

Auto/Biography Review

ISSN: 2755-2772

2022, volume 3(1) 62-76

©TheAuthors

[Published under a CC BY NC licence](#)

<https://Autobiographyreview.com>

Actually Autistic at 40: A source of my auto/biographical troubles

Peer Reviewed Article

Rebecca Twinley

University of Brighton, UK

Contact: r.twinley@brighton.ac.uk

Abstract

In October 2019, two months after my 40th birthday, I received a formal diagnosis that I was autistic. I joined all those other thousands of late-diagnosed women in the UK, previously undiagnosed and overlooked. I had spent my years being mislabelled, misunderstood, or misinterpreted. I dealt with feelings I did not understand and sensory experiences I could not bear to process. I felt a need to cope with the 'normal' aspects of everyday life. I never knew why I experienced these troubles and troubling feelings for all those years. The discourse surrounding autism is referred to as the cost of camouflaging. In this article, I critically discuss predominant discourses on autism and gender as I reflect on my auto/biographical troubles from my newly confirmed, acquired identity and perspective as an autistic, now 40-something-year-old woman.

Keywords

Autistic, Autism, Self-Diagnosis, Formal Diagnosis, #ActuallyAutistic

Introduction: The importance of language

People influence language, and language use is passed on; transmitted as part of culture. In linguistics, this is referred to as either cultural transmission, cultural learning, or socio/cultural transmission, which is the process whereby a language is transmitted (or passed on) from one generation to the next within a community (Nordquist, 2019). In some cases, the number of people in a society affects the language and its use. To illustrate, in the UK, over 70,000 Deaf people use British Sign Language (BSL) to communicate as their first and preferred language (SignHealth, 2020). British Sign Language continues to survive because around 10% of deaf

people come from deaf families, and so the use of BSL is passed on amongst those who can access learning it.

It is crucial to critically examine and highlight how language is part of a total ableist hegemony that continues to dominate how disabled people are spoken about and even the development of disability policies and the setting of priorities (Brown, 2014; Pulrang, 2021). This has certainly been the case for autistic people. For example, most autism-related research has previously been conducted by non-autistic people, with many researchers discussing autism as something that needs to be 'fixed' (Bottema-Beutel et al., 2021).

To identify as autistic (either formally or informally), we must consider the use of language. It is often asserted that language is a powerful tool as words have the capacity to empower or disempower people (Srivastava, 2019). A personal example of the tangible power of language is when I hear someone talk, I can feel *moved* (emotionally affected) or influenced or inspired in some way. Language shapes how we think about and understand the world and other people in it. These societies are – amongst other things – ableist, which is evident if the very roots of language generation and language use are considered. For instance, Beschen (2019: 1-3) suggests that discriminatory language has

often been wielded by those in power in order to separate themselves from some perceived 'other'... [and] can therefore become exclusionary language... Ableism is the bias or discrimination against people with disabilities. Like racism and sexism, ableism manifests itself in a myriad of ways, including but not limited to: education, employment, bullying, low expectations, lack of accessibility in the built environment, and ableist language... While many people are aware of exclusionary language as it relates to race, gender and sexuality, many are not aware of how deep-seated ableist language is.

Talking about ableism warrants discussion of the use of the term disability. The (UK) National Autistic Society (2022) defines autism as a lifelong developmental disability. Additionally, autism is recognized under the Equality Act 2010 as a disability because it is a lifelong condition affecting how people interact and communicate with others (Citizens Advice, 2020). Some critical autism researchers (O'Dell et al., 2016) draw on Goodley (2014) to consider autism through the split term 'dis/ability'. Goodley explains this as acknowledging the way in which 'disablism and ableism (and disability and ability) can only ever be understood simultaneously in relation to one another [...] the split term denotes the complex ways in which opposites bleed into one another' (Goodley 2014: xiii).

In terms of identifying as disabled, many autistic adults are thought to prefer this term because it does not camouflage or evade their very real struggles (Coffey, 2021). As an occupational therapist, my practice was strongly influenced by a resistance to the medical model of disability, which defines disability as a result of a physical condition and a characteristic or 'problem' of an individual that rests solely with them. Rather, the social model of disability aligned more with my practice as this sees disability as caused by the way society is, i.e., non-inclusive and with barriers to accessibility. Having its roots in the social model of disability, the neurodiversity movement was initiated by Judy Singer – an autistic woman – who coined the term 'neurodiversity' to challenge assumptions that autism is a disease or disorder that needs to be eliminated, prevented, treated or even cured (Bertilsdotter Rosqvist et al., 2020). As a member of the autistic community, I am aware of the rigidly dichotomous choice posed through the question: Is autism a disability or a difference? (Endow, 2016). My answer is that I experience it as both. In highly social, stimulating, and unpredictable environments, some of my differences manifest as disabilities, whereas in environments that would be considered 'autism-friendly', these disabilities can be lessened, which, in turn, enables some of my other differences to flourish in the form of my skills, capacities, and talents. I will revisit this latter point later.

