

I'm High-Functioning Autistic. Here's What the Neurodiversity Movement Gets Wrong.

I think it's great that people want to normalize autism. But sometimes they gloss over how disabling it can actually be.

By Gwendolyn Kansen



(Photo: Nicola/Flickr)

Autistic people might actually have some advantages if it weren't for the stigma. Many of us have a unique objective edge that makes us great at math, science, and music. Yes, we have to endure a lot of social challenges. But if people were to look past that, we could use our talents to make the world a better place.

Enter the neurodiversity movement. Many autism advocates (especially self-advocates) see it as the next step in human rights. They don't see autism as a disorder. They see it as a normal cognitive variation associated with a unique set of strengths and weaknesses. They think autism should be removed from the *Diagnostic and Statistical Manual of Mental Disorders*, just as homosexuality was in the 1970s.

As an autistic person, I respect the movement. I do. I'm thrilled to see our community having a voice.

But I think there's a lot that they're missing.

First off, many of us aren't high-functioning enough to benefit from depathologizing autism. The neurodiversity movement doesn't have much to say about lower-functioning autistics, who are decidedly less inspirational.

There's a saying that autistic kids don't grow up. And many don't. They live in group homes, where they have to be watched like hawks so they don't wander off and drown. They can't talk to you. Some can't even shower by themselves. And they certainly can't offer nuanced opinions about a cure. Some members of the neurodiversity movement will tell you that "most" autistic people don't want to be cured—but some studies show that over half of us have an IQ below 70.

Neurodiversity advocates want to distance themselves from the mental-illness community. But really, we could get more funding if we joined forces with them.

It's not just about IQ either. Many higher-functioning autistics also can't live alone. They'd forget to lock the door or turn off the stove. They might also need legal guardians to make decisions for them when they can't assess consequences well enough.

And there are plenty of otherwise capable autistic people who can barely function because of depression, fatigue, and a plethora of co-morbid disorders. The divide between low and high functioning isn't as clear as people think.

Autism isn't just a social disorder. Our processing functions are entirely different. Our "highly restricted, fixated interests" (we call them special interests) could come from the fact that our brains aren't as interconnected as other people's. We have more connections *within* some brain regions, but fewer between them. That makes it not only easier, but necessary for us to focus on a few specific things.

In other words, we're great with details. But we miss the big picture.

Seeing things in fragments means we have to put more of our attention toward the surface of what's going on. We miss important nuances, including

body language. I suspect I only process about 25 percent of what someone tells me.

This obviously hurts my social life. But what's worse is that I can't trust my own judgment. Neurodiversity advocates gloss over the fact that people like me have to be on guard every minute. And we're still about four times more likely to be raped and far more likely to be killed than our non-autistic peers. I've never had an awful experience, but I did have a boyfriend in high school whom I would have seen right through if I wasn't autistic. He was a pathological liar and he tried to turn me against my family. I didn't have friends in school to tell me he was off, so it just ended up being a humiliating experience that subtly destroyed my trust in people for a long time.

Our executive functioning problems are just as bad. I've been fired from almost every job I've had because of my low energy and problems transitioning between tasks. I'm skeptical about how many of us can be consistently productive. Even Specialisterne, an organization that helps autistic people find employment, places only one out of six people who start its program. And those are data-entry jobs.

But by far the worst thing about autism is the meltdowns. They're terrifying. Kayden Clarke was having one when the cops came to his house on a suicide call. Clarke pulled a knife on the cops when they arrived. They shot him.

There are autistic people who scream for hours on end, attack their social workers, and kill their parents.

How can anyone claim these are just normal cognitive variations?

People tend to think of autism as a mysterious disorder with no relation to any other problem. But research points out that it's not as isolated as we think. Autism actually shares chromosomal links with four other mental disorders: schizophrenia, attention-deficit/hyperactivity disorder, major depression, and bipolar disorder.

If autism is really a double-edged sword, then it's the sharpest one I've ever seen.

There's a reason autism used to be called "childhood schizophrenia": *because it looks like schizophrenia*. The negative symptoms that mimic schizophrenia—flat affect, poor eye contact, difficulty expressing emotion—are the first things that psychiatrists noticed in autistic patients. Schizophrenics and autistic people alike have less gray matter in the limbic system, which is responsible for emotions and memory. And both disorders manifest a deficiency in proteins that help code experience into long-lasting lessons in the brain. One hallmark of autism is the inability to transfer previously learned rules into new situations. If you're autistic, you've probably experienced this inability in social settings. And then there's the fact that autistic people are 12 times more likely to have a sibling with schizophrenia. Children with early-onset schizophrenia have a 28 to 55 percent chance of having autism.

Neurodiversity advocates want to distance autism from any mental-illness associations. But really, we could get more funding if we joined forces with the mental-illness community.

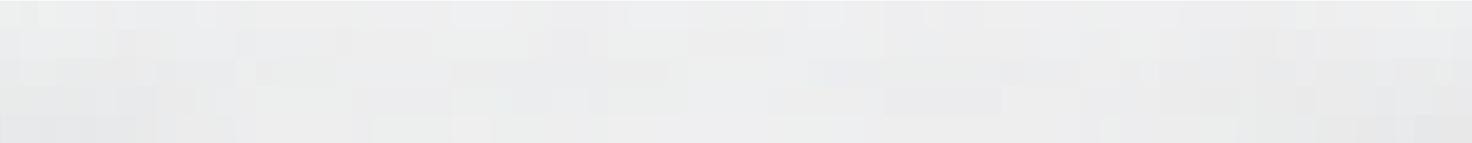
Autism Speaks is unpopular with autistic people because it spends way more money looking for a cure than it does on helping us right now. But it's by far the wealthiest autism organization in the country, with \$12,692,758 in net assets as of 2014. The Autistic Self-Advocacy Network, which supports the neurodiversity campaign, could barely cover its own expenses with the \$599,124 it earned last year. The National Alliance on Mental Illness, on the other hand, had \$8,586,669 in net assets in 2014. It has chapters everywhere, has established support groups for over 98,000 people, and runs awareness programs in high schools.

Some neurodiversity advocates go so far as to equate a cure with genocide. They feel they wouldn't be the same person without it. I've never felt that way. I still feel autism keeping me from achieving my potential. When I got a scholarship to a pre-opera program, I found I couldn't keep up with the conductor's cues and I couldn't handle the bright lights on stage. Granted, autism might be why I'm good at music in the first place. A lot of us have gifts we can't use. A friend of mine loves politics, but he couldn't pass the psych portion of the National Foreign Service exam. If autism is a double-edged sword, as they like to say, then it's the sharpest one I've ever seen.

A cure isn't really feasible anyway. There are thousands of genes that can cause autism. Most researchers are focusing on drug therapies to target

certain genes. Mount Sinai's Seaver Autism Center is having a lot of luck with an oxytocin study for children. Autism Speaks is trying to map out the genome itself to see which genes are most implicated.

I'm not scared of the genetic research. Gene editing could eventually help a lot of people, even given the obvious human-rights implications. It would be foolish not to look at the benefits of having autism in the gene pool. But we also have to consider all the people that it's hurting. We can't have a truly productive discussion about autism acceptance by sugarcoating the condition. Not until we accept every part of autism will we start finding solutions.



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