

Becoming Autistic: an Aut-ethnography

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Introduction

"I know that I exist, the question is: what is this 'I' that I know?" (Rene Descartes).

Notions of personality, selfhood and identity have been debated and analysed throughout human history by ancient philosophers through to postmodernist social theorists. A bewildering array of ideas have been formulated to help people come to terms with who they are, their position in the social world, and their aspirations for the future. Despite many talking of the difficulties and crises that humans can have in forming a sense of self-identity, it is often assumed that such identities are placed within a coherent narrative story. My own experience of identity has been nothing of the sort, however. Indeed, my experience of identity has had much more in common with postmodernist notions of 'fragmentation' and incoherence, although not an experience of fluidity or of an easily changeable or disposable identity. Some aspects of what it felt like to be me have seemed like immovable 'clumps' (Milton, 2013) (1).

In 2009 I was diagnosed as being on the autism spectrum at age thirty-six; this followed my son's diagnosis some years earlier. Of course, these events have had an impact on my own sense of identity, to the extent that I now identify as an 'autistic person'. This has focussed my academic pursuits toward the study of autism and I have become a fervent activist for autistic rights. Of course, aspects of this autistic identity were present all along but I and the other people around me did not have a categorical term to place these ways of being into, other than, that is, inaccurate and/or derogatory labels. In this article I try to piece some of these fragments of selfhood together. They form a somewhat chronological order, since this structure has been imposed upon these expressions of experience for the benefit of the reader.

Early years

"The ancient sages said: do not despise the snake for having no horns, for who is to say it will not become a dragon? So may one just man become an army." (Narrator from the TV program: The Water Margin).

I was born at the end of the summer of 1973. My parents were not married, having both previously been married and then divorced with previous partners. I also have an older brother. I was a healthy weight and height, with long arms and a very large head circumference; the latter attribute was also to be inherited by my son. I was a quiet and introverted child, who often looked to his brother for a 'lead' as to what to do in any given situation. My parents were to split up when I was twenty months old, and so me and my brother lived with my mother, and saw my father at weekends. This was to bring a very close-knit relationship with my mother and brother (although sometimes a tense and fraught one too as they had a far easier rapport with each other than I did). My father was an actor and Marxist activist and the way I got on with my father was mainly instinctual, as he seemed easier to communicate with, being more on my 'wavelength'. All my close family are bright and well-educated, all fairly to very left-wing politically, and all 'accepted me' and encouraged me and my interests. This secure base is something I will always be grateful for.

