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*Living as Disabled*

As a person with many different identities, I grew up in a world I felt was not built for someone like me. My mother called me the “patchwork kid” because there were so many unique parts of me. I am a woman with both physical, communicative, and mental disabilities who has strived to beat the statistics and work in a world not welcoming to those with disabilities; much less those with multiple disabilities.

I am a person with diverse identities as a person living with disabilities. I was born with a genetic blood disorder similar to hemophilia that has significantly impacted my life. I am unable to do many physical activities and require frequent medical monitoring and limits some of my life activities.

Secondly, I was born with sensorineural hearing loss, meaning that I have had hearing loss from birth that has continued to worsen and progress as I get older. I use hearing aids. Additionally, due to health issues, I have had 2 surgeries on my legs and hips, limiting my mobility and

causing me to have bouts of pain that also limit my life activities. I have also been diagnosed with the mental disorder Generalized Anxiety Disorder and the learning disability Dyscalculia.

All of these different disabilities pose their own challenges, not because of the disabilities themselves, but because we have a society that is not accommodating or understanding of anything different than the “cookie cutter mold.” However, despite those challenges there are many valuable things living with disabilities has taught me.

I think much of the conversation around disabilities focuses on “limits”. What a person can’t do. What a person misses out on. But there’s so much more to the conversation about what it is like to live with a disability.

I frequently use the elevator and have had some fantastic conversations with people I wouldn’t have otherwise met. Taking the stairs is great for the environment, but it does reduce the amount of chances to have spontaneous conversations with a stranger. Some elevator conversations I’ve had: heard a man receive a call telling him he was about to be a father, someone talking about how they plan to propose to their girlfriend, and I heard a child’s first words.

With my hearing disability, I learned to read lips to compensate. With the pandemic and widespread mask usage, I learned to read facial expressions (what is visible above the nose) to gain meaning. Although the language challenges are not fun, I now have an appreciation for the beauty of eyes that I never had before. I’m also the best in my friend group at charades, because living with a hearing disability is always like one big game of charades.

I’m an expert planner. At a young age I had to manage doctors appointments, surgeries, and other plans. Nowadays I have an appointment almost every two weeks. I know my doctors, nurses, and the office workers by name. I now love having color coded and organized schedules and I’ve mastered how to create a good “to-do-list”.

I have a honed sense of memorizing building layouts, because I frequently need movement or bathroom breaks. I'm the "queen of comfort" and know which pillows and chairs offer the most back support. I became adept at speaking and advocating for myself at a young age. As someone with diverse needs, I learned how to tell others what I needed to be successful early on. I now get to use those skills to help others.

As a young girl going to school in rural Wisconsin, I often wished to have a role-model that I could identify with. In my work with students, I know that their future aspirations often revolve around the representations they can see. I had a motto when teaching: "You can't be what you can't see." I hope to be an example for other students who have dual identities. I worked as an educator for 5 years, before seeing how school districts treat students and educators with disabilities and the fundamental lack of support and accountability in K-12 education. I became an educator to help improve systems for those with disabilities and I hope to continue work within education by working on education policy.

Currently I work at the Urban Economic Development Association (UEDA) and am working on my MA in Educational Policy Foundations at Marquette University. I've worked in many fantastic schools, non-profits, and other organizations in the past. However, each time I interview for a new job, join a new club, or am out in the world, there's still a part of me that is afraid of disclosing my disabilities.

In recent years, the world has become much more welcoming. But there is a long way to go. As someone with "invisible" identities, I felt growing up that parts of my identity were erased because they did not fit the traditional narrative of what a person with disability should be or what they look like. It took me years to appreciate all parts of myself.

I read stories written about what it is like living with a disability and so much of the narrative focuses on the negatives and limitations. I choose to focus on all that I've given and what I've become because of my disabilities. My disabilities are as a part of me as my other identities.