About one billion people worldwide – which equates to 15% of the global population – have some type of documented disability. The British Medical Association (2021) estimates that around 700,000 people in the UK are diagnosed as autistic. All disabled people experience widespread discrimination – the phenomenon known as ableism – which means discrimination based on disability OR – as the Oxford English Dictionary defines it: ‘discrimination in favour of able-bodied people’ (2021, ableism entry). Ableism can be experienced in various ways, and it can be intentional or unintentional. On a more individual level, personal ableism can include experiencing name-calling or violence. In addition, there is systemic ableism which refers to the inequity disabled people experience as a result of numerous barriers, attitudinal, communicative, physical, and those created or upheld through policy. My experience of some of these barriers is, in part, what I share in this here. Prior to doing so, I have purposely begun by raising the issue of language, especially in consideration of when it comes to talking about myself or when others – perhaps yourself - might talk about other autistic people. There is debate and difference over the choice of language or terms used for autism, with some people using other names. The NHS explain in their online autism guide (see <https://www.nhs.uk/conditions/autism/>):

There are other names for autism used by some people, such as:

- autism spectrum disorder (ASD) – the medical name for autism¹
- autism spectrum condition (ASC) – used instead of ASD by some people
- Asperger's (or Asperger syndrome) – is used by some people to describe autistic people with average or above average intelligence (2019, ‘Some people use other names for autism’, para. 5).

Further, there is disagreement over the use of identity-first language (so, for instance, saying ‘autistic person’) rather than person-first language (saying ‘a person with autism’), with most commentators (see, for example, Kenny et al., 2016) concluding the consensus amongst autistic people is for the use of identity-first language.

For myself, I am (now) open about being autistic; I think in part because I work as an academic/educator and often think of students who might benefit from knowing I welcome neurodiversity and have lived experience as a neurodivergent person. I feel Higher Education (HE) needs to better acknowledge the needs and skills of autistic employees and students. I am open because learning I am (and always have been) autistic put so much that was previously unexplained into perspective. Now I know this is my neurology – my neurotype, my wiring - and it is, therefore, integral to who I am. I am not ashamed of being autistic; I know it shapes me, the way I think, the way I feel, and what I do and what I do not do. And, of course, I – like all autistic people – am more than just autistic; my preference for identity-first does not equate to identity *only*.

Though not the focus of this article, many strengths come with being autistic; I can and do have good life experiences. For example, a primary source of enjoyment and relaxation of mine is to run. Running affords me routine and the ability to repeat a pattern of activity; a means to reduce feelings of frustration and anxiety, and a replacement for my regular self-stimulatory behaviour (stim) of biting my nails and picking at my skin (known as excoriation disorder). It is a way to connect meaningfully and become aware of what is happening in the environment around me.

The privilege and luck of formal diagnosis

At this point, it is also important to me to enhance recognition of the fact that not only do we know that women find it harder to get diagnosed, but the very experience of receiving a diagnosis is somewhat privileged. Before being formally diagnosed, I was aware that self-diagnosis is

generally accepted within the autistic community (Bennie, 2020). At this point, I want to acknowledge my use throughout this piece of discourse represented in various blogs and information/support sites about autism. These are resources I have found helpful when engaging with contemporary dialogue and debate, and this has, therefore, been an important part of my auto/biographic practice. As this tweet from NeuroDivergent Rebel shows, self-diagnosis is seen by many other autistic people as valid:

Diagnosis is a privilege many autistic people may never have. To all the autistic people who may never have a formal diagnosis: I see you. You are valid, accepted, and welcome here. #ActuallyAutistic #Neurodiversity #NeurodiverseSquad #selfdiagnosis #selfdx #selfdxisvalid (2019).

Self-diagnosis commonly leads to a formal diagnosis, especially for late or later diagnosed people, because they have lived experiencing the world differently and have often tried to find out for themselves. One research team advised that 'autistic people' should be considered 'autism experts' as they often build upon insights derived from the lived experience of being autistic by researching autism systematically' (Gillespie-Lynch et al., 2017: 211).

Having had my own experience of being informally diagnosed, of then seeking and, eventually, gaining a formal diagnosis, I recognize that formal diagnosis is a privilege that may be unavailable to many. A formal diagnosis can depend on various factors, including no access to a service, lack of income or finance to pay privately, fear of discrimination and rejection, and geographic location. The main limitation of not receiving a formal diagnosis is not then having access to support and services (Bennie, 2020), including having the right to reasonable adjustments being made by employers. Furthermore, Bargiela et al. (2016: 3291) investigated the experiences of late-diagnosed women and found that some, who stated having received a formal diagnosis, 'had fostered a sense of belonging in a group of like-minded people, and that this had promoted a more positive sense of self'. Therefore, they suggest that another loss related to not receiving a diagnosis (or remaining informally diagnosed) is that it denies autistic people the opportunity to identify with the autism community and experience the benefits this can provide.

What is more, and of great concern, beyond considering factors such as gender or socioeconomic status, autism identification 'appears to be generally lower in minority ethnic groups relative to the majority population' (Tromans et al. 2020: 241). Tromans et al. (2020: 241) conclude by suggesting that 'Diagnosis of autism may be missed or delayed in certain ethnic groups, leading to such groups being underserved relative to their needs'. Hence, we very conclusively know there are disparities in the receiving of a formal diagnosis and any associated support for many members of the autistic community, a community which in and of itself needs to continue to strive in its efforts to recognize and celebrate diversity and to challenge these inequitable experiences.