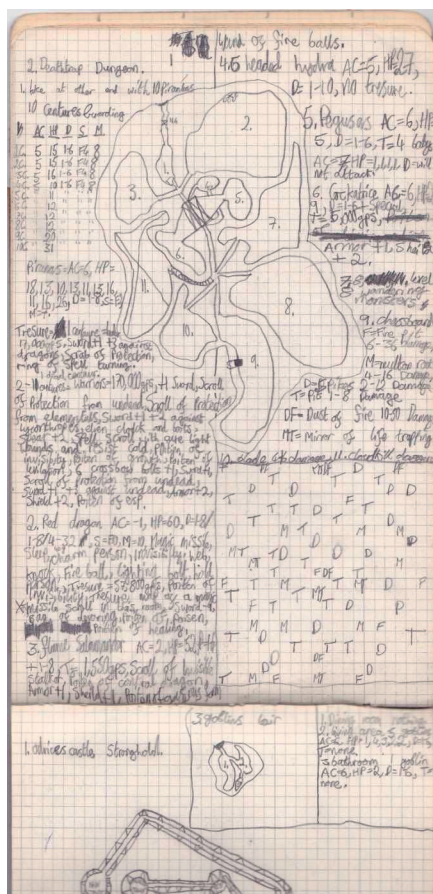


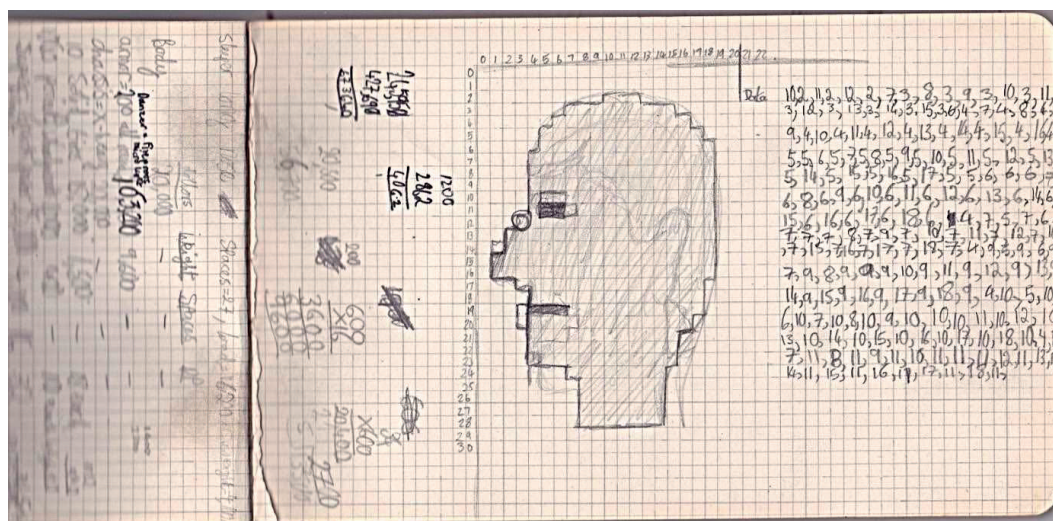
I entered into the school system at the age of four and eight days. I had a 'bumpy road' to travel in primary and middle school, often being bullied and teased, sometimes manipulated by others. I was clumsy and slow in interactions, with a deep monotone voice. Such attributes were to mark me out to those wishing to project their own insecurities onto me. At the time I felt deep resentment and when pushed too far, could fly into an uncontrollable rage. Being quite a big kid, this put some of the initial bullies off though, as people seemed to not want to 'mess with the mad kid'.

"Even the most primitive of societies have an innate respect for the insane." (The Motorcycle Boy from the film: Rumble Fish).

I also had some good experiences too, having some very good 'geeky' friends, plus the discovery of intense interests, some of which would stay with me, such as a love of castles, listening to music, or the playing of table tennis. I had an unusual take on life, often entranced by my favourite hobbies and pursuits, not being bothered a great deal by other people unless they shared such an interest, or were a member of close family. I would spend hours making lists, planning my latest game of Dungeons and Dragons, or programming for my computer. I also had an unusually gifted memory, memorising entire books, or every country in the world in size order.

Extracts from childhood notebook:





At school, my abilities were not really picked up on, other than in maths. I was poor at spelling and would often 'daydream' (in fact, just more interested in my own thoughts than what was happening in the class – my brain was very rarely inactive). The lack of pressure from teachers to perform and the generally encouraging attitude of adults often kept me on track though. A number of episodes from this period are particularly marked out in my memory, however: my first day at school, and being pushed off a bench I was sitting on by another child, only to make friends with them later. My first school sports day, when I had a 'shutdown', and refused to take part, and became increasingly overwhelmed by any attention or words used in my direction; being invited to a girl's birthday party, and then panicking, and ripping up the invite; being held upside down and panicking that I was going to be dropped on my head, and being the last in my class to tie his own shoelaces. Other experiences were more positive, such as observing an ants nest at break times in the corner of the playground, every time I held a table tennis bat in my hand; being picked for the class quiz team, and playing 'Paddington' in the school play. Life was hard, but it also had its 'up-side'.

My brother gained a scholarship to a private school and this seemed to me to be the obvious thing to do for me too. Despite my low mark for English I also won a scholarship, but to a different school because my brother's school decided that I was too 'socially naive and immature' and would benefit from starting a year later. Advice I rejected at the time but in retrospect may well have been advantageous.

