

The Neurodiversity Reader

Exploring concepts, lived experience and implications for practice

Chapter 11: An act of resistance

By Carl Cameron

To disclose one's autism is a deeply personal and complex decision to make, and once revealed it's impossible to take back. To mask or not to mask, that is the question; but make no mistake, whether you decide to disclose or mask, there is a risk attached. Revealing you are autistic may change others' perceptions of you, particularly professionally, and it may leave you vulnerable to manipulation and perhaps open to exploitation. Non-disclosure leads to a life of stealth, pretence, exhaustion and a life in which no adjustment is made, where no one has any idea you are struggling. Before the reader reads on, and since we are here at the beginning and we're talking about disclosure, I suppose I should do the decent thing and disclose first.

I am a privileged person, just so you know. I shouldn't be, but I am. I am an openly autistic person (and with a diagnosis) who has worked for a number of autism charities over the past 20 years, including the National Autistic Society. Currently, I work as a specialist mentor at Matthew's Hub, an autism charity in Hull in the East Riding of Yorkshire. The bulk of the work I do is mentoring autistic people who are awaiting a diagnosis and those who have recently been diagnosed, but I also support autistic people into work. I have my own office and have complete control of my environment. I write my own diary, have a fair amount of autonomy, and as a result I have never been as happy at work as I am today. I am an openly autistic person who works for an autism charity, so when I run into difficulties (and I still do) they understand and support me. I am a privileged person and I can measure that privilege by the occasions when I overloaded, had no support and could not go on.

I have been described as professionally autistic. I spend most of my working life in the company of other autistic people; I listen to them. I totally get how hard it is for others and the reasons why people don't feel comfortable that others know they're autistic. It's anyone's guess, of course, how comfortable I would feel disclosing if I didn't work in the sector, but since I am an open book it's hard to see how I wouldn't tell. What I would say with a degree of certainty, is that every time an autistic person discloses and is open about their diagnosis it makes it just that bit easier for the next person who decides they have had enough and does the same, but it takes courage and comes with risk.

I want everyone to know, especially young autistic people, that being autistic, like the colour of your skin, is nothing to be ashamed of.

Now I have just shared with you a little of the car crash that my career (and by extension my life) went through a few years back, and you may also have gleaned that I have never quite recovered, because as I have already said, I am an open book. I am far from alone in this.

As a people, as the distinct cultural group (for that is what I believe we are) we do have a tendency to over-share, I think we can all agree on that. We are a trusting bunch and tend to take people at face value. It's because of this, and because body language can be so tricky that we sometimes don't see the harm when it is staring us in the face. Information we share can be of

value to those with a deficit of scruples, and not always when delivered to strangers either. The truth is we find people confusing enough as it is, without trying to predict how they might react to the news their work colleague has an interesting neurological condition. Instinctively, I believe, autistic people want to be open, we want to 'tell', and sometimes because we need help; sometimes we are not OK.

Several years ago, and for reasons which escape me, I disclosed badly to a couple who my wife had a family connection with. They got talking about work and told me they thought someone in the office was 'definitely on the spectrum'. I had been meaning to tell them for ages I am autistic, especially as our paths were about to cross professionally. I had expected that I would just casually drop the 'A' word and me into the conversation and now seemed the perfect moment to do it.

Instead, I decided to blurt out, 'Did you know I am autistic? I am just telling you because I am on the autism partnership board and you are going to see my name at some point, we never need to mention it again!'

I have spoken about autism for over a decade, delivered training to 100s of people, spoken on the radio – it's a documented fact I am autistic. I think it's often to do with perceptions of the competence of autistic people; some people look at you funny after disclosure. I have been talked to as if I was five years old, talked down to at meetings and gatherings connected to autism, not taken seriously. It's only in the past few years that autistic people have been paid to speak at conferences; we didn't have a value before that. Until you can prove differently, all kinds of assumptions will be made about you, even by people who are supposed to know better. One minute you are a colleague, the next a subject of interest, and it's hard sometimes not to feel you are being watched, studied.

There has to come a time when to be autistic is a celebration of difference, there has to be a culture that goes beyond the lip service paid to such things at conferences.

