

ESSAY

ESSAY SERIES: EQUITY, DIVERSITY AND INCLUSION

Autism in science – ‘through the looking glass’ and the role of empathy in the equation

Mariana De Niz

I was diagnosed with autism around the time I turned 19 years old, back in 2006. The diagnosis brought with it both a sense of relief and a sense of fear. On one hand, I knew at last why I had felt most of my life as an outsider. On the other hand, I knew that great prejudice existed against people with my neurotype. So I decided at that time to remain silent. It would be another 13 years before I shared this diagnosis with anyone.

If you have ever read Lewis Carroll’s book *Alice in Wonderland* (or watched any of the movie adaptations), there are many parts where I feel it describes very much the autistic experience (from my point of view). In Tim Burton’s film version, Alice begins as a ‘misfit’ in the ‘real’ world, but when she enters *Wonderland*, everyone still questions whether she is the ‘real’ Alice (and whether she is enough, or whether she is the person they expect), and she spends most of her initial journey trying to convince everyone that she is. Only after much struggle and as she matures within the story, does she eventually reach this dialogue:

Alice: From the moment I fell down that rabbit hole I’ve been told what I must do and who I must be. I’ve been shrunk, stretched, scratched, and stuffed into a teapot. I’ve been accused of being Alice and of not being Alice, but this is my dream. I’ll decide where it goes from here.

Bayard: But if you diverge from the path...

Alice: I make the path!

I feel I only reached this point in my own life aged 31, once I shared this diagnosis, and saw the huge impact this had for me in my career as a cell biologist and in my personal life.

Before I knew I was autistic, my ‘special interests’ had been a lifeline for me. As a young child, I found it very easy to learn new things, and was fascinated by a few (science included). My teachers at the time described me as gifted or extremely talented, but very shy. However, I never understood social interactions, making it a lonely journey – to say the least. Aged 15, I entered an institute that changed my life: this turned out to be the first time in my life where I felt welcome. Most importantly, it was here I realized I could use my ‘special interests’ to build a career as a scientist. Aged 18, I entered university to study a degree in immunology, and again felt that my ‘social’ skills were required, yet barely existent.

As I’ve come to learn more about autism, I realized that among ‘survival’ strategies that many autistic people use, consciously or otherwise, are avoidance and masking. Masking is a term used to describe a behaviour whereby we ‘act’ or ‘wear a mask’ to hide our autistic traits in order to fit in, be better understood, and avoid rejection. As a young adult at university, avoidance was almost impossible, and so, unknowingly, I began masking. Sadly, both of these ‘survival’ methods can cause a lot of damage in a person in the long term. The suicide rate among the autistic population is high. I found ‘masking’ extremely harmful. I sought help and a doctor explored the big picture with me, and eventually tested me and gave a diagnosis of high-functioning autism.

For the next 13 years, I enjoyed a wonderful career in science, while still resorting to masking. None of the initiatives of equity, diversity and inclusion I saw during my early career included neurodiversity. This reinforced my view that if there wasn’t even awareness of this, I couldn’t just be openly autistic and a successful scientist. I thus tried to navigate academia in a different way, and decided to ‘split’ myself into two: ‘the scientist’ and ‘the person’. Successfully separating both, I did my best to show people around me ‘the scientist’ only, and I feel I was valued as such. But at the end of the day, we are not robots, and this ‘split’ took its toll. I suppose I wanted what every person wants – to belong. All the while, I was constantly changing countries, thus leaving anyone I felt even slightly close to behind.

Aged 30, I began a postdoc at the Institute of Molecular Medicine in Lisbon, Portugal. While I had hoped to continue being only the ‘scientist’ that previous colleagues and principal investigators seemed to value before, this was unsuccessful in the lab I joined. My principal investigator at the time was Dr Luisa Figueiredo – a world renowned expert in parasitology. The way I ‘the scientist’ communicate was not easily understandable to her, and we failed time and again in discussing science. This eventually became overwhelmingly frustrating.

For the second time since my diagnosis 13 years earlier, I again sought help. My doctor convinced me that ‘the view on autism has changed’, and that perhaps the right path would be to share the diagnosis. I was hesitant, but eventually reached the conclusion that if ever I was going to share it, this was the right time. When I shared it, to my surprise, Luisa offered more than anyone else has ever offered in any other program of equity, diversity and inclusion I have known: she wanted to learn more about autism in general; she asked about resources available for her to learn; she asked what an institute could do to better integrate people like me; she wanted to know from me what my challenges were; and she wanted to know how she, herself, could help. This was unique in my career and perhaps in my life. In my experience, many equity, diversity and inclusion programs and initiatives want to be helpful – to women, or minorities, or people with physical disabilities, but fall short in their attempts to reach their aims. It remains a poll, or a statement on a website, or a poster, or a box one ticks without a tangible effect, rather than an honest, human-to-human conversation with compassion and an open mind that aims to ‘change the game’. I think what Luisa showed me is not only what someone neurodiverse would want, but what anyone in any marginalized group would want too.