After one term into my secondary education, on a fateful Saturday before Christmas in 1984, disaster struck. On our way to visit family friends, my mother, brother, and myself were in a multiple vehicle road traffic accident.

Losing my 'self'

"Socrates: ...there are two types of madness, one arising from human disease, the other when heaven sets us free from established convention." (Plato, 1973) (2).

In her most recent book 'The Anger Box', Phoebe Caldwell (2014) (3) describes how a traumatised autistic person can lose their sense of self. In such a state of overwhelm, one can not only lose touch with what and where one is, but who one is. In many respects, this is what happened to me following 'the accident' (as I came to refer to it). In the period after 'the accident', I lost much of my memory of events before it. The scene of the accident often replayed in my head rather like a horror film, one which I was in, yet not. When I tried to think of visual memories of my mother, the image I got was of her in a hospital bed recovering from her injuries. I could not look at my mother for a couple of months. To me, in many respects, my mother (and security in life) had been replaced by someone who was like my mother, but was not the same person in my perception. It does not take a psychiatrist to work out that at this time I was a bit of a 'mess'!

I somehow managed to get through my first year of secondary school fairly unscathed, with my marks dropping slowly, but finding solace in history lessons and a new 'geek gang' of people I could escape with into lands of fantasy adventure (in our heads and by rolling dice that is). The beginning of my next year at school, however, saw a sharp downturn in everything. When work became more intense, the homework did not get done, I lost track of what teachers were expecting of me, and for a scholarship kid, I was meant to be 'top of the class', not bottom. With the derision of teachers, came the increased singling out by bullies. Although sometimes physical, this now took on a whole new range of psychological torture. School life became a fight for survival, and one I was not doing so well at. "It does not appear that he is very bright and therefore lack of effort compounds the problem" (my 'Form Master', 1987).

A saving grace came in the surprising shape of an American Football, a game I had been fascinated by on television, with its complex tactical strategies. I began playing in the park with a ball with my brother and a friend from school. One day whilst playing I met a young American who suggested that I joined a local team – the Ealing Eagles, and so I did. At first, my coach rightly described me as 'headless chicken', but in time, the training helped me to find some semblance of bodily awareness, building my fitness and strength and being able to use it. The sport allowed me to specialise in a position, utilising my size and speed to good effect. At my peak of playing the sport, we reached the junior national semi-finals, and my coach began calling me 'swivel hips', the elasticity of my joints and limbs at the time being utilised as an advantage. Where I was alienated and powerless at school, playing sport outside of school gave me confidence and self-esteem. I left school after doing poorly in my GCSEs and headed for Further Education College to study for my 'A' levels in history, economics and sports studies.

The psychiatric gaze

"Extremes of any combination come to be seen as 'psychiatric deviance'. In the argument presented here, where disorder begins is entirely down to social convention, and where one decides to draw the line across the spectrum." (Damian Milton – MA essay, 1999 – spectrum referring to the 'human spectrum of dispositional diversity').

Following 'the accident', my mother claimed for damages, having sustained significant and permanent physical injuries. She also claimed for the psychological damage to me and my brother, particularly me, as I seemed to have been so badly affected on every level. Due to there being a number of cars and therefore insurance companies involved, I was subjected to a number of consultations with psychiatrists working for the various parties involved. Each came up with their own theory regarding 'what was wrong with Damian?' One said that I was psychologically disturbed, another that I had a personality disorder. At one consultation, I was taken to Harley Street to see someone who had a plaque of their name outside the building entrance. He was an old man who immediately made me feel intimidated and started asking me questions about 'the accident'. I froze, found myself unable to speak, rocked, and stared at the wall, hoping the whole thing would finish as soon as possible. His report suggested that I was not suffering due to 'the accident', but that I had an underlying childhood disorder of catatonic schizophrenia. He also told my mother after the appointment that, if she pursued the case of psychological damage to me from 'the accident' that he would need to see me several more times. Unsurprisingly, she did not pursue this further. Following a number of sessions with family counsellors and others, I decided very strongly, that I wanted nothing to do with psychiatrists, or 'people who thought they knew what I was thinking better than I did'.