My Journey to a Formal Diagnosis

For me, the journey to diagnosis started years before I received it. It included many assessments, appointments, and fighting back and forth between National Health Service (NHS) Trusts with my General Practitioner (GP) trying to be assessed. At the time of my diagnosis, I was living in Plymouth, which, contrary to the Autism Act, had no diagnostic service for adults. In addition, the neighbouring local trusts of Bristol and Exeter were resisting 'out-of-area' GP referrals because they were struggling to see their own 'in-area' patients first. For me, the whole process included the completion of an array of screening tools which, if you were to support the assertion that gender plays a role during diagnosis, presents an issue because the majority of these tools (or behavioural instruments) used to diagnose autism have been standardized using male cohorts (Goldman, 2013). It remains the case that only a small number of studies have tested these tools for their sensitivity to identifying girls or women as autistic (Kopp and Gillberg, 2011; Rinehart,

Cornish, and Tonge, 2011). This reflects wider trends in autism-related research, which is grounded in male-only or male-dominant samples (Geelhand et al., 2019). It is clear now from research that the process of formally diagnosing women as autistic is lengthy and involves appointments with various professionals, often where there is some lack of or misunderstanding of the unique challenges faced, which, unfortunately, can result in misdiagnosis (Zener, 2019).

Returning to the process of my diagnosis: it also included a very draining, upsetting, and traumatizing two-and-a-half-hour interview with a clinical psychologist, during which she told me I'd soon 'get used to' the sound of the fire alarm that was incessantly going off just outside the room, even though she clearly did not understand its impact on me, as I was panicking and seriously planning how to run away. And then, at the end of this unpleasant session, she concluded by telling me she could not provide a diagnostic service, but she would send her findings to my GP anyway. All of this ended up with me using my bank overdraft (which I am privileged to have as a payment option) and paying for a private psychiatrist to complete the assessment and diagnostic process. At 40 years of age.

Since the first time it was suggested to me that I am autistic, it has frequently reoccurred about six times, most recently during psychotherapy sessions with a therapist I worked on and off with for about ten years. Over the past two years, I have thought a great deal about being autistic and reflected on myself as a child, my childhood and the conversations and experiences I had. One such occasion I have often thought of was when I was four years old, at my aunt's wedding. I was so excited to be her bridesmaid, but the entire day was exhausting and made worse by the fact the dress my aunt and grandmother had made for me felt so itchy and scratchy. In fact, as far back as I can recall, I have always instantly removed the labels and tags from clothes. By instantly, I mean as soon as I am home from shopping or as soon as I open a parcel delivered to my home, the scissors come out. These annoying pieces of material or plastic take me to the edge in that they make clothes uncomfortable to wear. I feel itchy and scratchy, and if I have somehow missed a label, it can do anything from completely distracting me to making me feel an angry need to rip the clothing item off. Sometimes it reduces me to tears. This highlights, I think, the different levels of tolerance to a neurotypical person I have to such a sensory irritation.

In my bridesmaid's dress, I think it was that sensory-related challenge, coupled with being forced to smile for staged photos, that led to me having an autistic meltdown. I started throwing stones at the cameraman and, from what I remember, it was only my grandmother (who passed away a few years later) who could relieve the situation. She walked me away from everyone, held my shoulders with her lovely big warm hands and just seemed to breathe in a pattern I was able to follow. I couldn't express my feelings at this time, not even to my grandmother, but I think I had thrown stones at the cameraman because it felt like he was incessantly requesting me to be fake – and yet, always in this kind of situation, I had an internal battle going on because I also cared (perhaps too much) about fitting in. Since my childhood, during most social situations, or events, I was acting, copying what I saw other children my age do, how they dressed or how they spoke, reacted, or behaved. This takes a lot of effort. Some days it was a constant check and re-check on what I said, how I reacted to a situation. Many times, I pondered over how to seem, or to come across to others, as sincere. This 'doing as others do', the camouflaging, the masking was happening.

The Costs of Masking

Now many (if not all) of us, including neurotypical people, often manage the way we behave, especially when conscious of how others perceive us in social situations (Izuma et al., 2011). Research by Cage and colleagues (2013) found that autistic people have a reduced ability to do this. This is supported by several other studies that confirm that 'camouflaging' of symptoms is

often reported by autistic people as a way to try to fit in social situations (Hull et al., 2017; Lai et al., 2017; Rynkiewicz et al., 2016). Hull et al. (2017: 2519) emphasize that:

Self-reported evidence suggests possible categorical differences between autistic and non-autistic camouflaging... For instance, camouflaging by [autistic people] ... has been reported as extremely effortful and challenging to one's identity (Bargiela et al., 2016), unlike ordinary reputation management in typically developing individuals.

There are certainly costs to masking or camouflaging. For me, a major cost is that it led to receiving my late diagnosis, which is now observed to be a phenomenon experienced by many women. Indeed, it has been confirmed that, compared to men, women are at substantially elevated risk of going undiagnosed as their difficulties are frequently mislabelled or just totally missed (Lai and Baron-Cohen, 2015).

On this, Bargiela et al. (2016: 3281-3282) and colleagues write that:

Compared to males, females require more severe autistic symptoms (Russell et al. 2010) and greater cognitive and behavioural problems (Dworzynski et al. 2012) to meet the Autism Spectrum Condition criteria. This gender bias has serious consequences for the health and wellbeing of [autistic] girls and women... and has been identified by the autism community as a key problem to be addressed by research (Pellicano et al. 2014).

