

VSA Playwright Discovery Program

Disability Experience Essays

ERICA SIEGEL

When I was growing up, I never knew anyone with a disability. There was a woman in my sorority in college who wore hearing aids. I felt sorry for her. I didn't talk to her because I didn't know how. Then, at twenty-one, I was told that I had a profound high frequency hearing loss and needed hearing aids. I was scared and cried for weeks. I knew that having a disability came with a stigma. I was now the girl with the disability that people felt sorry for.

The first time hearing aids went in my ears, the world of sound lit up. I could hear the pages turn of the magazines in the waiting room, I could hear the air conditioner turn on, I could hear birds chirping and other sounds I hadn't heard for years. It was overwhelming and over stimulating, eerily strange to hear previously silent things making noise.

Eventually, the use of the hearing aids became second nature, yet my fear over the social stigma remained. Should I openly tell people about my hearing loss? Would they treat me like I was damaged?

Ultimately, I decided I wanted to be open with people about my hearing loss. I wanted them to understand why I need them to stand right in front of me, not behind me. Or why I need them to annunciate more or interpret for me in a crowd of people. It takes more work to make sure I feel included, which is what having a disability is like for me.

As I've come to embrace my disability, I've also come to appreciate and love when people ask me about it, because it makes me feel like I'm important to them. In many ways, being hard of hearing is extraordinary and has helped me become the person I am. I've been lucky to work with deaf and hard of hearing theatre companies. As I've traveled to different countries, I meet people who are deaf or wear hearing aids and I excitedly point out that I wear them too. Even with our language differences, there is that deeper connection you create when you find someone who understands you.

Yes, if someone were to grant me my hearing back, I'd absolutely take it. I'd like to know what it's like to hear again, and it would be nice to fit in. It's hard to ask people to treat me the same as they do everyone else, while still treating me differently enough to accommodate my needs—a hard line to define. As much as I do not label myself as disabled, I have a disability and I need special services, which means different treatment. Yet I don't allow myself to be defined by my disability. I want people to know who I am before they know about my hearing loss. But I also want them to know that my disability is part of who I am.

Today, if I were to see that girl in my sorority with the hearing aids, I would immediately approach her and say, "Hey! You wear hearing aids. So do I." We might talk about it. We might not. But we would talk. We would be two humans, having a normal human interaction. And that would be the best thing of all.

VSA Playwright Discovery Program

Disability Experience Essays

GREGG MOZGALA

"[Disability] is endlessly fascinating because there is that universal element. . . . It is the one minority class in which anyone can become a member of at any time."

—John Belluso, Playwright

I turned twelve in 1990. One day the librarian, Mrs. Brown, took me to a room where there were several adults I had never met before. The adults had various physical disabilities. One older gentleman, who was blind, had a dog. That was cool.

There were greetings all around until Mrs. Brown turned on a television. I was excited at the prospect of watching a movie, but quickly disappointed. It was some boring news report featuring President George Bush behind a podium, speaking and signing some paper. By the end, I was engrossed in Mary Shelly's *Frankenstein*, which I was reading secretly under the table. The adults talked about what a momentous occasion this was. I remember thinking, "If this is such a momentous occasion, why isn't the entire school watching?"

I walked back to class alone. The sound of my metal braces echoed and reverberated through the cavernous hallways. As I glimpsed my ungainly shadow limping and looming huge beside me, I felt like Dr. Frankenstein's Monster. Gregg would return to class that day, but I became keenly aware of this other "thing"—a shadow-self that would always be beside me, that I could never get rid of, and that I simply could not live without.

This experience set the tone for my feelings and interactions with the disabled community for most of my life. I would enter into situations with a group of strangers whose only common trait was a disability. These experiences were intended to be inclusive, but instead proved mostly isolating and confusing. As I got older, I would engage less and talk less, and I suffered for it, because I was denying a huge part of my own humanity.

I've since learned that what makes disability hard to define is also what makes it inherently dramatic. My task is to observe and learn. This is why I have chosen theater as my life's profession. Art is my activism. Theatre is immediate and it demands participation. It also provides visibility, creates community, and serves as a forum to explore questions. Every time I work I want the questions to become clearer.

In 1990, the ADA became something more for me than an important, imperfect piece of legislation. Americans with Disabilities Act. Americans with Disabilities . . . Act! It became a directive. A battle cry. It reminds me that I am in control of my own life course. We all are.

I am a thirty-something crippled white guy. I was the third of four children raised by a first-generation Italian mother with strong Catholic beliefs and a father who spent twenty plus years in the United States Navy. I was born with a disability, but disability does not consume my life. Most of our lives are taken up with the same day-to-day struggles, just like anyone else.