'Me'

*A withered boy so afraid,
Hiding from society in the shade,
His solitary cries no-one did hear,
His confused mind full of fear,
His tortured soul locked inside,
With his faded dreams that had died.* (Damian Milton – 1989).

Explorations in theory – explorations in life

"I used to live in a room full of mirrors; all I could see was me. I take my spirit and I crash my mirrors, now the whole world is here for me to see." (Jimi Hendrix)

Following my A levels, I 'sent myself to Coventry' (literally) in order to study for a leisure management degree. I struggled to live away from home, despite desperately wanting my 'freedom' at the time. I struggled with the course I was on and began to lose interest in the area. My interest was becoming more focused on people and society, and the strange social habits that people performed. I withdrew from the course, and began to slip away from mainstream society altogether, becoming more involved in musical subcultures and being in control of my own destiny (as much as I could). From the outside, I looked as though I had some 'poor outcomes': no job, struggling in or with relationships, poor housing etcetera. Yet, for me, it was a time of exploration and learning – very difficult, confusing and upsetting at times, but a time where I began to feel more comfortable in 'my own skin'.



During this time, I also read many philosophy books, and became fascinated with the ancient Greeks in particular. I also came across the discipline of Sociology for the first time through a girlfriend. I decided to go back to college to do more 'A' levels, this time sociology and psychology. This set me on a path to return to university, where I finished with an upper second class degree in Sociology, followed by a Masters degree a year later. Despite learning a great deal, I struggled to extricate myself from some of the negative associations that were made about people of 'mental difference' at the time, yet these subjects began to give me a language in which to express my theories and also some frustrations:

"The box most applicable to my perceptions of selfhood in Kramer's (1994) analysis, is that of the 'socially isolative schizoid', which to me underlies a belittling of 'abnormal' dispositions." (Damian Milton – MA essay, 1999).

I continued on to doctoral research, but fell out with my supervisor, ran out of money, and dropped out yet again. I found myself being a highly qualified, yet unemployed person without much idea of where to turn next. My life was to become even more complex when I became a father in 2002.

He's not autistic, he's just like me!

"What is the meaning of life? You must make it for yourself. If you do, it may not be yet another illusion." (Narrator from the TV program: The Water Margin).

Following my son's birth, I worked hard to complete a teacher training course and then acquire a job as a sociology lecturer in a Further Education college. I had finally made it into a professional job, and was a proud dad.

"Sometimes it's a little better to travel than to arrive." (Robert Pirsig from 'Zen and the art of Motorcycle Maintenance').

Leading up to my son's second birthday, his mother began to remark on how he was not reacting and responding to her. One day she commented that a friend of hers had said that he might "have Asperger's". All I had heard of this mysterious syndrome were that people were 'uncontrollable' and a 'bit violent', not like my son at all. My son was to develop clear signs of autism and was diagnosed at the age of two. At first I dismissed such ideas, even saying that he was not autistic, but 'just like me' in terms of early development. Then one night my son's mother handed me a book with an extract from an autobiographical account from an autistic person. I found a narrative that I could have written myself. This was not how the medical professionals were explaining autism, that I had not really related to well, yet it suddenly dawned on me that my oddball alienated ways may not have been quite so unique after all.



In 2008, having fallen out with colleagues and struggling with office politics I was made redundant and was unemployed again. Immediately, I embarked on an Open University course in psychology (that I completed in 2010 with distinction), and sought a diagnostic assessment myself. The first GP I saw said that there was nothing that she could do to help me, as I obviously had an IQ above 70 and did not require learning disability services. I then asked a local autism charity to send a letter to the GP advising about referral, and eventually was diagnosed with Asperger syndrome in 2009. In this same year, I embarked on doctoral research studies at the University of Birmingham, where I am still based today.

Positive autistic selfhood

"When you realise there is nothing lacking, the whole world belongs to you". (Attributed to Lao Tzu).

