

Personal Experience Paper: Simulation of a Disability

A Day in the Life of Maria Torre: Living with Spina Bifida

Spina Bifida is the most frequently occurring permanently disabling birth defect. This birth defect affects approximately one out of every 1,000 new born babies in the United States. It is so common that more children have spina bifida than have muscular dystrophy, multiple sclerosis, and cystic fibrosis combined. Spina Bifida is a condition where the vertebrae of the spinal cord fail to close properly. People with Spina Bifida usually have cool control of their upper body but, have paralysis of the lower limbs.

I have been friends with Maria Torre for about ten years. However, I have never had a greater appreciation for the challenges that she faces everyday. As part of my disability simulation, I spent an evening, with Maria, shopping at Target. She let me use her spare wheelchair while she showed me how she works and drives her specialized car. She also impressed me with how she pushes a shopping cart when there are no mechanical ones left or she doesn't want to leave her wheelchair unattended. She also let me in on some of the challenges she faces everyday, as well as her experience in school. The following are some candid thoughts from a "real" person living with a disability.

What is the biggest challenge that you face on a daily basis?

My biggest challenge is public places not being accessible. Most stores are accessible but that's about it. Anything that has to do with entertainment isn't always accessible. For example: movie theatres, bars and restaurants. I always have to plan things out. I can't just decide to go somewhere. Either there are steps or no accessible bathroom etc. Also, people are not understanding about disabled parking. It's not just so I'm closer to the building it also wider so I can get my ramp down. But people still park in these spaces. The other challenge is people perceptions of disabled people. People think that we are dumb and we should be pitied. I don't need anyone's pity. I just want their understanding.

What was your experience like at school?

I had a good experience in school, I guess. I only had one year that was tough when I was in school. It was my 3rd grade year. This was the year that social "clicks" start and when kid's differences become a bad thing. I found myself getting teased a lot and made fun of not only for my physical disabilities but because of my learning disabilities. It didn't help that I had a teacher that didn't want to teach me. This is not speculation. It is a fact that she mentioned to another teacher when she thought me and my mother weren't listening on a field trip. She felt that I was un-teachable so she gave me "busy work," as she stated. Because of this teacher and next year's teacher, I was severely behind by the time I hit Fifth grade. I didn't want to go to school anymore. I was severely depressed that I spent most of my time in bed. It was not until my fifth grade teacher came to my house and promised me that he would get me back on track that I shouldn't let anybody stop me. He also told me to ignore the kids that they don't know the real you. They're only seeing your braces and crutches not you. Well, long story short, I jumped two readers and my grades jumped from D's to C's and then to C's and B's. I worked my butt off that year. I had Resource Room and Tutors 3 days a week and on Holiday Breaks. Plus I had 2 tutors over the summer and going into my 6 grade year.

High School was good. That's where I finally hit my stride. But again, I didn't have the greatest teachers there either. Plus, there wasn't any elevator in my school. So when I got my schedule for my classes I didn't have any social studies or science because those classes were upstairs. You didn't want to be in the room when my mother came down to school about that one. But all in all my high school experience was pretty good.

Has technology helped you with regards to your disability?

Technology has helped me get a car that I can drive and wheelchair that is more mobile than the ones I had when I was little.

If you could change one thing in this world that would make your life easier with regards to your disability what would it be?

I would change people attitudes towards people with disabilities. Like I said before, disabled people are not looking for pity just for understanding. Is that so much to ask for?

As with all people faced with physical disabilities, people with Spina Bifida are just like you and me. Spina Bifida may affect a person's cognitive, physical, social-

emotional and language development. Teachers must pay attention to these special needs, just how they would to any student in their class. This includes any health needs that may result from this disability. And, as you can see from Maria's story, families play an important part in the education of a student with a disability. Teachers should take extra steps to involve a student with a disability's family as much as possible. Students with disabilities in your class are just like all of your other students. Each student should be treated as an individual. And just like Maria said...these student's aren't looking for pity, just for a little extra understanding.

Works Cited

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