Twitter Thread by Dana Morales



Dana Morales
@saturnloft

Is Autism Self-Diagnosis Valid? A Very Long Thread

TL, DR: Yes. It's valid.

Now for the long version: there are some folks on Twitter that say that some of us have no right to claim we are #ActuallyAutistic without an official diagnosis by a medical authority of some kind.

There are some problems with this mentality. One of the biggest is that some of us simply do not have adequate access to the formal diagnostic process. There are many things that can affect access:
lack of financial resources, social anxieties or phobias —

— which may make it difficult to persist in going to offices and clinics that may be frightening, some of us may have trauma that makes it difficult to approach these places at all.

Some of us may have had specific negative experiences with the medical community already, we may have lost valuable trust, & we might feel discouraged from even trying to obtain a diagnosis for this reason.

Not to mention there might also be sensory issues associated with medical facilities and government institutions (waiting rooms can be an ordeal in themselves, sensory-wise!)

In some countries the process for autism DX may be inaccessible because the steps may not be clear, there may be bureaucratic hoops that are confusing and impossible to navigate without outside help, help which may be hard or impossible for some of us to obtain.

There may be further barriers to the diagnostic process associated with ethnicity or gender. People of Color already have a disportionate probability of misdiagnosis or even outright dismissal by medical institutions and autism may never even be considered in their case.

Autistic people who identify as trans or non-binary may have extra difficulty dealing with the biases and prejudices of some medical professionals. This can make the diagnostic process too problematic and distressing to pursue beyond a certain

point.

Still with me? Good. :)

So let’s imagine that a person suspects they have autism. They took some tests online or they talked to an autistic individual and a lightbulb turned on and suddenly a bunch of open questions from their life story may finally have much-needed answers.

Let’s presume that they manage to navigate the bureaucratic stuff in getting a diagnosis. They get the proper forms filled out, they go to the proper places. They are able to pay any fees associated, they have good insurance, they manage to get through uncomfortable exams —

— and they are able to effectively communicate the difficulties they are having. They may even have someone who can go with them to assist and advocate on their behalf.

Even if they manage all this, that doesn’t mean they are in the clear, because now we’ve run right into another huge issue: being misdiagnosed.

A misdiagnosis can come from lack of knowledge by the medical professional doing the examination; there are many disorders that have similar traits or symptoms.

It may require extra time and effort to come to the right diagnosis. Time and effort which some medical professionals may not be willing or able to spend.

Women in particular may run into difficulties with autism diagnosis because we often won’t present in “typical” ways. We may appear superficially more social, we may mask more effectively.

We might fall outside the old-fashioned cliche of the seemingly emotionless, hyper-logical Spock-like computer programmer or engineer that some professionals still carry around in their heads.

Older autistic adults may have difficulties with DX because masking or passing has become so ingrained and instinctual, that we may find ourselves “acting” or suppressing our autistic traits even during the diagnostic process (which definitely doesn’t help).

We may have developed work-arounds or coping mechanisms in our social routines, for instance: training ourselves to make eye contact despite the discomfort it might cause us.

The very methods some of us have used to compensate for our social difficulties can come back to bite us if we encounter a professional who discounts the possibility of autism because we don't behave in a stereotypically autistic way. We may "pass" too well.

Sadly, what they can’t see is the years of monumental effort many of us have expended to get to whatever point of social assimilation we happen to have reached. If these professionals could only travel back in time and see us as children, they’d

see a very different picture!

There is still a very large group of undiagnosed older adults who never obtained a diagnosis as children. When we were growing up the view of autism was much narrower. There simply wasn't the information and resources that are available now.

We may have grown into adults feeling very different but never knowing exactly why. We may have spent our entire lives wondering why things that seemed so simple for other people required so much effort for us.

We may have spent our entire lives wondering why we were always the only ones reacting so strongly to noises, smells, and other sensory elements that others around us seemed unaffected by.

And we may have developed comorbid mental illnesses from trying to fit into a social paradigm that wasn't made for us, we may have trauma from being bullied or abused.

As adults, we may end up being diagnosed with things like depression, Complex PTSD, social anxiety, and so on, long before we ever get diagnosed with autism.

We may also have other mental illnesses or disorders that are unrelated to our autism. These things can complicate the diagnostic process considerably.

Some of us may only realize we are autistic after having a bout of severe depression, or what could be seen as a nervous breakdown. We may find ourselves unable to work or manage daily tasks when we were able to before,

we may find ourselves suddenly unable to bear even the simplest social interactions, sensory issues that were previously just irritating may become outright painful, and we may lose functioning to a frightening degree. We may struggle with suicidal feelings.

