Twitter Thread by Dan Sohege



Dan Sohege
@stand_for_all

Thread: If you don't think that those who have to self-diagnose aren't #actuallyautistic then you really don't understand #autism or how hard it is to get a diagnosis. It took me years to get diagnosed, but that doesn't mean I wasn't autistic before I was. 1/

People I respect who talk advocate far more than I do have already spoken about this today, but it can't be said enough. It's incredibly hurtful, and can be harmful, for people to make judgements about anyone they don't know, but particularly autistic individuals 2/

We talk about #autism spectrum as if it's a straight line. It really isn't. Autistic children grow into autistic adults and things change. Yours, mine and someone else's experiences will be different. It's not a straight line you can put a pin in and say you're here on. 3/

I don't care who you are or how righteous you think your cause, you don't have right to tell #actuallyautistic people you don't think they are, whether they have a formal diagnosis or are self-diagnosed, and I will block anyone who does for starters. Just leave people alone. 4/

There's enough misinformation doing the rounds making it harder for #autistic individuals as it it. The last thing anyone needs is someone claiming to be advocating for them feeding that misinformation and hurting people who are #actuallyautistic. 5/

Sorry, one other thing to add to this. I've spoken in the past about how I was brought up in an incredibly masculine household where you were taught to bury emotions, be sporty, and if you weren't then take a slap. Not a great environment for an introverted autistic boy. 6/

For years I thought I was abnormal, weird, a freak. I try to act "normal" by copying things I had seen people in movies do, you can guess how well that worked. I completely lost any sense of who I actually was because, as I learned later it was called, I masked so much. 7/

I was never taught about #autism. I knew nothing about it, other than seeing representations on TV and film which hardly reflect reality, particularly back in the 80's and 90's. A lot of people have different but similar stories about growing up. 8/

For many self-diagnosis has been by chance, a weblink, something resonating which caused them to look more into things. It helped them make sense of who they are and in so doing helped them in many other ways. 9/

Now, for many people the knowledge of who they are in themselves may be enough, and they shouldn't have to explain that decision to some self-righteous imbecile on Twitter. For others it is the first step on what can be a long road to formal diagnosis. 10/

Because let's not split hairs about this, getting formally diagnosed isn't just a question of turning up at the doctor's and having a test. It's a long hard process, and it gets harder as you get older, to even get your foot in the door. 11/

Then you have the issue of the cost if you have to go private because of the wait, or even just a doctor refusing to refer you because you don't fit the very stereotypes that those complaining about self-diagnosed #actuallyautistic individuals are reinforcing on here. 12/

Just leave #actuallyautistic people alone. Let us have this one hashtag without people telling us who we should be, have to be etc. You don't know people's life story. Just let us have on safe community away from people telling us how to live our lives to fit their ideas. 13/

H/t to particularly @commaficionado, @Sara_Rose_G, @WoodIandWitch and @BootstrapCook, among others who I have seen talking about both this and getting flak from people who don't understand autism today. They're the ones who prompted the thread.

For a far more in depth and detailed explanation regarding why autism self-diagnosis is entirely valid and should be respected I recommend reading this excellent thread by @saturnloft.
https://t.co/bADQMDnlEw

> Is Autism Self-Diagnosis Valid? A Very Long Thread
>
> TL, DR: Yes. It\u2019s 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.
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> — Dana Morales (@saturnloft) November 24, 2019