Without receiving a diagnosis, it is said that women may not experience any sense of relief or vindication of their challenges (Moseley et al., 2020). In addition, I would suggest there are findings that also suggest some further, much-needed consideration of gender and gender diversity. For instance, the findings from a large study by Warrier et al. (2020) recruited cross-sectional datasets consisting of 641,860 individuals and found that compared to cisgender individuals, transgender and gender-diverse individuals have, on average, higher rates of being autistic. Hence, we know that researchers have frequently missed autism in cisgender girls and women because they tend to show different traits than cisgender boys and men do. I tend to agree with Janssen, who is reported to advise:

'Further research should move beyond quantifying the relationship between autism and gender... and focus instead on investigating the research priorities and clinical needs of autistic gender-diverse people, as well as underlying causes of the overlap' (as cited in Dattaro, 2020, paragraph 23).

My First Autistic Musical Obsession

Another childhood memory also relates to what I recognize as being one of my key autistic obsessions: music. Autistic people can have intense and – what others might call - highly-focused interests that often start from childhood. These can be interests that change over time, or they can be lifelong; music, for me, has been a lifelong interest. Of course, most people, including those who are neurotypical and those who are autistic, really enjoy music. For me, I feel more comfortable listening to music than, for example, engaging in conversation because the social demands and the rules are so much freer (or less, maybe) with music. In an interview (Levy, 2018, The Report) about music and autistic people, Michael Bakan, an ethnomusicology professor, explains:

In conversation, you're having to constantly modulate to satisfy the expectations of the other person, second by second, minute by minute... Because we live in a linguo-centric society, where language is so referential, certain words mean certain things, the connotations of the way you use a word, the gestures you make when you utter

something, are so deeply coded and so open for being misinterpreted or manipulated if you don't do it right, that if you are set up differently neurocognitively, that can generate a lot of anxiety. ('Music is a Powerful Tool for People With Autism')

As a child, I knew Guy Fletcher's—a keyboard player in the band *Dire Straits*)—family well. His mum once gave me a cassette tape with a blue label. No case. She just grabbed it from her car and said she could get another. She handed it to me as I sat at the bottom of the stairs, getting ready to say goodbye to her. 'Here, take a listen. It's a band my son – Guy – is in. They're quite good', she said. That album – *Brothers in Arms* – was played, and played, and played. It still is –though in digital or vinyl format! I literally wore the tape out. I have owned it in CD version, I have had a vinyl copy and, for some time now, a digital one. My music obsession is something I both really enjoy and find to be reliable. One commentator suggests this is because some autistic people can

'thrive within structure and music fulfils this need for structure and routine... Songs can therefore be ritualistic. Their structure can be something a... [person] can rely on, anticipate, and predict with ease and familiarity' (Thane, 2016, 1-3).

I would totally agree with that. Additionally, I use music to help me concentrate and to reduce feelings of discomfort of being in particular environments.

Not So Autism-Friendly Environments

On the topic of environments, many of the troubles I have historically experienced relate to this. My major bugbear is fluorescent lighting. Hahn (2012: 23) describes:

'[autistic people] may report pain when in contact with the visual stimulus that affects them. They see the flickering of fluorescent lighting as if magnified and therefore experience significant sensory overload'.

The human eye can see the flashing of the lights up to about 50 to 60 flashes per second (Canadian Centre for Occupational Health and Safety, 2021). The renowned author and speaker on autism, Temple Grandin, further explains that for many autistic people, fluorescent light is very difficult to tolerate because they 'can see a sixty-cycle flicker. Problems with flickering can range from excessive eyestrain to seeing a room pulsate on and off' (cited in Bogdashina, 2016: 94). Many environments, including offices, tend to use this lighting, and it has been something that I have always really struggled with or had to tolerate and still often do. Sitting in offices or meeting rooms with this lighting may distract me and/or hurt me and always drains me.

In terms of sound, I explained in an article written for *Occupational Therapy News* that I have 'auditory sensitivities to certain frequencies, loud noises, and combined sounds... 'My hearing is definitely a sense that is turned up too high'' (Twinley et al., 2020: 33). Some sounds can literally be unbearable and painful to autistic people, and often these are sounds others may tolerate or barely even notice (Cascio et al., 2008). An issue with this can also be that everything around me closes in, and this then results in being unable to process what someone might be saying right in front of me or directly to me.

At the same time as receiving my autism diagnosis, I also was diagnosed as having unreliable auditory processing. This is experienced as a delay in hearing and understanding what someone has said to me. This combination of issues has frequently led to some people misinterpreting both me and my outward presentation, as I have been perceived as disinterested or ignorant when, more probably, I have been trying to process what has been said whilst managing sensory challenges or overloads. It does not generally tend to bother me if other people have misinterpreted me, but it has become a concern when it is someone senior to me in the workplace.

This, coupled with the fact that I will always try to think of an excuse as soon as I hear of some kind of team event or social being planned, means that the way I am has become an issue. In previous employment, I have been told I often seem 'avoidant of teamwork opportunities'. But I often found that 'teamwork' was unstructured, and I just needed to know my role within the team and yearned for clear boundaries and expectations. Perhaps one of the most frustrating and diminishing experiences I have had in a manager-employee relationship was being made to sit with a manager and go through my diary for the previous year after being called to their office because they had concerns that I was doing my utmost to 'avoid team meetings' and, even when I was there, the look on my face implied I did not want to be. In twelve months of meetings, it appeared I had missed two; one when I was on annual leave overseas and one when I was on sick leave after a car accident. Sometimes it is not the facts that matter; it is the impression you have already so obviously made that continues to taint you or people's experiences of you.

