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The Curious Intersectionality of Being an Autistic Chinese Canadian

Joy Lu, Independent Author, Canada

 <https://orcid.org/0009-0006-5762-4334>

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The Curious Intersectionality of Being an Autistic Chinese Canadian

La curieuse intersectionnalité d'une Sino-Canadienne autiste

Joy Lu¹

Abstract

In this piece, I aim to explore the complex intersectionality of being both autistic and Chinese Canadian, a topic that is rarely discussed. As someone who is multiply marginalized, my cultural background and traditional Chinese upbringing played a significant role in delaying my autism diagnosis until adulthood. I want to shed light on the unique challenges East Asians face in relation to autism, especially since, despite Canada's rich diversity and large Asian population, autistic Asians remain significantly underrepresented and underdiagnosed. By sharing my personal journey, I hope to bridge that gap. The narrative begins with a personal reflection on my past misunderstandings about autism and how those misconceptions were shaped by my cultural context. It then delves into a broader analysis of why autism awareness is generally lacking in Chinese communities. Finally, I will demonstrate how I've taken on the role of advocating for greater autism awareness, particularly within these communities, while striving to educate others. Through my story, I aim not only to raise awareness but also to foster a deeper understanding and acceptance of autism, helping to create a more inclusive and supportive environment for people of all cultural backgrounds.

Keywords

Chinese Canadian, Chinese autistic, late diagnosis, autistic self-advocate, intersectionality

¹ Independent Author

 <https://orcid.org/0009-0006-5762-4334>

Resumé

Dans cet article, je souhaite explorer l'intersectionnalité complexe entre le fait d'être à la fois autiste et Canadienne d'origine chinoise, un sujet qui est rarement abordé. En tant que personne marginalisée de plusieurs façons, j'ai vu le rôle important que mes origines culturelles et mon éducation chinoise traditionnelle ont joué dans le retardement de mon diagnostic d'autisme jusqu'à l'âge adulte. Je souhaite faire la lumière sur les défis uniques auxquels sont confrontés les Asiatiques de l'Est en matière d'autisme, d'autant plus qu'en dépit de la riche diversité du Canada et de son importante population asiatique, les Asiatiques autistes restent largement sous-représenté-es et sous-diagnostiqué-es. En partageant mon parcours personnel, j'espère combler cette lacune. Mon récit commence par une réflexion personnelle sur les malentendus que j'ai vécus par le passé au sujet de l'autisme et sur la manière dont ces malentendus ont été façonnés par mon contexte culturel. Je propose ensuite une analyse plus large des raisons pour lesquelles la sensibilisation à l'autisme est généralement insuffisante dans les communautés chinoises. Enfin, je montre comment j'ai assumé le rôle de militante pour une plus grande sensibilisation à l'autisme, en particulier au sein de ces communautés, tout en m'efforçant d'éduquer les autres. À travers mon histoire, je vise non seulement à sensibiliser, mais aussi à favoriser une meilleure compréhension et acceptation de l'autisme, en aidant à créer un environnement plus inclusif et plus favorable pour les personnes de toutes origines culturelles.

Mots-clés

Canadien d'origine chinoise, autiste d'origine chinoise, diagnostic tardif, militant pour l'autisme, intersectionnalité

A recent study shows that nearly 80% of autistic females are undiagnosed as of age 18 (McCrossin, 2022). And I am included in that 80%. I do not want to talk about late diagnosis per se, because there are already so many amazing self-advocates out there talking about

their experiences of being late diagnosed, and the consequences of growing up with unrecognised autistic traits. Rather, I want to talk about being an autistic Chinese Canadian, and its impact on getting diagnosed late, how Chinese autistic people are often unrepresented within autistic communities, and the lack of autism awareness within Chinese communities.

I stand at an interesting (but rarely talked about) intersection of being an autistic person who is active in the online autism community, and being a Chinese person whose racial and cultural community is very often ignorant about autism.

