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Accepting My Older Brother; The Roller Coaster Journey

I used to cringe when people asked me if I had any siblings. Such a simple question made me go pale and stutter over my words. I didn't want them to probe me about my brother in case they could see through my smile, to the truth. I figured no one would understand, they couldn't unless they lived with him day in and day out. I avoided the subject as naturally as I could each time. It's a lonely feeling to know that a big part of your identity, such as a disability or a language, can be rejected and misunderstood by so many people. If it is ingrained in someone's mind from a young age that they are significantly different from the general public, they will crumple that difference up into a ball and hide it somewhere no one will point it out or ridicule it. My brother was that difference in my life, so I kept people away from him and pretended everything was perfect within the walls of my yellow house. However, maintaining this facade was an exhausting and damaging process.

My twenty-year-old brother, and only sibling, has high-functioning autism and a severe behavioral disorder. I tried to explain this to people when they asked if I had siblings or if we were close. This explanation was consistently met with confusion, nervous laughter, a sympathetic nod, or blatant disrespect, and it always made the conversation awkward. I heard the R-word for the first time in elementary school from a boy who had heard about my brother. My mom became choked up later when I asked what the word meant, and that's when I knew I would never use it. I wondered how someone could use that term so carelessly, and I felt angry and ashamed. I had never met anyone who understood how hard it was to have a sibling on the spectrum, so no one beyond my parents could truly empathize. Although even my parents didn't know what it was like to be the child or sibling in this situation. I felt alone and sorry for myself which led to guilt about focusing on me rather than my brother. “Why does he have to be this way?” I asked myself, my parents, and the universe over and over. Maybe it sounds selfish that I could resent someone who didn’t ask to be born with a disability. Nonetheless, I resented how he started explosive fights that dominated the attention of my parents for my entire childhood. I didn’t like having friends over in case they witnessed or heard one of my brother’s meltdowns; I always asked to go to their houses instead. I kept my home life separate from my school and social life. The struggles my brother posed to me and my family felt inexplicable to anybody, so I stopped talking about him altogether when I moved to a new town in eighth grade. Most people there believed I was an only child, and I was fine with that.

Autism is a mental disorder on a wide-ranging spectrum that takes many different forms. My brother, being high-functioning, presents to outsiders as a neurotypical boy from afar, but after one conversation with him, his atypical tendencies become obvious. He will talk anyone’s ear off about his hyper fixations, and he has gone through many phases of these obsessions which is common for someone with autism. For years, the few civil conversations we could have were solely about roller coasters: the speed of a certain coaster, the height of the tallest one in the world, and the theme parks he wanted to visit. He doesn’t ask me about my life because it’s hard for him to remember that other people have their own experiences separate from his own. I know that part is not his fault, but my chest felt heavy whenever he neglected to ask about the results of my soccer game or where I wanted to go to college.

The National Library of Medicine writes, “In addition to significant financial strain and time pressures, high rates of divorce and lower overall family well-being highlight the burden that having a child with an ASD can place on families” (Karst). Even the most loving parents, like my own, will struggle to wrestle with the difficult job of raising an autistic child. He required their full attention as they tried to calm him down from his third meltdown of the day, begged him to do his homework or take a shower, gently coaxed him to talk about school and making friends, and worked with him to do the basic things a child at his age should be doing. Locked in my room alone, it was hard to listen to the constant background noise of his obstinate screams. Children with autism have meltdowns due to their difficulty with communication, understanding social behavior, and sensory sensitivities. My brother cried at the overstimulating crackle of Fourth of July Fireworks so we watched them from the car, even though I wanted to be out in the field. Amongst all of these challenges, the hardest part is watching someone you love take a beating from life itself. Everything comes to him much harder than a neurotypical person, and he's always frustrated, born angry with his unfair circumstances. Everything seemed to set my brother off, so I grew up to be an expert in walking on eggshells.

In the essay "How to Tame a Wild Tongue", Gloria Anzaldua writes about the self-destructive desire to morph into what society expects from you instead of being yourself. She writes from the perspective of being a Chicano Spanish speaker wondering where she fits into the world, since Americans want her to speak English and Latinos want her to speak traditional Spanish. Similarly to how language is the essence of one's culture, a disability is an important defining trait. Society has given the term disability a strong negative connotation, and it's often tied to words like weak, slow, and broken. However, I've realized that my brother interprets the world differently from others, but its rarity doesn't mean it's inherently bad. Similarly, Anzaldua speaks a unique language that blends many cultures and words which is looked down upon by groups that make up the majority. Her language is beautiful and should be admired by others rather than diminished due to its combination of traditions and Spanish history.