We may develop serious stress-related physical illnesses. This is autistic burnout and unfortunately it may take something of this magnitude for some of us to get to an official diagnosis.

It can take years to recover from burnout and some of us may never be able to regain the same level of functioning we had before. Hopefully we can get to the point where autistic burnout becomes rare!

Some other ways autism can be misdiagnosed:

Autistics can be misdiagnosed as socially anxious or avoidant due to the anxiety/stress of trying to process social protocols that aren't natural to us.

(We're just shy or socially anxious? Maybe we've been living in a baffling and alien world our entire lives, desperately trying to assimilate and improvising as we go —

— until we're exhausted every day, all the time! Especially if we've already been bullied or mistreated severely as a result of our quirks and oddities.)

Autistics can be misdiagnosed as schizoid, schizotypal, or schizoaffective because of self-isolating and withdrawing behavior, strange mannerisms or affects, and because sensory or cognitive issues may lead us to see the world very differently than neurotypicals.

Some people with autism have synesthesia (a mixing of the senses) or overly acute senses as well, which can contribute to mislabeling our perceptual differences as delusions or hallucinations. (I know an autustic who can hear conversations in other rooms and all electrical hums.)

Autistics can have hyperacusis (super sensitive hearing), hyperosmia (super sensitive smell), or misophonia (in which certain sounds are uncomfortable to the point of anger or panic).

What does it feel like to experience the sensory world so differently that in some cases you can't even explain it to others? Or you've tried to explain and been dismissed or disbelieved?

In more extreme cases, what does it feel like to know that in order to go out into public, you will always be in some amount of sensory pain or discomfort,

but you still want to connect with other people, you still want to be able to do ordinary things like have a nice night out at a restaurant or go shopping…

Autistics can be misdiagnosed as obsessive-compulsive due to ritualistic soothing behaviors, rigid adherence to routines, and other repetitive activities. Not to mention perserveration or hyper-focus on areas of interest which can be mistaken for obsessive ideation.

When the sensory or social world can be so chaotic, intense, and confusing, our routines can help ground and calm us in ways that neurotypicals might not understand. And it can be hard to explain the joy that a special interest can give us. For some of us, it's how we meditate!

Sometimes, autistics can be misdiagnosed as narcissistic, due to a lack of appropriate reciprocal social behavior or an apparent lack of empathy. (I say apparent because most autistics have empathy, but may not always be able to express it in conventional ways.)

Some of us may monologue on our most beloved topics of interest, misread social cues in emotionally charged situations, and have poor conversational timing and this may make us seem self-centered or uncaring, when we are not that way at all!

Many autistics have something like social blindness. We may be unable to read physical cues in body language, facial expressions, and vocal tones.

Or we may have to expend all our mental focus and effort in a social interaction just to manually process these things, which is exhausting to say the least.

Expected behaviors and mental scripts are simply not available to some of us, we may lack the basic social-cognitive programming that most neurotypicals seem to be hardwired with.

We may upset people in social situations without even being aware of doing anything wrong. We may be blunt or honest to the point of abrasiveness.

Or, we may get to the point of constantly finding ourselves apologizing without knowing what we've done to cause such anger or hurt. In some cases, continually being in the wrong socially —

— without knowing why or how can lead some of us into states of extraordinary despair, resentment, and hopelessness. We may decide the social world is just not worth the trouble, withdraw entirely and become permanently alienated.

Some of us can be misdiagnosed as borderline, especially females for some reason. I'm not quite as certain about why this is, but borderline is associated with emotional regulation issues —

— and female autistics who have meltdowns due to sensory problems could be misidentified as borderline because the source of their volatile behavior may be misunderstood. Difficulties in conforming to expected social rules could also be a factor.

Many autistics who come from backgrounds of early trauma or abuse often have a particularly rough time trying to untangle their autistic traits from behaviors and issues associated with complex trauma,

especially if that trauma occurred in early childhood. There are a lot of commonalities. Some of these may include problems with interpersonal connection and bonding, communication and other social aspects.

This may be because extremely dysfunctional childhoods provide very poor models for learning normal social behavior. People with trauma may also have sensory problems, especially with sharp, sudden, or loud noises.

In some cases, autistics can be what is called "twice-exceptional", meaning they can have disabilities and exceptional abilities at the same time. For example: A child may be labeled gifted and placed in advanced classes,

but that same child has unrecognized autism and is unable to deal with sensory distractions within the classroom. They may be seen as merely inattentive or lazy, when they are actually overwhelmed and in need of help.

Autistic traits may easily be mistaken for the eccentricities and quirks of an unusually bright child. When the giftedness is recognized but the autism is not, that individual may find it particularly difficult to open up about problems they might be having.

