

Alyssa MacKenzie

This is a Montaigne-style piece I wrote for a Boston University literature class a year ago about my relationship with my oldest younger sister.

A Sister's Lament

My little sister is four days shy of exactly two and a half years younger than me. Newly twenty, she should be a sophomore in college. Maybe she'd live in a dorm, or in off-campus housing; we could have attended BU at the same time. Maybe she never would have chosen to go to college. Like me, she would have a car and maybe a boyfriend. I would be able to call her in the middle of the night with whatever troubled me, and she'd be able to voice her concern and empathy into the receiver.

We would go to the concerts of all of our favorite bands and she'd stand next to me, maybe a beer in her hand too, shouting the lyrics to all of our favorite songs. We'd sneak in together after a night with our friends, snuggled up in my bed, thoughts racing to beat the moonlight, divulging our most embarrassing moments, secrets from our siblings and parents, expressing our hopes, our dreams, our plans to marry or have babies or travel the world with just a backpack and a satellite cell phone.

But this isn't the relationship I have with my sister. While what I share with Cayla is something precious: invaluable, treasured, as much a part of me as it is a part of my life, my sister's world is one not many of us live in. And for that reason and that reason alone, neither is mine. Far from being eccentric or unstable, the conditions that have created my sister's "situation", for lack of a less sterile word, are far from her own choosing.

Admittedly this brings into question what we'd "choose", given the option. Would the same beautiful, conflicted, misunderstood, sunny and slightly devious young woman exist by any other name or genetic combination? I'd always choose Cayla: her strength, her ability, even her naughty behavior. I know for certain I would not be the same woman I am today were it not for my almost voiceless, though not unheard, counterpart.

If one were to type "sister" into an Internet search engine, most of the links that would pop up would accurately reflect the sacred bond between female siblings. Quotes, definitions, and the like would express the joys as well as the pitfalls of sharing your family and everything in between with another woman. What are left out are the specifics. Toni Morrison begins to hint at the complexity of sharing this special bond:

A sister can be seen as someone who is both ourselves and very much not ourselves - a special kind of double.

Toni Morrison

Everyone's experiences are varied in the same way every person is different than the next. To say Cayla is my sister hints at the closeness we share but never the specific struggles we face together, or more appropriately the struggles I watch her face alone; I secretly admonish myself for lacking the ability to carry more of her load.

While words can conjure pleasant memories enjoyable to relive, we all have an internal dictionary of words that prick at and jostle our insides as if feeling their very own definitions. A word is capable of feeling as though it is grasping at our throats, our hearts, our stomachs or even tongues, calling out as it awkwardly attempts to extricate itself. Fumbling for something to cling to it calls: "Here I am! You heard correctly. What are you going to *do* about me?"

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I have a laundry list of such words, and for the most part I internalize them, push them to the bottom of my person like unwanted acid. It would be unfair, irresponsible to explode with upset when you've seen your own flesh and blood silently synthesize a harsh reality you could never bare to know. Emotional Pepto-Bismol keeps instinctive, id-like responses at bay toward English's harsher words such as, let's try on for size, retarded (and all of its manipulations thereof):

re·tard verb \ri-□tārd\
1: to slow up especially by preventing or hindering advance or accomplishment;

impede

Okay, this is a definition I can keep down. I personally won't use it, and it was with great pleasure I watched the US Department of Developmental Services (previously the Department of Mental Retardation) change its name as the understanding of citizens with special needs evolved. My sister's growth and development certainly has from the day she was born been retarded in so much as it has been delayed, impeded. This is the first symptom of her condition. Her first set back. But add to this the symptom as it were of man itself, of the society she was thrown into only to be stagnated. Which brings us now to the definition that many in our society have chosen to define her as:

re·tard·ed adj \ri-□tār-dəd\
sometimes offensive : slow or limited in intellectual or emotional development or

academic progress

Sometimes offensive? When someone does something dumb, careless or unnecessary and they refer to it as "retarded", in accordance to what are they acting if not offensively? Sure, they might not realize the full scope of the language they are choosing, but does it not sting my sister when she hears others use such medical terminology as a derogatory statement? In what other situation is hurtful language allowed? I dare someone to utter a racist slur at a person of that ethnicity, or a sexist jab at a person who identifies with that gender. It would take someone with pretty thick skin to not be offended by that person's choice of actions. Many would speak up. They might say, "Who do you think you are talking like that?"

Not my sister. Her genetic malformations render her fairly incapable of speaking up on her own behalf. She is a member of a minority of individuals unable to stand up as their own advocates. A minority oppressed, misunderstood, and ill-treated. I would never wish to say that all people are small-minded or ignorant when it comes to individuals with handicaps, in fact I think many people *try* to be open-minded and understanding of others.

What I'm referring to are the bodies set forth to defend people like Cayla. Social services available to individuals with special needs? Pathetic. State-run vocational programs for people with cognitive disorders are barely funded. Of course this varies from state to state and even town to town. There are instances where people with special needs are accepted and nurtured.

It is basically a full time job to sift through government paperwork and legislature to know your loved one's rights- what they are entitled to medically, fiscally, therapeutically and academically. For 13 years of my sister's life my parents had to fight for her to achieve a level of education that resembled something more than babysitting. Thank goodness they could afford a lawyer and the time to do so. To think that equal education is a constitutional right.

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My interest in psychology originally festered from years of witnessing abominable treatment and discrimination of individuals who were not in control of their behavior. I naively believed that others associated with psychology shared this ideal; that all people were equal regardless of their genetic makeup or neurological development. The lack of compassion apparent in the professor's regard towards others and their beliefs, especially those with neurologically based developmental disorders, was disheartening at best.

I have lived twenty years staring back at faces staring at my baby sister. I have spent two decades standing up for someone I love who cannot stand up for herself. I care more about the abhorrent treatment of my sister and those like her than the way others care for me, but I sometimes feel at a loss. I understand why individuals cannot see what I see in my little sister, but I cannot for the life of me understand why there is no change in attitude: no progression, no evolution. TV still uses the word retarded, as do movies and the media and even some of my friends' parents.

I do my best to keep my mouth shut. I don't want people to not use a word because they think it makes me uncomfortable. I want to live in a world where people realize the implications of their language and make the change based on who they want to be. I don't want to have to shelter my sister from this world for fear of her feelings getting hurt. She hears what people say. She knows she's different. She tells us in rare moments or types it on her Dynavox device or iPad. If only others could listen, or I should say: could see. Until then, I will dream of a world that I could be proud to show her.

**If you are interested in learning more about my superhero kid sister, check out her blog Caylaspeaks.blogspot.com. There you can learn about her insights and interests, as well as her latest philanthropic endeavors.*

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