New potentials: Rethinking disability through my sister's eyes

Listen
Help with Listen Feature

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Sisters, Together and Apart

When I think back to the years when my sister and I were children, I remember a time when I could still fully relate to her. In her youth, she was a lot like me: a very shy and sensitive child who was acutely in tune with the emotions of others. We both experienced complex feelings but lacked the words to express ourselves. We empathized *on-demand*, giggling uncontrollably at curious coincidences or weeping quietly while adults whispered of serious matters. And we both knew when someone was talking about us.

We were six years apart, separating our interests and activities from one another. We loved being among friends, but making friends was much easier for me than for her. As I entered adolescence, I discovered "fitting in" meant I had to learn social graces to conceal and protect full emotional expressions. My sister, however, continued wearing her heart on her sleeve. I remember telling her, "You just need to grow up and get over it." I learned to fit in socially with my peers, but she never did.

During my teen and college years, my parents supported me but remained hands-off as I chased my dreams, setting many goals and high standards for myself. In the last year of my college degree, I thought about my family's hand in my success. And I began to realize one thing had been missing all these years: time spent with my sister.

Lessons from My Mother

My mother had always been in the forefront of social service. In her early twenties, she emigrated from the Philippines, taking her first job as a social worker in Kern County, California, in the mid-1970s. She later became director of the Jameson Children's Center for abused and neglected children, and eventually transitioned into the role of ombudsman with a non-profit that offers legal services to Bakersfield's low-income community.

My mother's involvement in social service opened my eyes to the complexities, fears, and hidden abuses that can emerge when a person becomes a ward of the state. She saw children move from one home to the next as they struggled to fit in with different families. She visited assisted-living centers where elderly residents sat quiet but restless in their rooms, lucky if they could express the profound loneliness or isolation they felt. My mom reminds us that, one day, she will take my sister back to the Philippines, where there will be "*plenty of relatives to take care of us*." Financial obligations, however, keep them here in the United States, where they will remain for many more years.

What Have We *Not*Learned?

Growing older, I am trying to envision how my sister will enjoy a fulfilling life in this world. She still lives in our old family home in California, cared for daily by my mother and our extended family. She remains shy and petite. Her smiling face is worn from all the eyes that have stared at her, and for the uncountable times that she has been misunderstood, mistreated, or ignored. I often see her sit near our living room window, watching for family members as they come and go, waiting for her turn to venture forth with the rest of us. Our society works such that it steadily turns without her, like a carousel that she can never ride. In her eyes, it's easy to see that she knows she will soon be left alone.

As an older sibling of someone with developmental disabilities, I want to believe that my sister will have better options than exist today. Policies such as IDEA and NCLB were founded on philosophies derived from civil rights and an individual's pursuit of happiness. These are meant to provide a semblance of equality and possibility for individuals with disabilities to grow and achieve their full potential. My sister, however, will never be able to fight for her happiness on her own. The state will always see her as a burden, and she will rely on a community to support and protect her.

We are used to asking questions like, *what can we offer people with disabilities? How do we give them the skills they need to survive?*What if we asked ourselves what individuals like her have to *offer*our society? What have we *not*learned from them? What is at the core of our deep-seated value system that causes our social and political architecture to limit the potential of people like my sister? Couldn't every facet of society benefit from the questions and challenges offered by their unique perspectives and worldviews?

Making Community a Principle of Personal Practice

I hear the word "inclusion" and accept that it moves us closer to embracing people with disabilities. Inclusion, however, should not only live in policy by mandate in schools or workplaces. Rather, it should lead as a principle of personal practice and understanding in order for it to spur holistic social change through a true cultural shift. Inclusion must occur across all levels of thought and human contribution. It will be present when we no longer have to identify it; it will just be the case. In other words, my sister should never feel that she is part of something because someone felt sorry for her. Instead, it will be because she is quintessential to the health of a community.

The existence of disability as an identity and the tension it elicits shows us how much our typical world takes for granted. It reveals the limits of our views on culture, creativity, success, biodiversity, and multiple ways of being. It exposes flaws in our personal psychologies. If we recognize that our own perspectives are limited or *disabled*, then we can begin to discover new approaches to living that are contained in the untapped human potential kept within the diverse thoughts and experiences of people we call "disabled." Their perspectives will guide us toward social progress, social justice, and the redesign of community that is sustainably inclusive.

Different thinking is where progress and invention and discoveries lie.– Temple Grandin

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