A Sensory Overloading COVID-19 Vaccine Experience

Sensory overload can be overwhelming, scary, and exhausting, and I recently experienced a horrible episode which led to a meltdown. *Ambitious about Autism* describes a meltdown as:

Often the result of situations which are highly stimulating or create high levels of anxiety which feel like they can't be escaped. When someone is in this situation their reaction is either flight, fight or freeze... Meltdowns are similar to the fight response. When an autistic person is having a meltdown they often have increased levels of anxiety and distress which are often interpreted as frustration, a 'tantrum' or an aggressive panic attack. (2021, para. 1).

I would say it is not a 'tantrum'. I have heard people calling meltdowns an 'emotional avalanche', which I feel describes them well, as they can be a complete loss of emotional control that leaves you feeling exhausted. Here, again, the language around autism is important. As O'Donoghue (2020) asserts in her description of an autistic meltdown: 'the term 'meltdown' is synonymous with a 'temper tantrum' and used to refer to someone who is overreacting to something trivial. This demonstrates how far society is from understanding the struggles of autistic people' (2020, para. 3).

To give an example of when I have been sensory overloaded (and please decide if you want to read this paragraph as it comes with a sensory content warning), I will describe for you the time when I received my first COVID-19 vaccine. Imagine a really large and bright hall through which you have to enter by going down many steps into the basement of a building. There is one door in (with queues of people leading up to it) and security stopping and checking you at the hall entrance. You look in, and the room is flooded with all the ceiling-hung fluorescent lighting that literally covers the majority of the ceiling space. There are voices and murmurs all around the room, and there are about ten kiosks to check people in, after which you enter another queue that leads to a maze of booths and screens where lots of people are being vaccinated at the same time. There is one door out on the furthest side of all the screens, which is also being supervised by a security guard. Enter me, already experiencing sensory overloading and really, really anxious about receiving my first jab, especially as a 42-year-old who will have the *Astra Zeneca* vaccine. I had been handed a leaflet to read, which, because my vision was starting to go blurry, all I could make out on it was the word 'clot'. It is well established that any existing feelings of anxiety or stress can often make sensory overload more acute for autistic people (O'Donoghue, 2020). Exactly right: it did! Getting hot now, blurry sight, hearing is fading, and after saying 'I think I am going to faint', I couldn't hear what the person trying to check me in was saying to me. The room was closing in. I was scared. I needed to get out. I somehow made it across the hall. I think I had to force my way past the guard (I honestly cannot remember now). I headed to the colder air

outside, ripping my face mask off. I wasn't sure if I was going to be sick, have an episode of diarrhoea, or just fall to the ground and cry.

When Plans Change

I understand now that autistic people like me have different ways of processing the world around them. Whilst I wouldn't say I do not like change, I do need to be somewhat prepared for it. New places and unfamiliar surroundings are so much easier to deal with if I can make them less new or more familiar to me. A prime example has been when I change jobs, which I appreciate can present challenges to many people. Planning routes has been something I have always used as a strategy. I lived in London during my twenties – firstly in Streatham, Southwest London. I lived there and commuted back to Brighton, where I had moved from, for my job as an occupational therapist in a rehabilitation centre. I quite liked that commute because I was in my own car, with my music, and pretty much going against the flow of traffic, which was largely going from Brighton to London rather than the other way around. But then I got a post at the Homerton Hospital in Hackney, Northeast London. I liked many aspects of living in London, but not travelling. I got used to knowing which underground stations it was quicker or took about the same time to walk between rather than using the underground. The use of headphones was a necessity at such times, which, I now know, is common for autistic people in dealing with unpleasant sensory and auditory stimuli (Ikuta et al., 2016).

As usual for a new destination, I had planned my route and got my then-partner to do the route with me before my first day, from Streatham to Hackney; a route that consisted of a walk, overground, underground, overground, walk. When it came to Monday morning, I set off, the first stop from the overground to Victoria. At Victoria, I headed for the underground, but then alarms went off, and barriers came down, blocking my entrance, blocking everyone's entrance to the stairs leading to the underground. I cannot even explain the sensations and panic I felt. I still remember the feelings so tangibly today. Victoria station around me, everyone in it, everything in it, the whole building started to close in on me. My hearing was going, and my vision was blurring. I could make out figures of people who were redirecting themselves and leaving the station, heading toward buses. It was like someone inside me was saying: 'follow them, get on a bus but I couldn't. I do not think I was moving. I cried. Then I realized I was crying in London Victoria station. I moved to a corner between the barriers that were still down and a pillar. I continued to cry because I just could not stop. I reached for my phone and called my partner: 'The barriers', I said. 'What, what about them?' she asked. 'They're down, they put them down, what do I do?'. 'Wait', she said. 'Wait? What for? Wait, for what? It's fucked. My first day, and I can't even get there. It's fucked. I'm fucked. I had it fucking planned. I'm fucking stupid because I can't understand this fucking world'.

