

Disorder, Condition, or Disability: A Look at the Fables of Autism Labels

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About eight years ago, I got a diagnosis that saved my life. At the age of 36, after three bedridden years filled with suicidal ideation, I found out that I am autistic. A formal, six-week evaluation confirmed that I was indeed, as many had long suspected, 'different'. Just like most folks do when they get a new diagnosis, I went into research mode. I knew I needed to educate myself about this new word in my life and I wanted to know everything I could about it. Finally, 'different' had a name, autism, and with this new label, an overwhelming sense of belonging flooded my life...or so I thought.

After months of reading all that I could find on autism and the experience of being autistic, I felt confident in my knowledge and understanding of it. By confident, I mean I had read and memorized the most current knowledge available about autism and had explored the varied opinions on the topic from the 'experts'. So much so, that I myself had become an expert with certifications in both autism, and cognitive disorders. Thus, I know that when asked what autism is, meaning how is it categorized, the shortest response is always that it is a 'neurodevelopmental disorder', but many would disagree and rightfully so.

To begin, many would argue with the word disorder. Recent statistics from the CDC tell us that autism affects 1 in 59 children. With the knowledge that autism is a lifelong condition, we can only just begin to understand the actual number of people for whom autism is a reality. With so many unaccounted for due to lack of supports, financial constraints, and language barriers, we can only assume that the actual number is even larger. At what point does it stop being a 'disorder' or a 'condition', and simply become another way of being human? How much of the population has must be diagnosed as autistic for the label 'disorder' to become the incorrect term? Moreover, since so many do not feel disordered by their autism, the label is inaccurate and perpetuates the stigma that autistic people are somehow broken.

For many, the alternative to autism being called a 'disorder' is to label it a 'mental health condition', which doesn't work any better. When we think of mental illness, we must remember that it is a human condition. Meaning, ALL brains have the capacity to develop a mental illness, autistic or not. The categories for mental illness include mood disorders, anxiety disorders, personality disorders, psychotic disorders, eating disorders, trauma-related disorders, and substance abuse disorders. While many autistics suffer from one, or many, of these co-occurring mental illnesses, autism is not one of them. Linked to genetics and neural connectivity, autism's cause clearly lies in biology, not psychology. And yet, with so much of the 'symptomology' of autism mimicking challenges commonly categorized as psychosocial behaviors, it is easy to see why the 'mental health condition' label gets used.

As if those two labels weren't enough of a burden, a diagnosis of autism brings with it another label, 'disabled'. Use of the word disabled in reference to autism is in many ways on point. After all, the hallmarks of being autistic are in direct opposition to the 'rules' of the society in which we live. Our struggles with 'social communication', our unique needs and habits, and our need for truth and honesty, defy the codes of our current behavioral climate. In a world that values sameness, our very 'difference' is disabling. Still, most of us will tell you that we don't feel disabled when our needs are met, but instead mostly feel disabled by the society we live in. When allowed to live as our authentic selves, the label 'disabled' feels incongruous.

Even within autism itself, the labels have been perpetuated. Thrown around like insignificant adjectives are terms like 'high-functioning' and 'nonverbal', though they do not at all describe the autistic experience. Having been called 'high-functioning' myself, it's inexactitude is as infuriating as it is damaging. While I might be 'high-functioning' on one day, the very next could find me having high support needs. Functioning can change on a moment to moment basis. Moreover, not all of us have visible, external challenges. Just because you cannot see the internal struggles, doesn't mean that they do not impact functioning. A similar case can be made for use of the term 'nonverbal'. Again, many folks who are 'nonspeaking', selectively or situationally mute, or use a device to communicate still have verbal cognizance. They are simply, even if temporarily, unable to use their mouth and voice to form words. It doesn't mean that they do not have the ability to listen and comprehend.

Prior to my autism diagnosis, I hadn't given labels, or their fables, much thought. They were just another way to categorize one's observations. But once a label was put upon me and I had to live with all the stigma that came with it, labels, and their accuracy, became incredibly important to me. Afterall, I use some of these labels to describe myself. The ones I choose to use reflect not only how I see myself, but how I want the world to see me. Years ago, I would have declared unabashedly that autism is a 'neurodevelopmental disorder' but all these labels later and I know it's not that simple. Yes, autism is neurodevelopmental, but it also plays a role in my mental health. Sure, there are some days when autism is disabling and some days when it renders me mute. And, of course, days when only I know I am struggling and days when I need all the help that I can get. This fluctuating dichotomy is too unpredictable, too complex and too human to be rigidly defined by one single term, leaving us drowning in the fables our labels create.

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