

The Autism Diaries: Storee's Story | CPD Blog

Storee Powell

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This is the first in an ongoing series about autism. Today's perspective is from CPD Social Media Specialist and Autist Storee Powell--because listening to actually autistic people is critical going forward in disability rights.

At 31-years-old I learned I was Autistic. It was one of the most emotional and profound moments of my life because it put everything about myself into context—I finally understood why I am the way I am. I realized immediately that being Autistic was the reason I excelled at the things I did, why I was more sensitive to both emotions and physical stimuli, and why the world treated me as it did and continues to do so.

Since I learned of my autism in November of 2019 (note that I do not use the word diagnosis in regards to my autism—more on that later), I have had multiple fits of sobbing, swearing, realizations, anger, and frustrations. It has not been an easy ride, but not for the reason most of the world seems to think.

Learning I'm Autistic has helped me understand myself—why I repeat phrases under my breath (known as echolalia—now I have answer for you, Sammy, on why I do this...), why I love rocking chairs (self-soothing), why I retreat after social events to 'recover,' why the drama of the neurotypical world leaves me baffled (Like what is with The Bachelor? Who derives joy from watching that soup of drama, real or perceived?), why I hyper-focus on things (art, dogs, history, news), why I avoid crowds and hellish places like Walmart (the noise and movement is too much sensory input), why I have never understood sarcasm, and many other things.

But while much of the world has told me over my life that these things about me are negative, I'm going to tell you that I always thought these things made me unique, strong and smart—and my feeling that way about myself brings even more hatred from others. Autistic people, especially girls, should not love themselves or think positively about themselves.

I do not see my autism as a disability—though I am not ashamed of my physical disabilities. Rather, autism is who I am. I don't need to change to make the neurotypical (NT) world comfortable. I deeply connect with the words of comedy icon John Candy in Planes, Trains, and Automobiles: "I like myself."

This flies in the face of everything that society has taught me about women and autistic people. We should not like ourselves, and even if we do, we shouldn't mention it—this means that girls and women mask their autism so they can survive in a sexist and ableist society. It is incredibly exhausting and depressing to hide who you really are. I've been called a bitch, uppity, a snob, a freak, a perfectionist (not in a complimentary manner), and many other things because of who I am.

My autism is not a tragedy, a disease to be cured or just something that I have. It is me. And that isn't negative. It is the reason I went to college on full academic scholarship and left with zero debt and a 4.0 GPA. It is why I've won multiple journalism awards. It is why I'm passionate about educating people on disability and gender issues. It's why at the age of 24 I bought a house with my husband and refurbished it from the ground up while unknowingly having multiple chronic illnesses.

It is also why I've never been into group socializing. I didn't go to college parties. It is why I won the Circle of Trust award from USU's The Statesman staffer awards. It was an internal joke thing; I was a person who allowed very few into my circle of trust. It is why I have serious trust issues with authority. It is why I pursue my passions doggedly. It is why I have an abundance of empathy and struggle to watch people and animals suffer (every time I pass road killed critters I wish I could stop and give them a little burial and funeral). It is why I'm hypervocal (not all autistic people are nonverbal—again it is a spectrum) and love to monologue about politics. Sorry, not sorry.

However, I do not think that I'm better than others—though that is how I know I'm often perceived, because again, autistic women shouldn't like themselves. But I am proud to be autistic. I wouldn't take a cure tomorrow if there was one. It would destroy who I am. Unfortunately, I have realized how disappointed and confused I am about the world after claiming my autism identity.

I have learned how much the world misunderstands and loathes Autistic people—I experience it weekly. There are Facebook groups of martyr moms that use the public space to whine and brag about how hard it is to be a parent of an autistic kid—even posting pictures and videos of their kids having meltdowns. If you understand what it is to have an autistic meltdown, you know how invasive and cruel it is to show that vulnerable moment to the world.

Online forums are dedicated to neurotypical people talking about why someone should never date or marry an autistic person because we are horrible human beings. Anti-vax lunatics scream to the world they would rather have their children exposed to dangerous diseases than become a tragedy (aka an autistic person)—even though research has repeatedly shown that vaccines do not cause autism. News stories abound about researchers that have 'found the cause of autism' (there's several of these a year. They promote curist attitudes about autism and are a serious waste of research dollars). Now there's talk among scientists how they can use the new genetic CRISPR technology to wipe autism out of humanity. Social media posts from people promoting stereotypes of autistic people (including savantism) show up in my feeds. TV shows do the same thing, showing white nerdy males are the only autistic people out there (hint: they aren't).

So you can see why I not only carry all of the trauma of my own life with autism, but a general trauma caused by the world constantly telling me how much they hate autistic people. A few weeks ago, a BuzzFeed news story listed Autism as a mental illness and I was so upset at the misinformation I had to immediately quit reading the story and go do some Serenity Now exercises.

Most autistic people have childhood trauma either from bullying (including from adults), poorly conceived therapy created by neurotypical people who want to 'fix' autistic kids, poor experience in school, and many other reasons. I am no different. And I was lucky to have neurodivergent parents and siblings who got me. Many kids do not.