As a Chinese Canadian, I was ignorant about autism, and so were my parents

I first heard the word ‘autism’ when I was 18 years old. I didn’t know anything about what being autistic meant (even though, unbeknownst to me, I had an entire 18 years of lived experience of being autistic) because I had never encountered the word or concept before. Interestingly, the person who introduced me to autism was an autistic classmate with Chinese heritage, someone who was talkative, very extroverted, and a very talented artist.

We were working on a group art project together during the winter session at Rhode Island School of Design (located in Providence, Rhode Island, USA), and he said, “I have autism”. I asked him what that was because I had never heard of that word before. He said 自闭症, which is the Chinese word for autism. I remember being surprised, not believing what he had just said. And then I replied, “Oh so you’ve gotten better now”. He told me, patiently, that there is no “getting better” with being autistic. Rather he had learned skills to manage it better. For a while, I simply could not believe him, even though I was

undeniably very interested in the topic. This disbelief stemmed from the fact that, based on my initial understanding of autism, I felt like *I* was the one who fit the “autism” description better. Let me explain.

I was born in Canada, but moved to China with my parents when I was around five. I usually tell people that I was raised bilingual, and even though that is true, that is not the whole picture. During my middle and high school years, I went to a school with a British educational system where everything was taught in English, and everyone communicated in English. So naturally my English would be at the ‘native speaking’ level. But there is a caveat: the school was in China, and within and without the school, culturally speaking, I was mostly Chinese. My way of thinking, my scope of knowledge, my values and worldview, my ignorance and biases, were all shaped by the Chinese culture around me. In Chinese culture, people didn’t talk about autism, neurodivergence, or mental health-related topics at all. So, in my first 18 years of life, I had never heard of the word ‘autism’.

I was, however, sure that I knew what the Chinese term for autism meant, even when I really did not. Chinese is different from English as a language system. In Chinese language, each character has an apparent meaning already, and a word or phrase is deciphered by connecting the meanings of the single characters together. This means that while many Chinese people (and the 18-year-old me) might not know what autism is, when they hear or read the Chinese term for autism, they would understand the literal meaning of the characters, and thus infer or assume that the condition is exactly as it is described.

The Chinese name for autism has two versions, and one of them is 自闭症, meaning ‘self-enclosure disease’. The other name is 孤独症, meaning ‘the lonely disease’. So naturally, people would often think that autism equals being shy or very quiet, and the

autistic person is either doing it on purpose or it is a disease that can be cured, since it is 'self-enclosure disease'. People might otherwise think that the autistic person was neglected or was not exposed to enough friendship or parental care, since it is 'the lonely disease'.

Now you might understand why, the 18-year-old me would think that the autistic classmate was not autistic at all: he was loud, passionate, and had a big personality. He was everything that autism was not - or so I thought. That is also why I thought that even I appeared more 'autistic' than he did: I have always been very quiet, introverted, and reserved, and I was aware that I came across as quite 'closed off' and 'strange'.

I was lucky enough to have the resources and opportunities to learn about what autism actually was, and how it can exhibit in different individuals. I was also (somewhat by chance) diagnosed as autistic as a young adult, a few years after hearing the word "autism" for the first time.

It was not my fault that I was ignorant about autism

Even though objectively speaking, my autism diagnosis would be considered a 'late' by many, I think that taking cultural factors into account, my diagnosis is actually quite early. Because I would imagine that it is quite hard to be diagnosed with something that you do not know anything about, including the symptoms and traits. Chinese people not only do not talk about neurodiversity and mental health issues, they also do not tend to go to hospitals for those issues, even when they are in fact suffering greatly from something. This is due to the deep-rooted sense of shame related to going to hospitals and admitting that you have an illness or abnormality. This is not only true for Chinese people living in China,

but also for Chinese Canadians (and Chinese people who live in other countries, especially newer immigrants). This is a cultural phenomenon, rather than a geographical issue.

The ethnically Chinese autistic people who I know, were all diagnosed when they had moved to English-speaking countries, or their parents were earlier immigrants to English-speaking countries. Their values are more aligned with Western culture than Chinese culture. They have somewhat successfully assimilated into the local communities instead of staying within the Chinese communities, so they could be exposed to information and resources about autism.

