

VICTORIA GRAY IN CONVERSATION WITH MEGAN RHIANNON

KEYWORDS

autistic, book, art, overwhelm, burnout, diagnosis, world, understand, sensory, laser, performance, lots, sound, language, communicate, joy

Megan Rhiannon is an autistic illustrator based between Reading and London.

Megan's work is inspired by day-to-day life and experiences and varied special interests. This and being autistic heavily influence Meghan's love and attention for detail, colour, texture and observational drawing.

In this conversation we discuss Megan's self-published book 'Existing Autistic' (2020) which documents and explores her experiences as an autistic individual.

Content Warning: This conversation includes discussion about diagnostic assessment processes, autistic burnout, and concepts of high/low functioning.

Victoria Gray: Megan, thank you so much for talking to me about your book *Existing Autistic*. I received my diagnosis in July 2017 (aged 35) and since then, like many other late-diagnosed people, I've been on a journey to make sense of my past, present and future. *Existing Autistic* has been really important for me in this process.



You were diagnosed, aged 19, and in the book, you recount how a diagnosis helped you to make sense of yourself, having previously accessed mental health services and received treatment for other health-related symptoms, such as debilitating migraines, to “explain” your differences.

What advice would you give to other people who are considering pursuing a diagnosis, or are currently undergoing the process of diagnosis?

Megan Rhiannon: I think my initial advice would be to trust your gut. Throughout my childhood and early adolescence, I knew that the diagnoses I was receiving didn't sit right. I was young so I obviously didn't have a wealth of experience and was really only just starting to form my identity and sense of self, but when asking questions about my diagnoses I often found that the doctors couldn't (or wouldn't) give me straight or simple answers. They spent a lot of time talking in circles and telling me not to worry about it. I only eventually discovered my true diagnosis as a result of spending my life reading medical articles and texts because I found a lot of comfort in the stories of others' "unexplainable" conditions.

The practical advice that I would offer is to bring notes to your diagnostic assessment. When preparing for mine I found a simplified breakdown of the criteria online and made notes about how each trait affected my life in the past and the present. It was really useful whenever I started to feel a bit stuck or overwhelmed and showed the assessor that not only was I taking it all very seriously, but that I truly understood what I was asking for. Unfortunately, many misconceptions and stereotypes about autism still persist, even within the medical industry and in those who are meant to be well versed in the subject. In a worst-case scenario, bringing notes feels like a sensible precaution to help rebuff an assessor who may not take you seriously at first glance.

VG: Reflecting on my own diagnosis, and my life up until that point, it was sensory differences and autistic burnout that had the biggest impact on my quality of life, and that led me to diagnosis. I had no idea that I was experiencing the world with a different sensory operating system to the predominant neurotype, and so presumed I was just failing at life, in so many ways.

In your book, you develop a beautifully illustrated visual language to communicate your sensory world. You also offer some really rich descriptions of your sensory experiences which gave me goose bumps! Could you share some examples of what autistic sensory experience feels like for you, from an embodied perspective?

MR: When trying to explain my differing experiences and perception to people, I often just say that autism is “a lot, all of the time” and that’s largely how it feels for me - everything is always incredibly overwhelming, from the clashing and conflicting sounds of traffic and movement in a street, to the clatter and clinking of a kitchen, coffee shop or restaurant, the combined smells of perfume, aftershave and body odour on public transport, and the indecipherable but ear-aching hum of overlapping conversations in a closed space- everything is just *a lot*, always.

The flip side of this constant overwhelm is being able to laser in on softer moments in an intensely unique way- finding a small, reassuring quiet in the feel of my puppy’s fur on my cheek, in the seamless fit of the socks that I prefer, in a reflection and refraction of light in a

window, a particular smell, colour, feel, sound. There is an alarming amount of give and take in autism, and one that I often find hard to balance, but in these small moments I find not only comfort but a sense of feeling “right” and “correct” and of knowing that this is how I am meant to be.



VG: As well as connecting with your book at the level of being autistic, I felt a strong affinity to your unique abilities to express as an artist-illustrator. I also have a background in art, performance and philosophy, and I see my abilities here as inextricably connected to being autistic. As you describe it so perfectly, I seem to have an innate capacity to laser in on almost imperceptible qualities and sensations. When this happens, I get a sense of “rightness” and settling in my body, and this gives me intense pleasure.

However, diagnostic processes and disability assessments can necessarily focus on autism in terms of deficit and need. Can you say more about the joyful aspects of your diagnosis, and of being autistic, in your experience?

MR: In the first year of my diagnosis, I think I felt only joy - I was so immensely relieved to finally have answers that I really leaned into it and embraced my differences, and the skills and techniques that I was uncovering in my post-diagnosis research and reading. The next couple of years after that I felt a little less confident, not in my diagnosis but in myself and my ability to carry the stigma and pressure that comes with it. I began to grow tired of explaining myself, of justifying my diagnosis, of accommodating others who did very little to accommodate or even listen to me, never mind understand me. I didn't grow tired or weary of being autistic or of having a diagnosis, but of existing around people who weren't autistic, and wouldn't even extend the effort of pretending to care about those who experience, perceive and exist differently to them.