I have readdressed the question originally posed for this essay: “has equity, diversity and/or inclusion shaped your experience as a cell biologist in some way?” to “how has being autistic shaped my experience in cell biology? And what would I change to improve equity, diversity and inclusivity when it comes to autism?”.

Being autistic helped me become ‘the scientist’ I am today: my ‘special interests’ and my wish to understand them better are the

basis for my career. Beyond that, I can easily recognize patterns in biological data. I have very high dexterity and spatial intelligence, both of which have been pivotal in my career. I have a very high capacity to work in a focused state for a very long time. This is one of the stereotypes commonly shown in film (albeit not always correctly): an autistic person being oblivious of the rest of the world while performing a task that brings them comfort. While a valued trait in science, it still poses its own challenges: the most important being that it can become physically taxing in the long term (my ophthalmologist often complains), and this includes an inability to stop a task to sleep. Finally, I have very high visual and acoustic memory. The first has been key for my career as a microscopist; the second in activities that help my interactions with others, such as learning multiple languages (the ones I find interesting) or playing music.

A major challenge for me ‘the scientist’, is that scientists are expected to be excellent communicators. While in writing I have enough time to shape the scientific messages I wish to convey, in speaking I do not – I try very hard though. When I have had colleagues that favour oral communication (and disfavour written), this can be problematic. Equally, science is also about networking – and for someone autistic, this can be overwhelming and exhausting. Virtual meetings have come a long way to make this more manageable. While I’ve faced other challenges in addition to these, I believe increasing awareness of autism, including communication challenges and needs, and promoting empathy and tolerance, would make it easier to find a compromise.

While those have been some of the realities for me ‘the scientist’, I ‘the person’ have faced enormous challenges, mostly of two

types: physical and social/emotional. I’ll touch on a few below, but this is by no means exhaustive. As perhaps do many other autistic people, I have hypersensitivity to sensory stimuli (light, noises, smells, tastes and touch). Sensory stimuli in a lab can be overwhelming, because they are ubiquitous and omnipresent – and painful. Most labs have an immense amount of light; they are full of noises, some of them very strong (including the noises other people don’t hear, like electricity everywhere); and they are full of smells – of chemicals or media. A comparison I read for overload sensory stimuli is being hungover. Imagine being hungover, in a room full of bright lights, with the loudest timer in the lab beeping, and an open bottle of β-mercaptoethanol near you. I believe accommodations can be made to diminish this overload. Moreover, better awareness would mean that autistic colleagues can wear protective items without being thought of as ‘exaggerating’.

When combined with social/emotional challenges, sensory overload can result in what in autism is known as a meltdown or a shutdown (perhaps the equivalent of the fight or flight/freeze response, respectively). While I try to make sure that when it happens it is only a shutdown, this is not always possible. Most of the social/emotional challenges I have personally faced come from the fact that I have masked for decades and unfortunately this is still expected – but it’s a harmful practice. While I have many examples of how masking, together with unfair situations or prejudices I do notice, impacts mental health and daily interactions, suffice to say that added to cultural adaptations (many relying on ‘unsaid’ things), linguistic adaptations (where even simple things may have different meanings in different languages), and the career demands of science, this can easily result in a shutdown (or meltdown). People