When they become adults, they might feel as though they should be smart enough to figure things out on their own or that they shouldn't need help with something that seems like it should be simple,

like going to a social gathering, making a phonecall, or shopping for groceries. It seems like undiagnosed autistic adults who were labeled gifted as kids are particularly prone to burnouts,

because they may demand more of themselves or may be under stronger pressures to mask their autistic traits, especially if those traits are causing difficulties.

So... obtaining an official diagnosis of autism in an adult can be a long and arduous process, and you can still go through the whole darn thing and get misdiagnosed.

Knowing all this, is it really up to random people on the internet to be the authoritative deciders of whether self-diagnosis is valid?

For some autistic individuals, self diagnosis is only the beginning of their journey and they may want to pursue a DX in order to get assistance or just for their own resolution.

For others, self diagnosis is either enough in itself or they simply do not have the resources physically, financially, or emotionally to go further. Should they be made to feel punished or shamed for this?

Should they be told they are faking or taking something away from autistic people with formal diagnosis?

In today's continual weird wars of identity nomenclature, it is an unfortunate fact that there are many who judge the validity of another's identity experience only through its similarity to their own.

If an identity is something you feel you can own for some strange reason and another person claims the same identity label and their pathway is not the same as yours then they must be marked as invalid, right?

After all if the identity is a territory that you feel belongs to you and others precisely like you only, then all others who fall outside this parameter are a threat. This is not just or logical thinking.

(There's probably an easier way to explain this part but it's very confusing behavior to me and I'm doing the best I can! Maybe someone else can help illuminate it.)

Now here's the part where I get sarcastic:
If those of us who are autistic and without official diagnoses aren't permitted to identify as #ActuallyAutistic, what should we identify as?

Suspected Autistics? Undocumented Autistics? Stealth Autustics? Feral Autistics?

Autistics Waiting For A Shiny Rubber Stamp of Official Approval?

Autistics Who Don't Need No Stinking Badges?

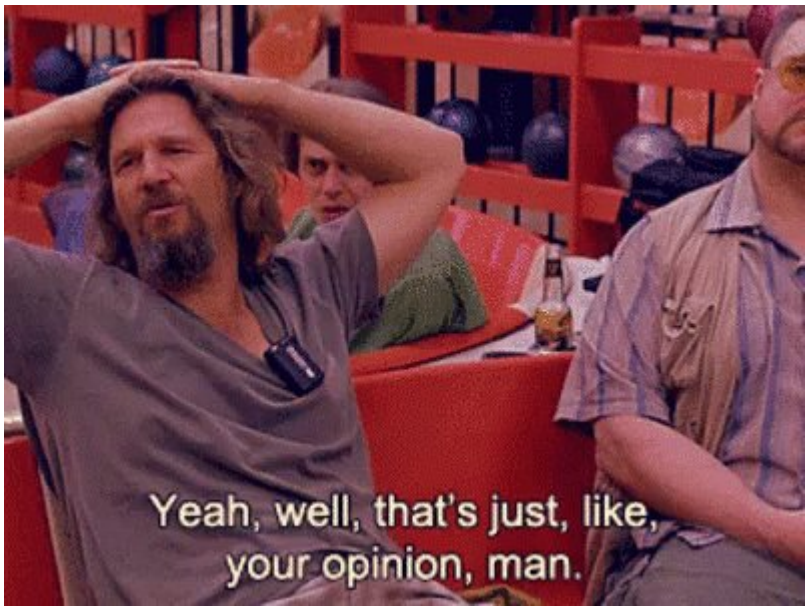
Tired Phantom Autistics Going Through Long & Exhaustive Bureaucratic Ordeals Just To Appease Random People on the Internet Who Are Not Medical Professionals By The Way?

Or perhaps they can just identify as Not Actually Autistic but Apparently Just Someone Who is Continually Having Sensory and Social Problems For Absolutely No Other Reason —

— Than to Get Attention,
Which Is Kind of Weird
Because a Lot of Autistic People
Don't
Actually
Want
Attention.
Like.. At All.

For those who have read through the entire thread, thank you for sticking around and I hope this has been helpful.

If you want to tell me that self-diagnosed autistics are not valid, go ahead... although I think you may be on a very unpleasant social validation power trip and should maybe rethink your life, but that's just my opinion.



Okay, last bit, I promise! I have some questions:
Have you ever been misdiagnosed as something other than autistic?

Have you ever had someone (a medical professional, therapist, psychologist, etc) tell you that you couldn't be autistic? Why?

Do you have comorbid disorders that have complicated your autism diagnosis process?
Have you experienced problems with accessibility or in understanding the steps you need to take?

I'm really interested in hearing people's experiences about this, and thanks in advance to anyone who participates! I want to hear your stories.