie, high (HFA) and low functioning and classic autism, etc. – a great many terms are used to label us, but we tend to use fewer to express our identities. One reason for so many is to reflect the diversity of autistics. A common saying, attributed to Lorna Wing, is that once you've met one autistic, you've met one autistic. Several of these words classify us along a spectrum with abilities ranging from very poor (low-functioning autism and classic autism) to above average (high-functioning autism and Asperger). This neat continuum, however, does not match the more complex reality. Some autistics will find some tasks very easy some days and impossible to do at other times; individual profiles tend to be spiky and changeable. Although my diagnosis was 'on the autistic spectrum – of the Asperger's type', I feel that it is more inclusive to identify simply as autistic and support everyone in this constellation of diagnoses and identities.

What about everyone else – the non-autistics? A word often used by autistics (and others) to describe most of those who are not is 'neurotypical' (i.e., have a typical brain), abbreviated as NT. The world is made up of neurodiverse individuals:

people with a variety of brains and minds, most are neuro-typical and some are neurodivergent including autistics and everyone else whose brain is not typical (e.g., epileptic, dys-lexic, etc.). Being neurodivergent is not intrinsically positive or negative. The social model celebrates a neurodiverse world in which autistics are fully accepted with all our differences, a world I want to live in.

To explore some of these issues in more depth, here are a few good starting points:

www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/OP1/html_1

www.autisticadvocacy.org/identity-first-language/

www.neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/

1 'Stimming' is self stimulatory behaviour such as hand flapping or spinning.

The previous pages are an extract from the book:

Being Autistic

Nine adults share their journeys from
discovery to acceptance

To find out more details and order your copy, visit:

<http://www.autangel.org.uk/being-autistic-book>