I've been trying a lot harder recently to find that joy again, and writing my book was a big part of it. I was able to sit, for several months, and document my experiences, describe my differences, and sort of explore and express all of my feelings, thoughts and ideas about being autistic. The response and feedback that I've received since (including your own!) have been enormous in rediscovering my joy and confidence in my diagnosis and my way of life.



VG: I really appreciated how you tackle the thorny issue of diagnostic terminology in your book, particularly the conceptualisation of autism as being on a linear spectrum from high to low functioning. I was diagnosed high-functioning, however this hasn't reflected my life-experience. Despite a career in academia, and achieving a PhD, I have also experienced several debilitating periods of burnout which led to me being so incapacitated that I was unable to work or function independently for several years. Subsequently, I have to manage my sensory diet and my workload with precision to maintain that delicate balance.

In your book, you offer autistic people some excellent strategies for managing meltdowns, shutdowns and autistic burnout. Can you share some of the techniques that work best for you. I'm particularly keen to hear of any new strategies that you have developed since writing the book?

MR: My first and main technique for coping with anything negative is to remove myself from the situation, especially in the cases of meltdowns, shutdowns and overload. I've spent years carefully decorating and rearranging my bedroom, curating my space, to be as soothing and supportive as possible, so that's where I retreat to. I have lamps set to specific hues and brightness levels, candles with smells that remind me of particular times and places, blankets with textures that are not only tolerable or soft but stimmy to touch, and photos, posters and scraps stuck to my walls and around my room that ensure I'm reminded of special interests whichever way I glance. This way, whether I'm only moving upstairs or returning home after a particularly hard day, I'm immediately soothed upon entrance to my "space."

My other main technique (and one of my oldest techniques) is engaging with my special interests, usually Sherlock Holmes. My phone allows me to always have access to this character and comfort e-books in a reading app, photos in my camera roll, fan-fiction tabs open in my browser, all ready, immediately when I need them. I find it immensely effective to be able to temporarily or momentarily absorb myself in a special interest when faced with a hard moment, to the extent that I have sentences and loops of text memorised that I can repeat by heart as a sort of grounding mantra or reassurance loop.



VG: As we know, diagnosis is only one part of the puzzle. There is a lot of complex work to be done post-diagnosis to develop these techniques, and re-frame our life experiences in that new context. This is sensitive work that requires a creative remapping and recalibration of our life-narratives on subtle and complex levels.

Can you tell me about the support you received, either formally or informally, post-diagnosis?
And do you think that peer-support from other autistic people is beneficial?

MR: I didn't receive much (or any) formal support. After my diagnosis I was very excited to discover what was out there to help me finally begin learning about myself and adjusting to life, but I couldn't find anything, locally or regionally. I was eager for some kind of counselling, for therapy, for a peer support group- anything, but there was nothing available to me. There were lots of groups and therapies for children, for the parents and carers of autistic individuals, but nothing for autistic adults or adolescents. I was pretty crushed to discover this, and it was a big part of my motivation for eventually writing my book. The only real place that I found comfort was on social media, from other autistic adults. There was solidarity in those of us newly diagnosed, sharing experiences, tips, tricks and thoughts on blogs and forums, and a lot of support and advice from those older and earlier diagnosed on platforms like twitter. Without those communities, I'm honestly not sure where I would be. I think support from other autistic individuals is crucial- it's all well and good to receive professional support and mentoring from allistics who may be better experienced and equipped at navigating life and greater-society, but there's a really special and important level of understanding, solidarity and reassurance in speaking to someone who shares your neurotype, even if your experiences don't match up exactly.

Even now, years after my diagnosis, I cannot find any local support- counselling, support groups, therapy- but I find comfort, reassurance, advice, friendship and love in speaking to

other autistic people (my friends) that I have met online. For this reason, I think peer-support is immensely important.



VG: You close Existing Autistic with a letter addressed; ‘to my autistic readers.’ It felt wonderful to be addressed so directly, and with such autistic peer-solidarity.

To close our conversation, is there anything from that letter, or indeed from the book, that you’d most like readers to take away?

MR: If it’s alright, I would really just like to reiterate the end paragraphs of the letter:

“and lastly- though I probably don’t know you personally, I am glad that you are alive. Please stay alive. The world needs autistic voices. Pursue your special interests and care for them quietly- shape them into a tool that will help you cope. Manage your sensory needs to the best of your ability and seek out the stimuli that makes the whole world feel a little clearer, brighter, even if it’s just for a second. Feel your feelings, express them, and above all- rest. Allow yourself the room you need to survive and grow, even if nobody else does. The views, opinions and actions of others hurt, but within us we hold the power to quietly build an autistic home for ourselves. It doesn’t make it hurt less, but it allows us to carry on.

Stare into the soft hues and floating motions of the jellyfish tank, look too long at the perfect segments of a found leaf, rock back and forth tiredly in the evening, hyper-fixate on a fleeting interest, mind your routines, ask for help where its available, and don’t forget to stim. I’m rooting for you.”

66



unashamedly • wholeheartedly • contentedly

VG: Megan, thank you again for sharing these insights.

I can't think of a more fitting way to end our conversation than with such a joyful expression of autistic solidarity...

LINKS

<https://www.megan-rhiannon.com/>