

JOHN PENDAL: Coaching For People Who Feel Like Outsiders

Autism Labels: “*High and Low Functioning*”

Disclaimer: *any discussion of the language we use to describe ourselves is tricky as emotions can run high. It isn't an academic exercise when you're talking about "identity language", and it can provoke strong responses. This article is entirely personal and I'm only speaking for myself. Whenever I'm talking with someone else I always try to use the terms they prefer to describe themselves. How you describe yourself is completely up to you. If your diagnosis included functioning labels I'm not trying to take that away from you.*

When I first wondered if I was autistic I took some tests online, some of which I paid for and seemed to come from reputable sources.

The results included the phrases: “*above average on the spectrum*”, “*high functioning autism*” and my favourite “*While you demonstrate close to normal cognitive, social and communication skills, you also exhibit certain characteristics that are Autistic Symptoms.*”

Don't you love the language? *I'm ALMOST NORMAL but I have SYMPTOMS!* What a way to empower someone.

I spent the next five years telling people I was “*a little bit autistic*”, because I didn't feel I could take up the space of someone who was genuinely 100% there.

Now I'm working with autistic clients, and at least once a session they describe something that I've always done, which they ascribe to being autistic and I had no clue that was a trait of autism.

I've come to realise I am 100% Autistic, and there is nothing wrong with that. It's not only normal to me but it's normal to all the other autistic people out there.

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The idea that some people have *"high functioning autism"* or *"low functioning autism"* means I often have to deal with people saying: *"but you don't look autistic?"*, which I think is code for *"but you're managing to hold a conversation with me?"*

Autism is not a flat, static spectrum with *"people who can't speak"* at one end and *"people who can speak"* at the other. Autism is a living, fluttering, moving dial of good days and bad days. My favourite non-medical way of describing autism is *"everything is fine until it isn't"*.

I can manage a social event until I'm cooked, and then I might suddenly disappear.

I can function at work until something upsets me, and then I'm a wreck.

I can hold a conversation and *"seem normal"*, but there's an invisible cost for me having to pretend to be neurotypical (we call this *"masking"*) and I will end up paying for it later.

(Masking can lead to autistic fatigue, burnout, trauma and complex PTSD and the best way to help an autistic person is to help change their lives to fit their autism, rather than change themselves to fit in.)

There are other issues raised by using low and high functioning labels:

- The labels don't help an autistic person who has learned how to mask their traits to fit in. At best they might be given a *"high functioning"* label, but more likely they will be misdiagnosed as not being autistic.
- If a *"high functioning"* label is seen as better than *"low functioning"*, that actually ENCOURAGES masking to get the *"high functioning"* assessment!

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- There is an assumption that autistic people who are *"high functioning"* are really smart, and people who are *"low functioning"* are stupid. That's not the case, and gives shame to those who feel like they are *"high functioning and not smart"* and ignores the skills of people who are *"low functioning"*.
- It assumes that autism has a fixed, static way of presenting itself, and ignores the fact we're unlikely to be able to face an assessment on a non-functioning day. If you wait for a day when you have all the energy to cope with the assessment you're more likely to get a *"high functioning"* label or misdiagnosis.
- *"High and low functioning"* labels are judging autistic people by how well they fit into a neuro-typical world, and why should we be judged by that standard?
- All autistic people have things that they are good at, and things that they are bad at. Labelling people as *"high or low functioning"* ignores that.
- The labels don't actually tell you anything about the person. If we assess people as *"autistic with the following needs..."* Instead, that gives you clear information about what that person needs, and that leads directly into a conversation about what accommodations can be made.

If you're wondering what I mean by "accommodations" *Thriving Autistic* has a webpage about the kinds of adaptations that could be made in a workplace and also a workbook you can complete on your own to have greater clarity on your needs: <https://www.thrivingautistic.org/workplace-resources/> - you don't need to be autistic to check this out.

I'm writing this because these ideas have helped me ... sharing in case they help you.

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