

Raising A Voice For BLM, Disability And Neurodivergent Rights | CPD Blog

Storee Powell

08/10/2020

Lou-Michél McKee isn't the sit-by-the-sidelines-and-wait-to-see-what-will-happen kind of person. McKee, who uses they/them pronouns, is at the point in their life where using their voice for positive change on social justice issues just occurs naturally. While they admit putting themselves out there can be scary, they know that their voice is needed in the movement for Black Lives Matter Utah, disability and neurodivergent rights, women's rights or environmental justice.

"White people have always been humanized," McKee said. "They've been recognized as a whole of humanity—not fetishized or denigrated or glorified, stripped of humanity—as people of color have been."

As a queer, Latinx-presenting Afro-Mexican who is autistic/ADHD and physically disabled, McKee knows a thing or two about being fetishized, denigrated and glorified.

"I learned I was autistic three years ago, though I always knew there was something different about me—I just couldn't describe it. I had a sense of trying hard to fit in and never quite did, or if I did, it was how much labor I could contribute as a token to whatever group was recognizing me," McKee said.

This means a lot of presumptions and labels have been put on McKee, even down to the things they most are interested in and enjoy in life. McKee is a self-professed lover of words and information—not something always associated with people of color or disabled people.

"I love information in a way that's kinetic, like building or repairing something," McKee said. "I learn about steps and processes almost to a level of obsession."

For example, McKee is a lover of music and dance. The process of dance, particularly for those with physical disabilities, is what brings sheer joy to them. They are interested in making dance accessible to all body types, neurotypes and cultures. McKee has a genetic condition of hypermobile Ehlers Danlos Syndrome and a chronic neuromuscular pain disorder of Fibromyalgia, which they attribute to developing as a result of childhood trauma.

"I think someone who doesn't meet traditional aesthetics should feel empowered to dance or do yoga regardless of what the standard is," McKee said. "A black girl can do Irish dancing. A larger person can do yoga. If you have dyspraxia as a neurodivergent, but still enjoy music and want to move, that embodies what dance is all about. It doesn't matter what you look like when you move."

Part of the appeal of music and dance for McKee is the kinetic stims (repeated movements or actions neurodivergents do to provide self-stimulation and soothing) like tapping and slapping. Using music means they can combine therapeutic modalities of stimming and music therapy.

Realizing later in life they are autistic and disabled has been difficult for McKee, not because of shame, but because McKee does not have a supportive family. They also struggle to access quality, affordable healthcare.

"We have no public health system that really cares if I get quality care," McKee said. "I'm stereotyped as a lazy disabled person using a power chair, and an emotionally absent parent as an autistic person of color. It is degrading and humiliating."

McKee admits to having no vanity left—rather they mostly live in survival mode. Those around McKee have made it clear that as a disabled person, they are not allowed to enjoy life and have a disabled identity. While they reject this thinking, McKee still struggles with self-harm and suicidal ideation; something they note is common for neurodivergents.

Something that has helped McKee is medical marijuana, which is now legal, though somewhat inaccessible in Utah.

“Medical marijuana has been life changing for me,” McKee said. “When I’m medicated I do not harm myself because it eases my mental and physical pain. My back pain becomes tolerable.”

Promoting disability and neurodivergent acceptance isn’t something McKee does just for the self-benefit. McKee has a daughter whom they think is autistic, and they strongly believe their daughter needs them as a neurodivergent parent. However, they have not been allowed to be a parent in the last ten years, and do not have custody of their child.

“So many barriers have been put in my way, and I’m just now being able to overcome them,” McKee said. “All I’ve ever wanted in life is to be a good parent. I used to write in my journal as a kid, ‘I hope to be a good mother.’”

Having a child was an intentional act for McKee, but their capacity for being a parent has been dismissed. When this occurs, to McKee, it is just another way to say, ‘We’re not human enough.’

One such barrier for McKee was the mark on their record when they were jailed in Texas for an autistic meltdown—an incident that left McKee with an understanding to never call the police in such situations.

Other barriers have been homelessness, not having a bank account, and having no positive social guidelines as they grew up.

“I didn’t know how to become an adult until I was in therapy, because as a child I had no positive social role models,” McKee said.

Physical, sexual and emotional abuse defined their childhood. They experienced jail as both a minor and as an adult.

“Black indigenous brown girls are characterized as less innocent to justify sexual and physical violence and neglect in the justice system and medical field,” McKee said. “I was literally told I’m not so innocent after I was raped by my stepfather.”

A later confrontation with him ended in juvenile detention for McKee. The incident left them traumatized and at the time, dealt with it by having “an autistic response.”

“I started hitting my head to cope,” McKee said. “I am just really lucky I haven’t been killed by police. Once I had a knife in my hand during an autistic meltdown with a cop there. But I’ve almost become numb to it after a while, even though I know I shouldn’t, because it is what I have to do to survive.”

Another struggle for McKee is that they are a first generation American. As a child of immigrant parents; it meant that McKee had to socially assimilate.

“Assimilation doesn’t mean conformity,” McKee said.

One way in which McKee refuses to conform is person first language in regards to disability.

“I don’t have to be a person first. I’m already a person,” McKee said. “It was needed once to force non-disabled people to remind them of disabled people’s humanity, but I think it is just now social laziness. I’m an autistic. If you correct me and say I’m a person with autism, I’m going to ask you to unpack that baggage; it’s not on my shoulders.”

The expectation of anti-racism and anti-ableism is something McKee now demands from medical providers.

"If I get a provider that does not have an understanding of my specific needs as a brown skinned neurodivergent, I won't pay them," McKee said. "I am the patron, not a patient: a patient is below a provider. This is true even if I'm paying them through Medicaid or Medicare."

McKee advises others in a similar situation: "If you are getting the service, you have every right to empower yourself in both physical and mental healthcare. Ask them, 'Are you going to advocate for me?' Serving you correctly isn't them doing you a favor – it is what they are being paid to do. Doctors are not above reasonable criticism."

McKee attributes their late diagnosis of neurodivergence and physical disability to their brown skin, and says it is why they 'take up the mantle of activism because I won't let others be unheard.'

And take up the mantle they do. McKee has been volunteering with Black Lives Matter protests in Salt Lake, working as a street medic. Another cause they have been involved with passionately fighting against is the proposed inland port in the northwest part of Salt Lake City.

"Because justice is a multidimensional fight, I've had to make my fight multidimensional," McKee said. "Intersections of marginalized people and environmental injustice means more health problems, more pollution, more low paying jobs – which are usually given to people of color, who are more likely to have a disability. Jobs can't ensure progress or mobility."

To help local organizations push back on the port, McKee writes grants, helps fundraise, and speaks out publicly on the issue.

"At this point in my life," McKee said, "I'm fearless because I have nothing to lose."