

A Disability Is Not a Disease

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My parents began having children in 1990. Their first baby was a boy, named Alex. Everything seemed normal until he was about 2 months old and my parents horrifically realized his frequent startling was really seizures. They knew, at this point, their lives would drastically change. When Alex was sixteen months old, my parents gave birth to my healthy older brother, Justin. To this point, no one knew the cause of his daily seizures. Doctors decided it was a “fluke” that wouldn’t happen again, since he had been tested for everything they could think of. He had not learned to speak, walk, or reach other developmental milestones of a healthy one year old. My parents devastation must have been heart wrenching. In December 1993, Alex caught a cold, followed by the flu. On Christmas Day, my parents woke to discover Alex, just three and a half years old, had sadly passed away. The loss of a child must be indescribable. Parents are not supposed to bury their children, but rather, the other way around. One year and three days later, my parents were blessed with a late Christmas present; me. I was born healthy; no seizures or incapacities. When I was almost two, my mom gave birth to what we thought was another healthy boy, named Andrew. At five days of life, he had a seizure. My parents must have been horrified to know Alex’s problems were genetic, and they now had another handicapped child they could do nothing to help. I imagine my parents felt completely helpless.

As Andrew grew, doctors evaluated him. He had blood work, MRIs, skin and muscle biopsies and EEGs. My parents traveled to other states for appointments with

specialists to find a name for his disorder. Test after test came up negative, and every trial to diagnose him failed. The fact that even top-of-the-line doctors could not come close to telling us a name for his condition was frustrating. If that was not enough, doctors told my parents they didn't think he would live as long as Alex. Andrew proved that thought wrong. When he was about nine, doctors had a breakthrough. His neurologist recommended a brain biopsy be done, and after seeing the results, connected my parents with a specialist in Georgia, who did more testing and at last, diagnosed him. Andrew has Adenylosuccinate Lyase Deficiency, also known as ASLD. It is a rare, inherited metabolic disorder due to a lack of the enzyme adenylosuccinate lyase (ASL). When we heard this, we had no idea what it meant for Andrew's future. There was little information, no treatment, and less than 100 other cases in the world.

As my brother Justin and I grew, we knew we were different than other families. We had a little brother who could not walk or play, or even speak to us. He took so many medications that we designated a corner of the kitchen counter to him. The medications prevented seizures. He also had a fragile respiratory system, causing him to get very sick with little warning, at times. He doesn't get sick as often now, and is fifteen years old. At age nine he got a feeding tube, since feeding him became so hard. Growing up with a severely handicapped brother is difficult. People stare at him everywhere we go, and we have an active family that goes everywhere! It used to bother me so much, I sometimes felt embarrassed and pretended to not know my family. Now, when I remember this, I feel ashamed.

Research shows that one in five people have a disability. This is shocking. If every one in five people have a disability, why are they stared at, mocked, and teased

so much? Why are they still ostracized today, if disabilities are so prevalent? Everyone is able to think of a time they saw someone who looked different, yet stared because of that person's appearance or actions. This should not be the case. Being different is actually "normal", because we are all unique. We live in a society that critiques and picks apart aspects of a person's appearance, down to hair and outfits. This harsh reality is the scary truth. People need to be aware that everyone is different and we all need to be more accepting.

Growing up with a handicapped brother has significantly impacted my life; I have learned many important lessons. I am more accepting of others and their differences, and I grasp the true meaning of the saying 'Don't judge a book by its cover'. Disabilities come in a million different forms and to varying degrees. Some disabilities are visible, while others are subtle or invisible. If people are more accepting, and acknowledge the prevalence of disabilities, the disabled will feel more a part of their community. We all seek acceptance. Being handicapped does not make someone gross, or even contagious. Personally, it bothers me when people act as if they are going to catch an illness by being around someone in a wheel chair, like my brother. You are not going to get sick by touching or comforting someone with a metabolic disease.

Every school, community, and family in the United States is affected by someone with a disability in some way, shape, or form. By helping others become more accepting of those who are handicapped; we all become more understanding. In becoming more understanding, we transform together and become more connected with those who have disabilities. They are like us in almost every way, shape, and form. If we all

change our ways, our world can transform into a more pleasant, accepting community.

Just because someone has a disability does not mean they have a disease. They

simply need friends and support, no different than you or me.