As a sister, I wanted to protect my brother from the harshness of this world and protect myself from the judgemental eyes of outsiders. It became easier to distance myself from him and avoid telling my peers about him. However, Anzaldua says “Until I can take pride in my language, I cannot take pride in myself” (Anzaldua 7). Although language and brothers seem quite different this sentiment cuts deep. Until I can accept that I will not have the brother I’ve always dreamt of and love the one I have, I cannot fully take pride in myself. When referring to her culture Anzaldua writes: “We know how to survive” (Anzaldua 12) and I’m inclined to remember my family. We are resilient and full of love, despite the fights and tension. I happily remember moments from childhood when the four of us created harmony despite our challenging circumstances. My parents treated every day as a new opportunity for improvement and did not hold a grudge against my brother for the fights he put up. When my brother was calm we’d listen to him intently as he rambled about his newest interest, speaking in the focused detail that comes with autism. My parents would remind him that I get a turn too and he would let me share about my day even as he fidgeted. My parents did everything to help my brother thrive in school and make friends, and to a degree he did.

This is the first time I’ve written a piece fully dedicated to him, which is a big step toward acceptance in and of itself. Anzaldua’s story on acceptance of one’s truth, no matter what that looks like, forced this idea into my head. Anzaldua wrote half of her sentences in Chicano Spanish and the other half in English, shamelessly intertwining the part of her she’s no longer ashamed of into the essay. That’s what I am trying to do here, stop hiding my brother. I am undeniably grateful for him. I can’t imagine how I’d see the world if not for him. I am a good listener and empathizer because I learned to hear out my brother even in moments when he hurt my feelings. Now I am better equipped to work through my friends' grievances and interpret their behavior. As a writer and journalism major, my brother has helped me step into the shoes of those I want to write stories about. When people I've just met ask me if I have siblings I don't freeze up anymore. I say I have an older brother and if they push further I describe what he's like. I can say he's autistic and difficult, we aren't very close, but I love him. At the end of her essay, Anzaldua describes the Chicano people as going through life "Possessing a malleability that renders us unbreakable" (Anzaldua 12). Her language was persecuted and made to feel wrong coming out of her mouth.

Similarly, the world can be unkind to those with disabilities, even if our culture says they are accepting, I've seen firsthand how people react to my brother. A few years ago my brother and I were hanging out with our next-door neighbors and they began subtly making fun of him. He has difficulty detecting sarcasm, but I picked up on their snarky tones as they questioned him about the "sped (crude slang term for special ed) school" he attends. It would have been easiest to laugh along with these kids who had been my friends for a long time, but instead, I stood up for my brother and told my friends off for being immature and rude. It felt good to defend him, in the way I always wished he would protect me as neurotypical older brothers would. Even if he can't embody that role for me, I can do it for him.

Society pushes the disabled aside, hoping they will keep their issues in the home and act "normal" in the face of strangers. Schools with disability support cost tens of thousands of dollars as if only rich disabled kids have a chance to learn in the way their brain requires. Many kids like my brother go undiagnosed because their families simply don't have the means to conduct testing and pay immense psychiatry bills. My brother has been let go from many jobs because “he couldn’t keep up” even though he was trying. Bosses don’t want to deal with the struggles he comes with or take the time to teach him skills that come to him more slowly. Public schools don’t have the resources to build him the curriculum he needs. The task comes back to the family each time and we are malleable, bending to fit his needs. My mom, dad, and I advocate for him as much as we can. Even though the world isn’t built for him to succeed, we do all we can to give him a fighting chance. My brother is hard to live with, I can admit that, but I will never stop going to bat for him to watch him grow as a person, and to be happy. I won’t sweep him under the rug because he’s not a shameful part of my identity, he’s family.

Society would benefit from a broader education on the topic of mental disability to become a more understanding place. If you’ve never been close to someone with a mental disability, it’s easy to avoid the difficult subject matter altogether and turn a blind eye to how they’re treated. However, when you do cross paths with someone like my brother, take a second to listen and learn about the lens through which they see life. Or simply let them ramble for a minute about roller coasters or another fixation, they happen to know a lot of fun facts.

Works Cited

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