I have been writing and delivering autism training for years. It's fun to do and I get to tell it like it is. Earlier this year (2019) I was asked, with a colleague, to deliver some autism training across the other side of the city. The session was to a medium-sized group of around 60 delegates for an NHS well-being thingy with various stakeholders and third sector organisations. My colleague (and boss), Gill Emerson, is a well-known personality in nursing and health board circles, so it was no surprise to hear her introduced first as we approached the stage. What was a surprise was when the facilitator asked, 'Is this one of your patients, Gill?'. It took me a moment... Wow, is she talking about me? I muttered something about being neither a patient nor a service user before introducing myself. I told them that I am employed, that I am specialist mentor and currently deputy chair of the Hull Autism Partnership Board with 20 years' experience working with autistic people across the Spectrum and with Masters degree, an MA in Autism.

She judged me! She called me a patient! She automatically medicalised me, and from that positionally made a whole set of assumptions about who she thought I was and what my capabilities were, and she made them instinctively, too. I know several professional people in the field of autism who won't disclose for fear of what might come next, that they would be treated differently.

It's not surprising we mask, we learned early, too, didn't we? We were not like the other kids and they knew it, and kids don't like kids who are different. I think it was Uta Frith who said that bullying among autistic children was so common as to be almost diagnostic.

Much of my working life is spent working with autistic people who are awaiting an autism diagnosis, people who believe they may be autistic, often walking in straight off the street to ask questions, and sometimes to begin a new journey through life. It's a privilege to contribute to the referral process and follow their diagnostic journey through to assessment, diagnosis and beyond.

One of the first questions I always ask of someone who believes they are autistic is, 'Were you bullied at school?' Most of us were, you see. I recently asked the 'Dungeons & Dragons' group at Matthew's Hub in Hull the same question. Out of a group of eight young autistic men, every person, including myself (number nine) had been bullied at school. Now, I am not saying that every autistic person has been bullied – of course not – but it feels rare and always comes as a shock when someone says they were not.

I recently ran an autistic over 40s group with a dozen or so members of the Hub; all had been bullied at school and later went on to be bullied in the workplace. It seems adults don't like adults who are different either.

We mask for safety, despite the damage it causes. No, it doesn't make sense, but we do it all the same. Hiding/masking one's autism is about as helpful as a gay person staying in the closet – he/she are not less gay, just more miserable. If the reader might allow me to make the same analogy, the same is true of autistic people, yet most of us continue to mask on some level. To mask one's autism does not make you less autistic, it just means that you are covering up well and on the road to a mental health crisis: masking comes at a price. As famously adept at masking as women and girls on the autism spectrum are, masking is not the preserve autistic females alone: boys and men do it, too. We must, we don't have much choice if we want to survive in the schoolyard or the workplace. The harder we try to fit in, the better we are deemed to be coping and even less adjustment is made and the more we struggle. Autistic people are great people watchers, we watch and copy, it's how we build our masks and hide, it's how we get by.

Masking is essentially camouflage, it's a well-practised survival technique that comes with an inner dialogue, an ear worm that says, 'I mustn't let 'em find out I'm a weirdo'; a soundtrack to accompany an environment which appears to be poorly organised chaos, the workplace.

As you may remember previously, mentoring autistic people into employment is an important part of my role. Recently, I supported a young autistic woman, newly graduated, and who had just been bullied out of her job from a well-known art space. Soon after commencing employment she disclosed she was autistic. Shortly thereafter, and I do mean shortly, questions began to be raised about her ability and suitability to perform certain tasks, to attend conferences and meetings. In time, her position became untenable and she could no longer work there. Sometime later she was able to secure a similar position at another gallery elsewhere, a city some 70 miles away. However, while she was comfortable disclosing that she suffers from anxiety, their sexuality, gender and other aspects of her neurodiverse life, she won't tell them she is autistic – once bitten, twice shy. This talented young woman continues to mask and tells me she struggles because no adjustment have been made.