Now, consider that this is way before my diagnosis process had started and was also during a relationship with another health care professional, one in which we were trying to explore (mostly through me going to psychotherapy) why I did often struggle in these ways. Her reply to me, after my inarticulate, 'effing' response, was something along the lines of: 'Darling, they close the barriers as a form of crowd-control. Give it about two to five minutes, and they will be back up; it's just to stop too many people from being underground at once at peak time'. When I did get to my new workplace, everyone reassured me that there isn't really such a thing as being late in London because of the acceptance of unreliable commuter traffic. It was 08:35 when I got there. Five minutes late and feeling exhausted from the sudden and unexpected change that I had faced during my London Victoria crowd control experience.

I now identify as autistic. I also use or identify, at different times, with other terms, such as disabled and as having difference to (some) others. Of note, however, is that 'not all autistic people identify as being disabled or are comfortable with an approach that positions them as disabled

people; others do and are' (Jackson-Perry et al., 2020: 126). Times such as that recounted above bring this awareness of being either or both to the forefront of my conscious experience. It is a truth (my truth) that having a neurodivergent brain brings its challenges, and it is a disability. Be it from getting painfully overwhelmed or struggling with what neurotypical people perceive to be very basic daily living tasks or struggling to follow and understand conversations between neurotypical people with meanings that appear hidden to me; these experiences make me feel different and disabled. For instance, I will soon need to seek reasonable adjustments in my workplace when I am made to move to a new campus. I will do so on the grounds of disability because there will be barriers that will need to be considered so that I can access my place of employment (especially with regards to my experience of its physical features) and do my job as well as an employee without a disability (Citizens Advice, 2020). I am additionally aware that gendered prejudices frequently dictate roles in the workplace, with research suggesting there are sexist expectations of autistic women to behave and interact as a neurotypical person would at work (Gemma, 2021).

Is Everyone a Little Autistic?

One thing that has become a more tangible sense of trouble has been people's reactions to me when I either state I'm autistic or when I try to explain some of the symptoms and how I feel. I have received comments such as: 'You don't look autistic'; 'You seem fine to me'; 'There's no way you're autistic'; and 'Well, we're all a little autistic, aren't we?'. With regards to that final comment, I know that this often comes from a place of well-meaning, of wanting to perhaps demonstrate some empathy or understanding or acceptance. However, this is not how I, or indeed others I have spoken to, receive this. Rather, it can be experienced as feeling flippant, dismissive or minimizing of our experiences, which often include experiences of being othered, marginalized, and facing challenges, daily. Nancy Doyle, an organizational psychologist who specializes in neurodiversity, suggested, 'It's a little bit like saying to someone with chronic cluster migraines that 'we all have headaches, don't we?' And the answer is no, we don't all have headaches like that' (2021, para. 2).

Concluding Thoughts

When I gave the presentation that this article is based upon at the Auto/Biography Summer Conference, 2021 (Twinley, 2021), I called the paper: *Officially autistic at forty: a source of my auto/biographical troubles*. In concluding the presentation, I reflected that I would probably amend this slightly to *Actually autistic at 40* (as I have for this paper) to reflect what I have come to embrace as the use of the hashtag #ActuallyAutistic as an intentional form of disability activism. On Twitter, #ActuallyAutistic is used to connect with other autistic people and to support each other. The hashtag is also used to communicate with less chance or occurrence of misinterpretation. It was created and is used by actually autistic people to critique the dominance of conversations about them without them (or about autism).

Being #ActuallyAutistic is a mix of both very challenging but also very unpretentious, real experiences. But always, to me, it comes with the feeling of being different to other neurotypical people and peers. With this feeling of difference, I often felt isolated and experienced a strange conflict of fitting in by camouflaging but then not being able to fit in at times or in places where I could not effectively mask or camouflage. When preparing this piece, I discovered this is the experience for many people in much of the research related to diagnosis amongst adults. For instance, Crane et al. (2021) ran a ten-week autistic-led programme aimed at helping autistic adults learn more about autism within a peer group context. They found that:

The identification of autism (either formally or informally) can have a huge impact on the life of a person and those close to them; particularly if identification first occurs in adulthood. After years of not 'fitting in', autistic adults often report relief (and even

elation) in finally having an explanation for their feelings of difference (Hearst, 2019; Williams, 2019). Moreover, diagnosis in adulthood can lead to better self-awareness and an appreciation of personal needs (Stagg and Belcher, 2019). ('Supporting Newly Identified or Diagnosed Autistic Adults: An Initial ...') (Crane et al. 2021: 892).

My self-awareness has grown from my own greater and ever-emerging knowledge and understanding of my troubles, and I have some explanation as to why I experienced (or experienced) these troubles. But I do not think that learning and developing such self-awareness has stopped; perhaps there will be a future paper: *Actually autistic at 50*.

Funding

The author received no funding for this piece.

Notes

1. For assessment and diagnostic purposes, the term autism was changed to autism spectrum disorder (ASD) in 2013 by the American Psychiatric Association. ASD is now used as an umbrella term covering Autistic disorder, Pervasive developmental disorder, and Asperger syndrome (Cleveland Clinic, 2022). When the update to the Diagnostic and Statistical Manual, fifth edition (DSM-5) occurred, it combined all the diagnoses into the ASD diagnosis and is favoured in the US. In the UK (where I was diagnosed), the World Health Organisation's International Classification of Diseases (ICD) is the most commonly-used diagnostic manual which until release of ICD-11 this year (2022), divided the 'spectrum' into three subtypes: Childhood autism; Asperger syndrome; Pervasive developmental disorder – unspecified (The Open University, 2017).