In the years leading up to my own diagnosis, I had already been researching autism extensively. In these travels I had come across work that was to transform my own understandings of my place in the world, my own theorising, and sense of belonging. This being the work of autistic self-advocates and activists, scholars and artists, too many to mention. Coming across the notions of neurodiversity echoed my own earlier academic work. Then in 2010 I attended my first autism related conference, where I met some of these people and heard them speak. Later that year I began to present on the topic myself. One of these topics was something that had been causing me deep concern, the notion that autistic people 'lacked empathy'. For me, this was missing the point, and something had to be said.

"I may lack a social imagination, but I have a sociological one." (Milton, 2011) (4)

I began discussing how there was a 'double empathy problem' between autistic and non-autistic people – due to differing dispositions and outlooks on life, both would have difficulty understanding one another. This was to become a published journal paper (Milton, 2012) (5).

Natural non-conformity

"The idealisation of normality becomes a hindrance to the acceptance of diversity, with people deemed to be in need of changing themselves to access social life, rather than questioning the exclusionary practices of society." (Damian Milton, NAS 'Ask autism' conference, 2014) (6).

In the last few years I have presented over seventy times on topics related to autism, have had a number of articles published, co-chaired two conferences, been invited to sit on advisory boards, reviewed guidelines and publications, and produced work for projects ran by the Autism Education Trust. I am now employed as a lead consultant for the National Autistic Society 'Ask autism' project, looking to employ autistic people in training and consultancy roles (NAS, 2014) (7). I have certainly found a voice. I also managed to climb to 350th in the English Table Tennis Association rankings last year! Yet this journey is not over, and nor are the journeys of many other autistic people – of whom, not many would have a very high IQ, an unusually gifted working memory, and some having an accepting supportive family behind them. Even with these things, life thus far has been anything but simple and easy. For all my success, I am no less 'autistic' than I was when I was a child, when one uses the term to describe one's cognitive style and way of being in the world. I have not overcome my autistic ways, and nor would I wish to!

"I've not become who I am today, by not being autistic." (Larry Arnold, autistic scholar and activist).

GP Comment.

What I learned from this paper?

1. I found this a very insightful article. It reminded me that autism is a spectrum that can range from obvious presentations to more subtle ones.
2. I identified with the 1st GP that the author approached: I have an inherent dislike for 'labelling people' (my own term) and can fail to appreciate that for the affected individual it is of enormous importance to be taken seriously, to be assessed properly and to be diagnosed correctly. This article gave me a great understanding and empathy of how all of these aspects will help that individual to cope better and to access relevant services more easily in order to reconcile their condition and their lives sympathetically.
3. It is also a cautionary point of discussion for the profession that several psychiatrists are able to arrive at several different diagnoses after assessing the same patient

(Love that author quotes from The Water Margin, Rumble Fish and Jimi Hendrix!)

Dr John Albiston
GP, Glasgow.

References

1. Milton, D. (2013) 'Clumps': an autistic reterritorialisation of the rhizome. Theorising Normalcy and the Mundane 4th International Conference 04/09/13. Sheffield Hallam University.
2. Plato, trans. Hamilton, W. (1973) *Phaedrus and Letters VII and VIII*. London: Penguin.
3. Caldwell, P. (2014) *The Anger Box: Sensory Turmoil and Pain in Autism*. Hove: Pavillion.
4. Milton, D. (2011a) 'Who am I meant to be': in search of a psychological model of autism from the viewpoint of an 'insider'. Critical Autism Seminar 18/01/11. Sheffield Hallam University.
5. Milton, D. (2012) On the Ontological Status of Autism: the 'Double Empathy Problem'. *Disability and Society*. Vol. 27(6): 883-887.
6. Milton, D. (2014) What is meant by participation and inclusion and why can it be difficult to achieve? National Autistic Society – 'Ask autism' conference: participation and inclusion from the 'inside-out': seeing autism from an autistic perspective 28/01/14. Friend's House, London.
7. National Autistic Society (2014) Ask autism. Accessed on 09/03/14, from: <http://www.autism.org.uk/our-services/training-and-consultancy/ask-autism.aspx>