When someone tries to converse with me, someone I don't know I may make little or no effort to engage. If I attempt to mirror them in conversation, they will view this as encouragement, and they end up wanting to talk even more. I struggle to maintain these interactions; I just can't keep the conversations going. I usually let my wife do the talking if we are out and about or on holiday and just chip in the minimum in an attempt to be polite. I find maintaining a conversation to be a poor use of resources. I have rarely found 'small talk' to be beneficial, only exhausting. When I am obliged to engage socially, the anxiety levels begin to rise days or weeks in advance. I find it

almost impossible for the date or time of these proposed interactions to stick in my mind. It is almost as if my brain rejects them, and I am good with dates. I start the scripting process in the hours leading up to the event. It's such a dilemma, just how much information do I disclose about me? Do people want to hear? How much do I disclose? What's appropriate? How much detail do they want to hear? When is a good time to shut the hell up? If I don't find a way into a conversation quickly and find my place, I won't find my way in at all and may not say a word.

When I was young and someone asked me how I was when I met them, I told them, and in some detail, too. Now I have gotten a little older and I know now that they don't really want to know how I am, it's just a greeting like saying hello. Nothing has changed for me however: today when someone asks how I am, I am still bursting to tell them and find it difficult not to, but I know that it's not the 'done thing' and they don't really want to hear. Despite my age and all the societal practice, I still need to coach and script my way through social events, even family occasions. I still attempt to turn the conversation around to something I know about – either that or I might not talk at all. I still find social situations uncomfortable or unpleasant no matter how I try to cover up that fact. Tolerating social occasions does not make me less autistic. Unless I am on safe ground, and that tends to be autism talk, my global stability begins to shift, which in turn triggers my adrenaline and anxiety levels, and then there is the internal debrief from the interaction you never wanted to have in the first place, its is exhausting.

When forced to visit or be 'visited' by other people, I used to constantly be told, 'Just relax and be be yourself' or, 'You don't need to tell everyone exactly what you think all the time'. And, somewhat less charitably, 'You don't have to be a weirdo'.

Really?

Just relax and be myself, do they really mean that?

If I was to be myself, I wouldn't visit or interact with anyone outside the workplace or family in the first place; I just wouldn't go out.

I don't enjoy social occasions in rooms full of neurotypical people and I do not believe it is wrong to seek solitude. It doesn't make me a bad person because I prefer to be on my own, it doesn't make me less because I don't need all that social stuff to make me a happy person. What my solitude does is give me lots of autonomy, which is anxiety free, safe and protected. I manage my own global stability; I maintain my spoon count my units of energy and reliance), my well-being, and I take autonomous action for myself and the choices about my well-being about my life.

Just relax and be myself... Do they really mean that?

They really want me to talk at my natural volume and talk about topics and things which interest me?

Are they sure they are comfortable with me doing that?

People have been telling me my entire life to stop shouting (I have no volume control and hate the volume I naturally speak at) or to stop banging on and on about some interesting fact I have told them before.

And are they really happy for me to say exactly what I think about whatever it is I feel strongly about?

What is so wrong about telling it like it is and being clear? Neurotypical parents tell their children not to lie, but they don't want them to tell the truth, either; to give an honest reply to a question they have been directly asked. (This is where things start to get confusing.) No, what they really want is an adjustment to the truth, just a tiny little lie, a lie which may or may not be made, dependant on the context of environments which are fluid and not ours. Why would anyone ask a question that they don't want to know the answer to? I sometimes think we don't stand a chance.

When I am the only autistic person in the room I am an actor playing games I hardly know the rules to and which I struggle to replicate consistently.

Just relax and be myself?

They don't mean it.

They don't want me to be myself.

What they mean is, 'We want you to pretend to be someone else; we don't like you the way you really are'. Society does not want autistic people to be autistic.

Society wants autistic people to appear 'normal' regardless of the damage it causes. Applied Behavioural Analysis, so beloved among professionals (sic) in the United States, brutally demonstrates the lengths to which society will go in order to obliterate autistic traits in what appears to be an obsessive drive for social conformity. To be autistic is to challenge neurotypical norms, our directness, focus, interests and honesty they find alarming.

I seldom leave the house unless I am going to work, and it is because of my work that, other than speaking to my lovely and rather patient wife, I rarely talk to anyone who is not either autistic or a genuine ally. Despite the belief that autism is something white boys 'have', I have worked with autistic people from many different cultures, genders, races and social classes. Why is it that the single most important detail in these interactions is that we belong to the same neurotype? Why is that intersection so important? Why are relationships between autistic people built quicker and more successfully than those with members of the predominant neurotype?

I have worked with people who had never spoken to another autistic person before and who expressed their relief at being able to talk to another autistic person for the first time, not having to explain and be understood.

