
BEING HUMAN: LIVING WITH A DISABILITY

Why do I have a disability? Why me? Why does anybody have a disability? These are questions that anybody might ask. Why do we have struggles and challenges? And why do some have more than others? It's not that easy for me to do what I want to do because I have a condition called kernicterus.

What is kernicterus? I can tell you. When I was hardly a day old, I got sick with newborn jaundice. Did you know that severe newborn jaundice can cause brain damage called kernicterus? For me that means athetoid cerebral palsy or CP, auditory neuropathy, which means my hearing is like a static-y radio, visual tracking difficulties and so much more. And did you know, it could have easily been prevented with a \$1 blood test and treatment? What happened to me was an easily preventable medical mistake.

So, what is it like to live my life? Sometimes it's really hard and I have down days. It's as if my muscles all have their own individual brains and none of them are listening to the brain in my head. Think about having to rely on someone else to give you a drink of water or feed you or arriving at restaurants where you simply can't go in because there are stairs. A 3" step or curb is a mountain that can't be climbed when using a power wheelchair. Imagine that most people cannot understand your voice and that it takes you one or two minutes to type every sentence that you want to share. It is annoying sometimes when people don't realize that I have a lot to say and need them to take the time to listen. Part of the reason that I write these kinds of essays is because I have the time to make my voice heard.

I didn't get to choose whether or not to have a disability, but I do get to choose how I live with a disability. A lot of the time, I find a way to fight my goofy muscles and try to do what I am able to do. I work hard to live life without limits. I love to learn, especially about creative writing, literature, and history. I love school and I love to read. Being an author means the world to me because writing calms my soul.

Can I fight the difficulties on my own? Can anyone face challenges on their own? No. I am lucky because I have amazing parents, helpers and friends. I have a team of doctors and therapists. All of them try to figure out what will help me do the things I want to do. I also have a brother who loves me and is my best friend. Grandparents, aunts, uncles, and cousins are part of my team. People, even strangers, hold me in their hearts. I find courage in knowing that people believe in me and support me.

What is my dream and what is in my future? I will do what I want to do and live where I want to live. Minnesota is failing countless people with disabilities by providing little support other than in sheltered workshops and group homes. (Serres) Do I want to be forced to work and live where I don't want to? Nobody does. I'm going to go to college and figure out how to live where and with whom I want to live. Even though the employment rate for people with disabilities working full time is only about 26% in Minnesota, I will do what it takes to work in a meaningful job where I will give back to society. (Mourssi)

I am determined and want to live my life without limits. I am a human being like any other. We all have challenges and struggles we face. I choose the possibilities not the disability.

SOURCES

Mourssi, Mohamed. "Department of Employment and Economic Development." *Disability Employment in Minnesota*. Minnesota Department of Employment and Economic Development, Oct. 2013. Web. 03 Jan. 2016.

Serres, Chris, and Glenn Howatt. "Sheltered: How Minnesota Is failing the Disabled." *Star Tribune*. Star Tribune, 8 Nov. 2015. Web. 18 Nov. 2015.

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