ORCID iD

Rebecca Twinley <https://orcid.org/0000-0003-2128-0921>

References

- Ambitious about Autism (2021) *Meltdowns and shutdowns*. Available at: <https://www.ambitiousaboutautism.org.uk/information-about-autism/behaviour/meltdowns-and-shutdowns>
- Bargiela S, Steward R and Mandy W (2016) The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An investigation of the female autism phenotype. *Journal of autism and developmental disorders*, 46(10), 3281–3294.
- Bennie, M. (2020, June 29). *Am I Autistic? A Guide to Diagnosis for Adults*. Available at: <https://autismawarenesscentre.com/am-i-autistic-a-guide-to-diagnosis-for-adults>
- Bertilsdotter Rosqvist H, Stenning A, and Chown N (eds.) (2020) *Neurodiversity Studies: A new Critical Paradigm*. Abingdon, Oxon: Routledge.
- Beschen E (2019, August 15) *The Use of Language – Passion or Problem*. Available at: <https://www.socialconnectedness.org/the-use-of-language/>
- Bogdashina O (2015, May 27) *Sensory Intolerance in Autism*. Available at: <https://www.integratedtreatmentservices.co.uk/blog/sensory-intolerance-in-autism/>

- British Medical Association (2021) *Autism spectrum disorder*. Available at: <https://www.bma.org.uk/what-we-do/population-health/child-health/autism-spectrum-disorder>
- Brown LXZ (2014, February 11) *Violence in Language: Circling Back to Linguistic Ableism*. Available at: <https://www.autistichoya.com/2014/02/violence-linguistic-ableism.html>
- Bogdashina O (2016) *Different Sensory Experiences - Different Perceptual Worlds*. London: Jessica Kingsley Publishers.
- Bottema-Beutel K, Kapp SK, Lester JN, et al (2021) Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood* 3(1): 18-29.
- Cage E, Pellicano E, Shah P et al (2013) Reputation Management: Evidence for ability but reduced propensity in autism. *Autism Research* 6(5): 433-442.
- Canadian Centre for Occupational Health and Safety (2021) *Lighting Ergonomics - Light Flicker*. Available at: https://www.ccohs.ca/oshanswers/ergonomics/lighting_flicker.html
- Cascio C, McGlone, F, Folger, S, et al (2008) Tactile Perception in Adults with Autism: a multidimensional psychophysical study. *Journal of autism and developmental disorders* 38(1): 127-137.
- Citizens Advice (2020) *What counts as disability?* Available at: <https://www.citizensadvice.org.uk/law-and-courts/discrimination/protected-characteristics/what-counts-as-disability/>
- Cleveland Clinic (2022) *Autism Spectrum Disorder*. Available at: <https://my.clevelandclinic.org/health/diseases/8855-autism>
- Coffey LT (2021, August 13) *Autism glossary: What to say, and what not to say, when talking about autism*. Available at: <https://www.today.com/parents/autism-terms-words-can-be-considered-insensitive-why-t227779>
- Crane L, Hearst C, Ashworth M, et al (2021) Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme. *Journal of Autism and Developmental Disorders* 51(3): 892-905.
- Doyle N (2021, January 16) *Is Everyone A Little Autistic?* *Forbes*. Available at: <https://www.forbes.com/sites/drnancydoyle/2021/01/16/is-everyone-a-little-autistic/?sh=48bd0a76566>
- Endow J (2016, November 10) *Is Autism a Disability or a Difference?* Available at: <https://ollibean.com/autism-disability-difference/>
- Gemma N (2021) Reconceptualising 'reasonable adjustments' for the successful employment of autistic women. *Disability and Society* 00: 1-19 [accessed 01 March 2022]
- Gillespie-Lynch K, Kapp SK, Brooks PJ, et al (2017) Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts. *Frontiers in Psychology* 8: 438.
- Goldman S (2013) Opinion: Sex, Gender, and the Diagnosis of Autism - A Biosocial View of the Male Preponderance. *Research in autism spectrum disorders* 7(6): 675-679.