In the years before my own diagnosis I often said that I preferred being with autistic children and adults to socialising with the staff. I was asked me how I seemed to built relationships and achieved the outcomes I did with autistic children who were considered 'complex' or 'hard to reach' when no one else could? I didn't understand why I succeeded when others failed. After all, I didn't seem to do anything. Now of course I have come to realise it was because I did nothing, didn't back kids into a corner with needless communication and interaction. I watched and worked with them when they were ready, I engaged by sharing interest and built bridges with them. Spoken language is overrated – you can do without it and still find mutual understanding.

Damien Milton talks about the 'Double Empathy Problem'. That autistic people have some difficulty understanding, interpreting and using reciprocal social communication as well as problems reading social cues used so instinctively by neurotypical people. Neurotypical people have similar difficulty understanding and interpreting autistic communication, culture and the reasons why somethings are so important to us. Milton argues that neurotypical people

understand each other better than they understand autistic people and that autistic people understand each other better than we understand neurotypical people; that there is better empathy between us than between mixed groups.

Recent research by Crompton and Fletcher-Watson (2019) appears to confirm Milton's 'problem'. The study examined the transfer of information between neurotypes. Information or skills were passed through 'chaining' – exercises where information was passed between members of a group. The study found where the transmitted information was between autistic people, or non-autistic people, there was little 'noise' and the information was transferred successfully. When the communication transfer was between a mixed group of participants (Au – NT – Au – NT – Au – NT etc) the flow becomes corrupted and begins to fall into a state of decay.

The autistic participants of the study also reported higher levels of relaxation and empathy when they socialised or worked together than when they were with neurotypical people. Autistic people have no need to mask in each other's presence; we are culturally the same. To be with other autistic people, on the whole (we can fight and fall out like everybody else), is to be free, free to be who we are without judgement or explanation. Watch what happens when groups of autistic people meet, like at autistic-led conferences, retreats, meetings, pride picnics and social occasions. We take off our masks and we throw them away, we have no need for them. Eye contact appears to be easier and stimming becomes the norm, which is a good thing, stimming it's an important part of our culture, heritage and well-being.

Autism is my life, my passion, interest and profession, but I do have other interests. I speak a little Swedish and have something of an interest in that post-punk gem The Fall. I like The Fall; I have seen them dozens of times live since 1979. I own over 150 vinyl records and a hoard of over 300 live recordings. I like The Fall, and surprise, surprise, I know a little about them (try me out!).

Of course, not every autistic person has the same passions and interests that I do. I might not have a thing for electricity pylons, a deep understanding of the Spanish Civil War or have a detailed knowledge of Norwegian Railways, but what I can do, what we as autistic people can do, is to understand and respect how important to us those interests are to us, why talking about them is important, why the drive to pursue them is so strong. To deny them or seek to restrict access to a special interest or item is a cruel thing to do. My wife understands I have to utter every part of my information distribution, including any preamble, back story or what-have-you, or I am unable to move on, or at least have great difficulty in doing so.

Now I need to say this and I need to say it loud (like I usually do) and clear: if we need a 'data dump', we need a data dump and that is all there is to it. If there is something we need to talk about then we need to talk about it, and it seems only fair that given that autistic people are exposed daily to the mindless banality of small talk, something which is painful for many of us and an inefficient use of spoons (our units of energy). It's a verbal avalanche of neurotypical flotsam and jetsam which we can do without but which we try to accommodate. If that accommodation was reciprocal I am sure the majority of the autistic community would be eternally grateful.

Autism is exhausting, but hardly anyone outside of the autistic community talks about it. Why is that?

Organisation and planning is difficult for autistic people for many reasons, including anxiety – it's an anxiety provoking business. As autistic people we sometimes become so interested, so focused on a task or a subject that the rest of the world appears to disappear, and stuff we need to get done, doesn't. I believe autistic people are monotropic people. Monotropism, as described

by Murray, Lesser and Lawson (2005), suggests that we have limited channels of attention that are available to us and these channels are used far more intensely than neurotypical people classically do, the polytropes of this world. Monotropism helps explain so many aspects of autistic life, such as our intense focus and interests and the flow states and attention tunnels we form as we pursue them. We are the Marmite people: either we are completely into something, or completely uninterested.

