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Empowering self-diagnosed Autistics to be the architects of their own identities

Empowering self-diagnosed Autistics to be the architects of their own identities

By [Oralie Loong](#) / January 5, 2024

In recent years, many adults have self-diagnosed (or self-identified) as Autistic. The term “TikTok diagnosing” has arisen as a way to denigrate self-diagnosis and make it seem less valid than professional diagnosis. While it is true that you can’t (or shouldn’t) self-diagnose from seeing one TikTok about Autism, I have yet to meet a self-diagnosed Autistic who only saw *one* TikTok and then self-diagnosed. Within the Autistic community, self-diagnosis is considered valid due to the many barriers that can exist in accessing diagnosis, including long waitlists and high costs. So let’s explore this more...

Autism is an identity, not a diagnosis

Under the [Neurodiversity Paradigm](#), Autism is not considered an illness or a problem, and as such, it does not need to be “diagnosed.” Instead, the process of figuring out if a person is Autistic is really a process of identification.

Claiming an identity is a personal act and not one that requires a professional to confirm (e.g., consider any other part of your identity – did you need a professional to confirm that you were allowed to identify as a parent after you had children? or as a university student when you started attending university?). Identity is fact, however, realistically the process to arrive at claiming an identity is not always as easy as the two examples I provided.



Adults who begin to suspect they may be Autistic often follow similar paths to being identified. Usually, they first relate to Autistic experiences being shared on social media or in a recently-diagnosed family member or close friend (this is the step that many professionals think self-diagnosis stops at). Then, they take a deep-dive into researching and learning about Autism as they try to figure out if they are actually Autistic. In the end, they usually know more about Autism than most professionals.

At this point, some Autistic adults choose to self-diagnose (while “self-identification” is more accurate than “self-diagnosis,” I will continue to refer to “self-diagnosis” since this is still the most commonly recognizable term). Self-diagnosis is widely accepted as valid within the Autistic community both because accessing Autism assessment is often difficult due to various systemic barriers (e.g., high cost, long waitlists, few qualified assessors who can see the individual behind their neurotypical mask, and bias by professionals who are unwilling to see different presentations of Autism in seemingly successful adults, women and gender diverse people, and people of colour) and because of the neurodiversity-affirmative belief that Autism is not an illness or a problem that requires “diagnosis” but rather an identity, a way of being.

Just like any other aspect of your identity, claiming an Autistic identity through self-diagnosis is something you are allowed to do and you do not need a professional to tell you otherwise.

Late identification is better-late-than-never

As our understanding of Autism has expanded over time, researchers (Lai & Baron-Cohen, 2015; McDonald, 2020) believe there is an entire “lost generation” of Autistic adults who were not identified as Autistic in childhood. This is likely due to:

- how narrow the diagnostic criteria for Autism was at that time in history (the most current version of the DSM – DSM-5 – was launched in 2013, and prior versions of the DSM had more restrictive criteria which did not account for the wide variety of Autistic profiles that can exist)
- less awareness (amongst both diagnosing professionals and society in general) of the wide variety of ways Autism can look outside of more “classic” presentations
- limited access to Autism assessment



But why is knowing you are Autistic important? One study found that not being identified until later in life impacted quality of life and was associated with more mental health challenges even if the individual appeared outwardly “successful” by societal standards: “despite academic and professional success, participants were painfully aware of how they struggled socially without knowing why, and this led in many instances to depression, anxiety and even victimization” (Atherton, Edisbury, Piovesan, & Cross, 2022). Being identified as Autistic in adulthood offers the opportunity to understand life experiences through a more self-compassionate lens and to access supports to improve quality of life. As a late-identified participant in one study said: “For me, it’s not a label. It’s a signpost. And it points to the help you need and how to look at things a different way and embrace that as a strength” (Atherton, Edisbury, Piovesan, & Cross, 2022).

Professional diagnosis vs self-diagnosis

Are there any downsides to self-diagnosis?

In short, no, there are few downsides to self-diagnosing with Autism. While self-diagnosis may be discouraged for some health-related issues due to the potential for improper care that could make the issue worse, this is typically not the case with an Autism self-diagnosis. Research shows that in adults who have experienced stigma related to their Autistic traits (whether they were diagnosed or not), the development of a positive Autistic social identity improves mental health (Cooper, Smith, & Russell, 2017), and that quality of life is improved by access to appropriate social support (which includes both practical help in areas where challenges exist and quality social relationships where an individual feels accepted) (Charlton, McQuaid, & Wallace, 2023). McDonald (2020) found that both self-diagnosed and

professionally diagnosed Autistic adults reported similar experiences of stigma, low self-esteem, and poor quality of life. Realistically, if an Autism self-diagnosis allows an individual to begin to accept themselves more positively and to access supports that address their specific support needs, there is little downside to self-diagnosing.

When is a professional diagnosis necessary?

Professional diagnosis may be necessary to access certain government programs or accommodations for post-secondary. Other than those scenarios, it is rare that a professional diagnosis is required in adulthood.