However, I think Chinese people, including Chinese Canadians, are severely underdiagnosed when it comes to autism. I am not solely blaming the Chinese communities for this. I also believe the medical field and self-advocacy groups should do better to address this issue as well.

As a Chinese Canadian, I do not see myself being represented in the autism community—whether it’s social media, mass media, films, discussions, or autism groups. In fact, I do not see a whole lot of conversations around Chinese autistic people at all. Partly, it is because Chinese autistic voices are indeed rarer, and also because Chinese people, in general, are less likely to actively speak up given their cultural habits (especially about “shameful” topics such as autism). Also, it is possible that most people within the autistic community do not really think about Chinese autistics, because we get very little representation overall. People say that we need to uplift and listen to racially diverse autistic voices, but they tend to forget that Chinese, or even East Asian autistics exist. People say that we need to listen to Black and Brown voices, but what about Chinese voices?

Autistic people complain that a lot of media portrayals of autistic individuals often fit the stereotype of a lower support needs white male, who often speaks in a robotic tone and lacks empathy. Some well-known characters who fit this stereotype include Shaun Murphy from *The Good Doctor* (2017), Sam Gardner from *Atypical* (2017), and Sheldon Cooper from *The Big Bang Theory* (2007). I have come across a lot of commentary online, especially from medium-to high support needs autistic individuals and BIPOC autistics, pointing out that these characters reinforce a somewhat one-dimensional and biased portrayal of autism. I am sure autistic people who fit the stereotype exist, and I can also understand the excitement when films and TV shows finally feature female and non-binary autistic characters who are more talkative, extroverted, and empathetic. There are also occasional portrayals of autistic people of colour, such as in the Pixar short film *Loop* (Burke et al. & Milsom, 2020), although most autistic representations in mass media are white. This is still great, because we are seeing a real transition and progress happening regarding autistic representations. But what about Chinese autistic people? Or even East Asian autistic people in general? We are also autistic—late-diagnosed, early-diagnosed, or undiagnosed—we are still part of the autistic community. Yet we do not exist in films or discussions about autism. We are even quite invisible at in-person autism events.

This racial bias and lack of racial representation within the autistic community run so deep, that I sometimes feel a disconnect between my cultural/ethnic identity and my autistic identity. Sometimes when I look at myself in the mirror, and see a Chinese girl in her 20s, with bespectacled deep brown eyes and shoulder-length deep brown hair, I would think to myself: “Huh. How can someone who looks like this be autistic? An average-looking

Chinese girl with average height and average body weight, with a not-so-average brain. Is that even possible? No wonder I got diagnosed so late.”

It is just a vicious cycle: Chinese people have a very limited understanding of autism. There are no Chinese autistic representations in the media, medical field and advocacy groups do not include Chinese autistic voices. Thus, it becomes even more unlikely for Chinese people to be educated about autism. This leads to severe underdiagnosis, misdiagnosis, and late diagnosis for Chinese autistics.

Now I'm no longer ignorant, I want to help educate ignorant people

I wanted to break the cycle, even just a tiny bit (because how much can a single person accomplish by themselves anyway?). So, I created an Instagram account, under the name “*The Auti Anthology*,” that talks solely about the intersectionality of being a Chinese Canadian autistic person. My account, to my knowledge, is the first and currently only account ever on Instagram that posts entirely about experiences and insights of being autistic and being Chinese at the same time. I talk in-depth about my lived experiences, as well as first-hand and second-hand research I do in my daily life.

I also write about how Chinese people around me, including family friends and neighbours, react to my autism diagnosis. Some reactions were more positive than others, but all the Chinese people were very ignorant about this topic prior to my explanation, which is not really their fault. Some of them did say some very shockingly harmful and perhaps hurtful things about autism, autistic people, and autism diagnosis. Which again says a lot about the general lack of awareness of autism within Chinese communities. My Chinese neighbour in Canada said that “Western doctors are all crazy! They randomly give out

diagnoses to people. Autism is not a real thing!” Well, okay, I guess she had just discredited the entire Western medical field, as well as an entire autistic community.