- Geelhand P, Bernard P, Klein O, et al (2019) The role of gender in the perception of autism symptom severity and future behavioural development. *Molecular Autism* 10(1): 1-8.
- Goodley D (2014) *Dis/Ability Studies: Theorizing Disablism and Ableism*. Milton Park, Oxfordshire: Taylor and Francis.
- Hull L, Petrides KV, and Allison C (2017) 'Putting on my best normal': Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders* 47(8): 2519–2534.
- Hurlbutt K and Chalmers L (2002) Adults with autism speak out about perceptions of their life experiences. *Focus on Autism and Other Developmental Disabilities* 17(2): 103–111.
- Ikuta N, Iwanaga R, Tokunaga A et al (2016) Effectiveness of Earmuffs and Noise-cancelling Headphones for Coping with Hyper-reactivity to Auditory Stimuli in Children with Autism Spectrum Disorder: A Preliminary Study. *Hong Kong Journal of Occupational Therapy*, 28(1): 24-32.
- Izuma K, Matsumoto K, Camerer CF and Adolphs R (2011) Insensitivity to social reputation in autism. *Proceedings of the National Academy of Sciences of the United States of America* 108(42): 17302–17307.
- Jackson-Perry D, Bertilsdotter Rosqvist H, Layton Annable J et al (2020) Sensory Strangers: Travels in normate sensory worlds. In: Rosqvist H, Stenning A and Chown N (eds) *Neurodiversity Studies: A new Critical Paradigm* Oxon: Routledge, 123-140.
- Kopp S and Gillberg C (2011) The Autism Spectrum Screening Questionnaire (ASSQ)-Revised Extended Version (ASSQ-REV): An instrument for better capturing the autism phenotype in girls? A preliminary study involving 191 clinical cases and community controls. *Research in Developmental Disabilities* 32(6): 2875–2888.
- Kenny L, Hattersley C, Molins B, et al (2016) Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism* 20(4): 442–462.
- Lai MC, Lombardo MV, and Ruigrok AN (2017) Quantifying and exploring camouflaging in men and women with autism. *Autism* 21(6): 690–702.
- Levy G (2018, June 8) *Music is a Powerful Tool for People with Autism*. Available at: <https://www.usnews.com/news/the-report/articles/2018-06-08/music-is-a-powerful-tool-for-people-with-autism>
- Moseley R., Druce T, and Turner-Cobb JM (2020) 'When my autism broke': A qualitative study spotlighting autistic voices on menopause. *Autism*, 24(6): 1423–1437.
- The National Autistic Society (2022) *Advice and guidance: What is autism?* Available at: <https://www.autism.org.uk/advice-and-guidance/what-is-autism#:~:text=Autism%20is%20a%20lifelong%20developmental,and%20children%20in%20the%20UK.>
- NeuroDivergent Rebel [@NeuroRebel]. (2019, August 19). *Diagnosis is a privilege many autistic people may never have. To all the autistic people who may never have a formal diagnosis: I see you. You are valid, accepted, and welcome here. #ActuallyAutistic #Neurodiversity*

#NeurodiverseSquad #selfdiagnosis #selfdx #selfdxisvalid [Tweet]. Twitter. Available at: <https://twitter.com/NeuroRebel/status/1296170725699719168>

NHS (2019, April 18) *NHS autism guide* Available at: <https://www.nhs.uk/conditions/autism/what-is-autism/>

Nordquist R (2019, July 3) *The Cultural Transmission of Language*. Available at: <https://www.thoughtco.com/what-is-cultural-transmission-1689814>

O'Dell L, Rosqvist H, Ortega F et al (2016) Critical autism studies: exploring epistemic dialogues and intersections, challenging dominant understandings of autism. *Disability and Society*, 31(2): 166-179.

O'Donoghue S (2020) *How it feels to have an autistic meltdown and how you can help*. Available at: <https://www.bbc.co.uk/programmes/articles/38f5MsC2mB5fnnCr5v77zDn/how-it-feels-to-have-an-autistic-meltdown-and-how-you-can-help>

The Open University (2017) *Understanding autism*. Available at: <https://www.open.edu/openlearn/mod/oucontent/view.php?id=98815andsection=unit4.2.2>

Oxford English Dictionary (2021). *Ableism*. Available at: <https://www.lexico.com/en/definition/ableism>

Pulrang A (2021, June 14) *Fighting ableism is about much more than attitudes and awareness*. Available at: <https://www.forbes.com/sites/andrewpulrang/2021/06/14/fighting-ableism-is-about-much-more-than-attitudes-and-awareness/?sh=2cd4341a19c0>

Rinehart NJ, Cornish KM and Tonge BJ (2011) Gender differences in neurodevelopmental disorders: autism and fragile × syndrome. *Current topics in behavioural neurosciences*, 8: 209–229.

Rynkiewicz A, Schuller B and Marchi E (2016) An investigation of the 'female camouflage effect' in autism using a computerized ADOS-2 and a test of sex/gender differences. *Molecular Autism*, 7(1): 1-8.

SignHealth (2020) *BSL Health Access for the UK's Deaf community*. Available at: <https://signhealth.org.uk/resources/bslhealthaccess/>

Srivastava SB (2019) Language: A Powerful Tool in Promoting Healthy Behaviors. *American Journal of Lifestyle Medicine* 13(4): 359–361.

Tromans S, Chester V, Gemegah E et al (2020). Autism identification across ethnic groups: a narrative review. *Advances in Autism* 7(3): 241-255.

Twinley R (2021) Officially autistic at forty: a source of my auto/biographical troubles. *BSA Auto/Biography Summer Conference 2021: 'Troubling Auto/Biography'*, Oxford, UK, 15-16 July.

Twinley R, Hitch D, Wong B, et al (2020) Feature: Neurodiversity: Together, we are all kinds of minds *OTnews* 28(8): 32-37.

Zener D (2019) Journey to diagnosis for women with autism. *Advances in Autism* 5(1): 2-13.

Author Biography

Rebecca (Bex) Twinley, PhD, is a Lecturer in Occupational Therapy in the School of Sport and Health Sciences at the University of Brighton. Bex's research focuses on the dark side of occupation and emphasises the need to critically examine the assumed link between occupation, health, and wellbeing. Bex is interested in the ways in which people may cope during and after traumatic events and is also furthering her doctoral research into woman-to-woman rape and sexual assault