VSA Playwright Discovery Program

Disability Experience Essays

MICHAEL PATRICK THORNTON

In terms of how it can often *feel*, I would say the disability experience is one that necessitates consistently reminding yourself that you have eminent value. Looking or moving or talking in ways anomalous from the “norm” certainly has a way of making you feel different, but the fact of the matter is that everyone who’s ever moved over the Earth has, at one time, felt this way. There is no such thing as “normal.” You own who you are and do the most good for others that you can, in any and every way you can—especially in ways you may initially think you can’t.

I’m not a big fan of labels or qualifiers such as “disability” or “disability experience.” I think they’re useful initially to repair a lost sense of identity and erect a new existential foundation, but who we are is something far greater. We have more potential than the best of the limiting adjectives and adverbs at our disposal would lead us to believe. I don’t define my experience based on ability or disability. We are more than our bodies. As my buddies at The Rehabilitation Institute of Chicago say: *The Spirit moves first*.

For me, “disability experience” meant losing a lot of friends who didn’t know how to react when I got sick (but the ones worth your tears will boomerang back to you, better people and friends than they were before). My experience requires getting up about four hours before I have to be anywhere in order to go through my bathroom routine, shower, and get dressed. For the first two years, it meant heartache and crying myself to sleep. It meant daily panic attacks. And then, there comes a crystalline moment where you simply have to decide that you are worth this journey and this struggle, and that *you* define what you’re fighting for. And when you build yourself up from the ashes, you become a sort of phoenix. In struggling through what I lost, I came to appreciate what I have. I’m grateful for every cup of coffee, every breeze, every sock. And on days when I’m not so YodaZen, I’m like everyone else, caught in the hamster-wheel of trying to get somewhere I think will afford me peace or ascendancy. But as Gertrude Stein wrote, “*there is no there there.*” There’s just here & now.

And people are people. Everyone has a wheelchair of the heart, a crutch of the mind—they’re just not as noticeable as mine. Like anyone’s experience, mine relies on my attitude going into and participating through it. On my best days, when my mind is quiet and the dreams of my heart sing quiet notes of gratitude, there is no such thing as a “disability experience”; there’s just Experience. There’s just Life.

VSA Playwright Discovery Program

Disability Experience Essays

MIKE ERVIN

There are so many aspects to the disability experience. The aspect that interests me most as an artist is the great humor of it all.

Much of this humor stems from the huge gap between the outside perception of disability and the inside reality. There are certain words outsiders commonly use to portray disabled people that just make me laugh when I apply them to myself. One of those words is courageous. I laugh when I think anyone would consider me to automatically be courageous just because I have a disability. My idea of courageous people are those that stormed the beach at Normandy in World War II, knowing the odds were high they would be killed. If someone asked me to do something like that, I'd run away crying and hide under a bed.

Another one of those funny words is frail. Many people consider someone in a wheelchair like me to be frail. But when I hear the word frail, I think of a baby chick—all wet and trembling and barely able to stand on wobbly legs. Everyone's afraid to touch a baby chick because it's so delicate it might fall apart. I laugh when I consider that some people think if they touch me I might fall apart.

But my favorite one of those funny words is IN-va-lid. That word really makes me laugh because it says so much about how some people think. Whoever came up with that word just took the word in-VA-lid and put the accent on a different syllable, as if that changed what the word is supposed to mean. When I consider how some people think having a disability means I lose all validity, the absurdity of that really makes me laugh.

So when I write plays about the disability experience, I write comedies. My disabled characters are struggling to avoid being defined and thus diminished by others. It's a struggle against oppression and it is an absurd, harrowing adventure.

VSA Playwright Discovery Program

Disability Experience Essays

TALLERI McRAE

As a young person, I avoided the word disability at all costs. I didn't like it when other people decided how significant my disability was, or when people tried to tell me what my disability should mean. I just wanted to be treated as myself, because I felt normal. I would get mad if people made too big a deal about my requests for accommodations, and I would get mad if people ignored them.

As an adult, when I started to study disability culture, the idea that the word "disability" describes an environmental barrier made so much sense to me. Yes, I need accommodations in my life, but not because there is something wrong with ME, but because there is something lacking around me. Yes, it bothers me when people focus too much on my disability because their extra focus on it means they do not understand that my impairment is simply one part of who I am. Like any noticeable personality trait, I don't want people to ignore my disability, and I don't want people to hover over it. I want to decide how much to focus on my disability, and I want to be able to change my mind about my disability.

My disability is a paradox. I know that my disability makes me different, yet at the same time I want to be treated like everyone else. As a teacher, my disability reminds me to embrace difference. As an artist, my disability is an environmental limit that can inspire endless creativity.