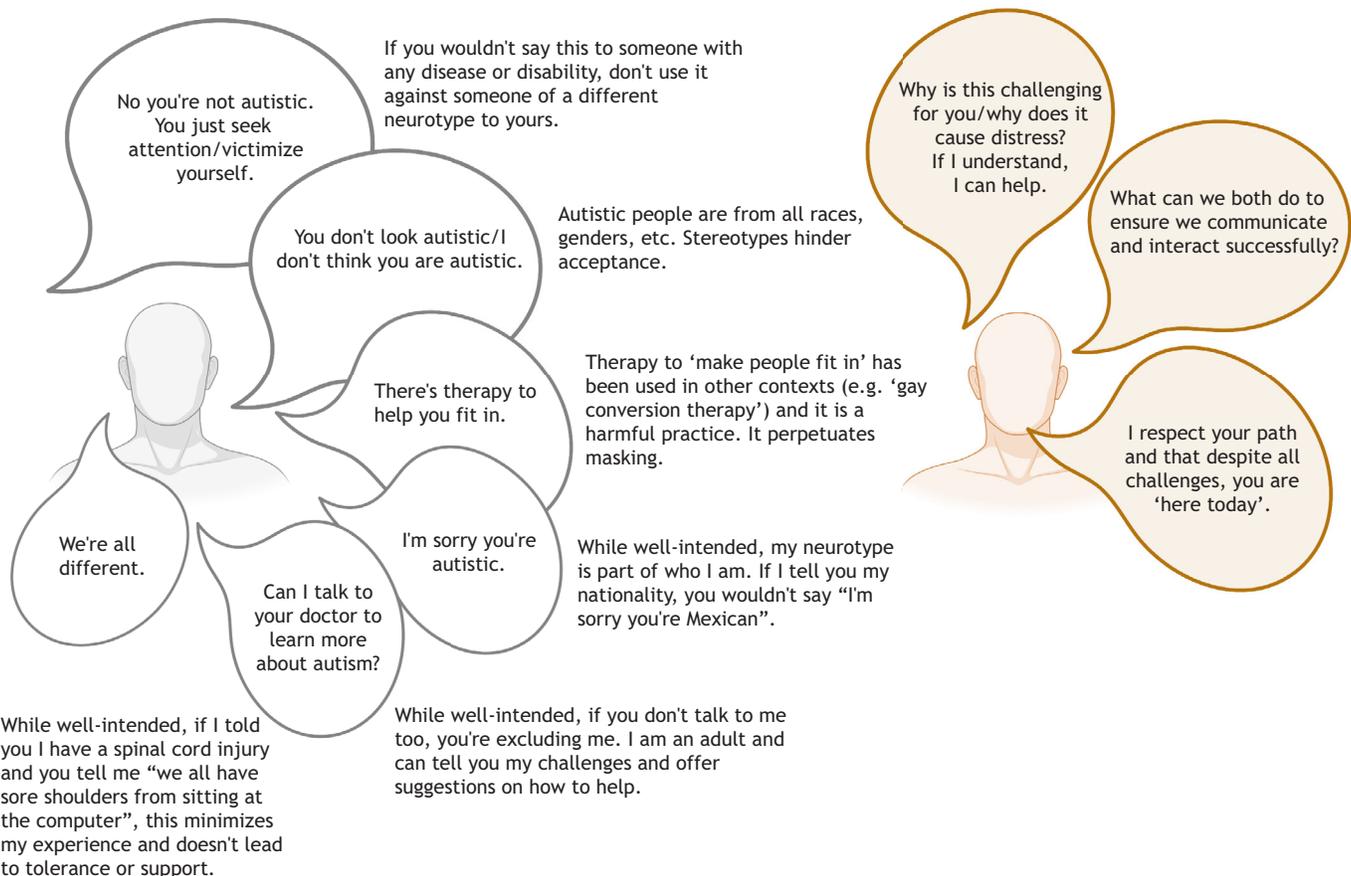


Fig. 1. Personal examples of speech I have encountered and found non-supportive (and why) or supportive. Created with BioRender.com.

and institutes can provide better support. Moreover, I believe autism – and the challenges of autistic personnel in science – should be discussed at an institute and at a group level, both to improve support but most importantly, to remove stigma. To do so, the input of autistic scientists should be sought too.

Finally, when I shared my diagnosis, most of my friends who knew became an invaluable source of support. I do not always understand what people mean, or how best to communicate a message. My friends help me navigate this: “Was this a joke? What did this person mean?”. I think their support has been game-changing for me, and perhaps is something that could exist within groups to help non-autistic and autistic colleagues to better communicate and understand one another.

While science is a very demanding career, to be truly inclusive to all the talented people forming the scientific community, I believe we are all capable of dedicating our time to listen and understand (Fig. 1). I hope that sharing this experience makes science a safer ‘place’ for other autistic scientists who haven’t felt comfortable disclosing their diagnosis, or who suspect but ‘fear’ this diagnosis,

as well as to young autistic people who wish to become scientists. I hope I have managed to convey to my non-autistic colleagues that perhaps people you know mask or avoid – and suffer in silence, facing challenges you are not aware of. Ultimately, I hope this is a small step towards creating an atmosphere of belonging and tolerance, where neurodiversity can be recognized and valued equally to other forms of diversity.

Acknowledgements

I’d like to thank Joana, Jenny, Sonia and Sara for reading this essay and sharing their opinions with me. Thanks to Luisa Figueiredo for her comments but most importantly, for ‘changing the game’, and to Claudio Franco for his role in making it all work out. Thanks to the friends who have shown me kindness: those who were there long before I made the diagnosis public, and especially to those who unknowingly, saved my life (Gesine, Caro and MC). Thanks to the friends who stood by, and showed me enormous kindness and support before and after knowing I am autistic (Idalio, Sara, Lara, Juan, Ludmilla, Kannan), and to those who have helped me ‘translate’ both ways to facilitate communication (Sara, Idalio, and Aline).

The author, Mariana De Niz, is a Human Frontier Science Fellow at Institut Pasteur, Paris, France, and can be contacted at mariana.deniz@gmail.com (Twitter: @mariana_deniz).