When I was in the tenth grade, I was suffering from severe depression—a very common experience for autistic people (not caused by autism itself but because of a world that is constantly hostile to us). I'd come home from school and lay the floor of my bedroom and hope to die, to just go to sleep and not wake up. Every day at school was an experience in personal humiliation. I didn't learn to drive until I was 18 because processing all of the information required to do so wasn't something I was ready for. Obviously I made the safe decision to wait, but it wasn't socially a joy.

But because I had straight A's and rarely got into serious 'trouble,' my struggles emotionally and mentally was ignored by doctors (who misdiagnosed me with OCD, a not-uncommon experience for girls with ASD), teachers, and other adults in my life. I did have a track record of telling teachers in high school what I thought about them if they were doing or promoting unethical or inappropriate things. I was bullied and gaslit by adults as a result—and it was a terrifying experience as a child.

Looking back, I think I was seen as a stuck up smart ass. While I am lucky to be academically gifted (I learned during my autism evaluation I scored in the 99th percentile in many intelligence testing categories), I am not stuck up. I struggle to process social interactions, understand true motivations of people (I'm a very straightforward person—not a quality loved in women by our society), and I have always struggled to understand my own emotions (I truly prefer logic to feelings because I feel things so deeply). Feeling so intensely can cause me to freeze up. I needed friends and allies as a teen. Not critics and bullies.

As I put my life into context through the lens of autism, I keep coming back to one incident that I realize now, hurt me deeply. The emotional scar was reopened, like many others, during the evaluation process—thus my frequent gnashing of teeth within my soul or Id or whatever you call it these past few months. I literally break out into tears at random times during the day as I relive trauma from elementary school to present day because of a neurotypical world who wants people like me to not exist.

The story is likely familiar to other disabled and/or neurodivergent people. I was 16 and completely baffled by teenage social norms. The made-up drama and cliques of teenage angst left me mystified. So when I thought I made a friend in yearbook class, I felt like maybe I could finally have someone to confide in and enjoy inside jokes with. It was February, and I thought I'd ask him to the Valentine's dance (strictly as a friend; dating wasn't something I was seriously interested in). I got candy, paper hearts, and left them at his house with a note asking him to the dance.

To my horror, later that week, after waiting days for an answer from him, I was told by someone else he had been asked after I had asked him by some other girl. He said yes to her. The whole school seemed to know. The humiliation was overwhelming. That day I asked him in yearbook class why he'd done that and he asked me to go for a walk around the hall. He told me in a low voice, as if he was telling me some scary secret, he'd only befriended me because he'd heard from other kids that I was a freak and he wanted to find out if it was true. He had decided it was true and wanted to keep a distance from me. He may as well have stuck me with a dagger. The pain of shame and isolation was so intense it physically hurt. I was a freak. It would have been a near compliment to be called a nerd. But I was a freak.

The word was so ugly. F-R-E-A-K. I wanted to know why my peers thought this about me, but I also didn't want to ask because I liked me and didn't want to change me. I just couldn't understand why others didn't like me too. That year my only salvation was academics. There were no real friends. And my ability to trust peers had been nearly obliterated. I trusted no one. In March I started counting down the days to summer break. All I wanted to do was read and not see anyone.

If you've come away at this point thinking a cure or an ability to mask my autism would have been the answer, you should know you are wrong. The CDC now estimates 1 in 59 people are autistic. We are your siblings, neighbors, friends, students and co-workers. Neurodiversity is a strength of humanity, not a weakness. What I needed was acceptance. What I need now is acceptance. Researchers and 'professionals' continue to try to fix autistic people. Martyr moms march for awareness – something associated with deadly diseases. But autism isn't killing me. Society is killing autistic people though.

Autistic people experience higher unemployment, higher rates of suicide and mental illness, social isolation, discrimination in healthcare, police brutality, lower life expectancy and the list goes on. I never refer to finding out I'm autistic as a diagnosis because that word is for something that is pathologized: A disease. Autism does not need to be pathologized. Instead of teaching autistic people how to be neurotypical and 'compliant,' in essence extinguishing who they are and causing lifelong trauma, we need professionals and disability advocates to teach the public to accept Autistics. We are whole people, despite what many think.

The stupid puzzle piece that has come to be synonymous with autism is now considered incredibly offensive by many autistic adults. We are not missing a piece. We are not a mystery to be solved. We are full human beings. We do have challenges from being autistic, but that doesn't make us invalid human beings. Also, I think we have more strengths because of our autism—not in spite of it. Erase autism from humanity, and you erase people who are innovative, diverse thinkers, curious, and deeply empathetic. Eugenics is nothing new, but the newest technological capabilities make it more real than ever. We have a choice going forward to circumvent a genetic holocaust of autistic people. And it starts by having neurotypicals quit speaking for autistic people and deciding our fate. It is time to listen to autistic people (yes, this includes nonverbal people who can communicate in a myriad of ways) and quit trying to fix us. We aren't broken.