Apart from Instagram, I am also active on a Chinese social media platform called 小红书 (which is basically the Chinese equivalent of Instagram). Autistic self-advocates on this platform are rare, and often divided, with rampant Aspie Supremacy and outdated information and sometimes questionable intentions. Almost all of them are late-diagnosed, and many of them are filled with resentment and anger from being undiagnosed and unsupported for years or even decades.

I am not an angry person, in-person or online. I am just a quiet Chinese Canadian autistic girl, who is bilingual and wants to spread true autism awareness from the perspective of an actually autistic individual. So, I make posts that differ from the ones I post on Instagram: I introduce the more up-to-date information about autism, recommend books for the newly diagnosed, and explain what the autism community and general awareness are like in the English-speaking world.

Even though self-advocates are rare, there are so many parents of autistic children (living in China, Canada, the US, the UK, and around the world) active on Chinese social media, desperately trying to find cures for their newly diagnosed autistic children. Many of them have never heard of the word “autism”, and do not know a single autistic person, and unfortunately many assume that autistic people are not even capable of forming thoughts or ideas. And yes, this includes parents who have already immigrated to Western countries including Canada. The parents think that they have a demon as a child. They are lost, angry, and very much hopeless. In a society/community in which autism is seen as a terminal

illness, the parents cannot see a single speck of hope for their children, and the diagnosis came heavier than a death sentence. The parents cannot see any representation of happy autistic people, let alone autistic people who can go to universities, live independently, have jobs, have families, and have a life. (This is a testament to the lack of autism awareness in some communities, so yes, autism awareness is still very much needed. Autism acceptance is a pure luxury in some cultures) Their anxiety and desperation build up, hurting both them and their autistic children. This is another vicious cycle. Another thing that I wanted to do something about.

I leave comments under online posts made by parents of autistic children (often complaining about having an autistic child or expressing extreme desperation after receiving a new diagnosis), and I tell them my story. I tell them about how I was a withdrawn child who did not interact with other children, that I went undiagnosed for many years, and that with support I could go to the best design school in the US and the world's premiere art university for my masters, that I can now make friends on my terms, that I can handle some freelance design jobs, that I grew up and learnt new skills and have accomplished things that no one dared to imagine that I could. I tell them nothing is impossible, that a diagnosis is just a diagnosis, that this is the start of a unique but nonetheless hopeful journey, and that they should learn from their children and not punish autistic people for being autistic. I tell them that I, just like anyone in this world, have limitations, but I, also just like anyone in this world, can mature and change.

Whether the parents listen or not, whether they thank me or attack me, it's none of my business. I have done my part, and I leave the rest to them. There is only so much a person can do, and I am not, nor should I be, omnipotent.

I also leave comments under online posts made by people who are questioning if they are autistic, and wondering if they should be assessed. I also tell them my story, but from a different angle. I tell them in detail about my autistic traits through the years, I tell them how gratifying it was to find an autistic community, and I tell them the accommodations I could access after receiving a diagnosis. I tell them that they are not faulty, they do not have an illness, that there is an entire community made of people just like us. I tell them that I understand that it's extra hard in China, that I recognise the difficulty of not having supportive parents, and that I still encourage learning more about yourself regardless.

I tell all of them that, being autistic and being Chinese at the same time, is a truly odd experience, no matter where you live. I also tell all of them that, even though Chinese communities are currently quite ignorant about autism and autistic people, things will change, for the better. Things will be better for autistic Chinese people, no matter where they live, because the world learns, gradually and slowly, that an autism diagnosis is in fact not a death sentence, but an opportunity to embrace differences. Even though Chinese autistic voices are rare right now, we are still speaking, still writing, still contributing, still actively fighting for a future in which we can all be heard, be accepted, and be truly included.

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