Monotropism explains our black-and-white thinking styles and our polarisation in the way we process the environment, our hyper and hypo sensitivities to sensory stimuli. When we have a reaction to the environment, we usually feel it strongly.

Now if you want to make Carl sick, make Carl work in an open-plan office; the results are spectacular and quick. The hell hole which is your average open plan office serves no purpose except to save ground space, they do not improve efficacy. What they do is make life a living nightmare for autistic people and exclude them from the workplace.

When I first went to work at Matthew's Hub, I didn't have a home, my own space, just a Chromebook which I wandered the building with. When the main office was rearranged and I was asked to take a desk at one end of the room – after all I was 'one of the team' – I knew it was going to end badly, but they were lovely people who for all the right reasons wanted me to feel like one of them. But of course I am not, I am not one of them at all. I was so completely overloaded by the end of the day, even with ear defenders, that I went straight to bed when I got home and stayed there. I woke in the morning wondering how in the name of God I had allowed this to happen, again.

This was far from the first time I had overloaded like this; it's happened before, it always happens.

For my lovely neurotypical colleagues the very thought that they might be on their own all day with no one to talk to fills them with dread, but I am not the same as them, I just don't need that level of interaction to function; I need control of my environment.

Before I went to work at the hub I worked in an open-plan office delivering health and social care qualifications remotely, a job I had done for years previous at the college in Lincoln. Despite having the light turned down over my desk, it was still too bright, the radio is turned on the moment anyone arrives and stays on all day. By five past eight the small talk has been turned up to full volume, some nonsense about TV. The heating has just been turned up full and has been on all night, again. The phone starts to ring and the volume of the office has begun to rise, the sharp 'ting' of text messages, emails, WhatsApp and eBay messages fill the air. I struggle to stay focused, to create my bubble, but I am disturbed again and again (would you like another coffee?). It feels like my head is fit to burst and all I want to do is focus and work. I was so overwhelmed and overloaded by the end of each day that I would retch hard (no, it's not pleasant to read or experience) from the effort of holding in my discomfort the moment I got to my car (cars are mobile safe spaces). I was exhausted – my work days spent in purgatory, my evenings trying to 'reset'... after all, tomorrow is another day.

If you are forced to work or learn in an environment which hums and bristles with sound, people endlessly talking about nothing in particular until the chatter becomes inaudible, your world is full of unpredictable events and you only have so many channels open to process them with, then eventually you (as an autistic person) are going to overload, meltdown or worse.

Autism + Environment = Outcome (Breadon, 2017)

Breadon argues that an autistic person thrives or fails depending on the environment they find themselves in, and that also includes the people who inhabit that environment. Masking sensory processing difficulties is like trying to mask a broken leg or a heart condition – not terribly useful and just perhaps a little dangerous. Inevitably, and out of fear, many autistic people will attempt to ‘tough it out’, at least in the short term, and I do mean short.

Masking is a one-sided activity. It’s all about us making unreasonable adjustments for others, and it’s hard work. Masking is exhausting. Autistic people are expected to engage in all aspects of neurotypical culture intuitively with little if any effort being made to understand ours. No one sees the damage we do to ourselves, twisting ourselves out of shape for the benefit of others.

When we mask we become the allies of a culture which discriminates and which is neurologically imperialist.

We permit expectations of ‘norm’ and support our own discrimination. By ‘being autistic’, by taking off our masks and being true to ourselves, we are not only taking back control of our lives and celebrating our culture, we are also making a political statement.

It’s an act of resistance.

Chapter 11: An act of resistance

References

- Beardon, L. (2017). *Autism and Aspergers Syndrome in Adults*. London : Sheldon Press
- Crompton, C, J and Fletcher-Watson, S (2019a). Efficiency and Interaction during Information Transfer between Autistic and Neurotypical People [poster presentation] Retrieved from: <https://insar.confex.com/insar/2019/webprogram/Paper30110.html>
- Milton, D. (2012) "On the ontological status of autism: The double empathy problem'," *Disability & Society*, 27(6): 883–887. doi: 10.1080/09687599.2012.710008.
- Murray, D, Lesser, M and Lawson (2005). Attention, monotropism and the diagnostic criteria for autism. *Autism: the international journal of research and practice*. 9. 139-56. 10.1177/1362361305051398.