Are there any downsides to professional diagnosis?

In short, yes, there can be. There have been reports from single parents who are professionally diagnosed with Autism that their diagnosis has been used against them in custody battles or by social workers. A professional diagnosis may prevent you from getting life insurance with most providers and may prevent immigration to countries that don't accept Autistic people. A couple of articles for further reading are (note: some of the information in these articles is US-specific, such as references to the ADA and SSDI):

- [Seeking an Autism Diagnosis? Here's Why You Might Want to Rethink That.](#) by Devon Price
- [Is An Autism Diagnosis Right For You?](#) by Autastic

Reasons for seeking professional diagnosis

So if professional diagnosis has potential downsides and usually isn't necessary, why do so many Autistic adults who don't require a professional diagnosis still seek one? I have found three main reasons why adults who don't need a professional diagnosis typically pursue one:

- **Self-doubt:** The most common reason seems to be a need for professional validation because of self-doubt on whether they got it right and are *actually* Autistic. I believe this self-doubt stems from a lifetime of being told that Autistic ways of being are wrong (which of course leads to a lack of self-trust).



- A need for certainty: Autistic brains love certainty – in fact, we thrive on it so much that it is part of the **diagnostic criteria**. So there is a misconception that a professional diagnosis provides certainty. Unfortunately, even a professional diagnosis is just a subjective opinion based on knowledge and training. There is no blood test or brain scan that can say you are Autistic. While there are some highly trained diagnosticians out there who are excellent at diagnosing Autistic adults, it's also true that most self-diagnosed Autistic have done a deeper dive into Autism and Autistic traits than most health professionals.
- Belief in professionals as experts: There is a societal belief that professionals are experts and therefore always get it right. Spoiler alert: professionals are humans and therefore can be wrong.

Being a professionally-diagnosed Autistic myself, I can very much relate to self-doubt and a need for certainty as reasons why I chose to seek a professional diagnosis. Would I do it again if something like my **Adult Autism Screening** had been an available option? I'm honestly not sure. But what I can say is that never in the five years since my diagnosis has anyone asked me whether I am professionally-diagnosed or self-diagnosed. Where my diagnosis came from has been a non-issue, both for those that have readily accepted my claim to Autistic identity, and for those who have questioned it. However, if you decide to seek professional diagnosis, know that this is okay – you are allowed to do what you need to do to become comfortable in your own Autistic identity.

Empowering self-diagnosed Autistics to be the architects of their own identities

And so this leads us to the headline of this blog post. How can we empower self-diagnosed Autistics to be the architects of their own identities? I would suggest the following:

For self-diagnosed Autistics:

- Screening Questionnaires: Do a bunch of screening questionnaires. If they are all coming back as likely Autistic, think logically about this – would it be logical that a non-Autistic person would score above the threshold on multiple questionnaires? Of course that wouldn't be logical! So hold on to that fact and

remind yourself regularly whenever self-doubt creeps in. [Embrace Autism](#) has a wide variety of questionnaires available. I'll also soon have a course available for self-diagnosed Autistics to explore how they fit the DSM-5-TR diagnostic criteria, much like I offer in my [Adult Autism Screening](#), but as a self-study course instead. [Sign up for my mailing list](#) to be notified when it is available.

- Curate: Be sure to surround yourself with both people and [resources](#) that support your self-diagnosis. Find [social media advocates](#) that you can relate to. Read [books about Autism](#). [Find other Autistics](#) so that you can see your own traits reflected in others. Until you are confident in your Autistic identity, curate your world to ensure your self-diagnosis isn't questioned. This isn't confirmation bias, this is identity nurturing and development.
- Counselling: I'm biased being a counsellor myself, but I believe in the power of [neurodiversity-affirming counselling](#) to re-build self-trust and reduce self-doubt. Once you work on what drives your self-doubt, you may find it easier to be confident in your self-diagnosis. If you live in British Columbia, you can find a neuro-affirming neurodivergent counsellor using our [Find a Neurodivergent Counsellor](#) directory.



For everyone else:

- Education: More needs to be done to educate the world about the wide variety of ways that Autism can look in adults, and on seeing Autism from the non-pathologizing lens of the [Neurodiversity Paradigm](#). If we can shift societal views of Autism, we can begin to see that Autism is an identity to be claimed and not a disorder to be diagnosed. As individuals, I would encourage you to start the ball rolling towards societal knowledge by educating yourself about Autism. [Unmasking Autism by Dr. Devon Price](#) [affiliate link] is a great book to start with.
- Support: Self-diagnosed Autistics need to be supported in their self-diagnosis. It needs to be validated by the people close to them and by the professionals they access services from. If someone tells you that they are Autistic, never say, "but you don't look Autistic." Instead, try saying, "congratulations, do you want to tell me more?"

In the end, the choice of whether to self-diagnose as Autistic is a personal one. No one has the right to tell you that your Autistic self-identity is wrong. You are the

architect of your own identity.

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