

Encountering Disability

*“Disability is everywhere once you start noticing it.”
-Rosemarie Garland Thompson*

Clapping

When I was a baby, my dad thought I might be deaf. For several weeks during my first year of life, he would sneak up behind me and clap his hands right behind my head, while looking for some sign of a response or a reaction. I guess at some point I started responding because eventually my dad stopped clapping. This was just one of the many tales my parents shared with me later in life about having twins and becoming parents for the first time.

Although I can't remember this happening, I've wondered more and more about it as the years have gone by. I wonder what was going through my parents' heads and what my dad's intent was when he started the clapping. Were they scared that I was deaf? Disappointed maybe? Or did they just want to know? Were they simply looking for information? Or were they trying to prove that I was “normal”? I wonder now how they would have reacted if they had found out that I was indeed deaf.

Now I know that being deaf could have meant being Deaf, but I doubt that my parents knew that at the time. I doubt that they understood the rich culture that deafness could have drawn me into. I don't think that at the time they considered the potential worth in a deaf life, so I ask myself: if I could go back to that early moment, what would I tell them? I would tell them that Deafness can be beautiful and that some people are choosing to have deaf babies over hearing babies. I would explain that hearing is not better than deaf but just different, and it comes with a valuable identity and culture. As Dirksen and Bauman write in their piece *Designing Deaf*

Babies and the Question of Disability, “To begin to grasp the worth of living a Deaf life is to begin the reworking of the language of disability and our entire moral perspective. Such a reworking may lead toward a more dynamic intersection between disability and culture, in which those like Winterson can see that it is not a simple fact that being hearing is better than being deaf.” If I could go back in time, I would ask my parents to help rework the language of disability, and to appreciate having a Deaf baby.

Wheels

I remember my mother driving my sister and I to preschool day after day during our toddler years. Sometimes it was hard to find a parking space. We would stare out the window and try to help her find an empty spot. Some of the spaces had big blue squares in them, but when I pointed those out to my mother, she would tell me that they were handicapped spaces. I didn't know what this meant, so she explained that they were for people who used wheelchairs to get around. I imagined riding around on a chair with wheels and it sounded like great fun.

I wonder what the world would be like if everyone could go back to that moment when navigating the world on a chair with wheels simply sounds like pure fun. My preschool mind had no idea that wheelchairs and the bodies that use them are considered “abnormal.” I just accepted wheelchairs as another delightful way of moving around. As Lennard Davis writes in his introduction to *The Disability Studies Reader*, “There is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated... the “problem” is not the person with disabilities; the problem is the way that normalcy is constructed to create the “problem” of the disabled person.” (Davis 2). If everyone could go back to that childhood state of mind, perhaps our conceptions of “normal” would no longer exist, disability would be entirely

different, and wheelchairs would be just plain fun.

Puzzle Pieces

Dara was my mom's best friend growing up, and they are still best friend's today. My siblings and I grew up having dinners with Dara's family, going on outings together, and gathering for special occasions such as New Years and Chanukah. Dara's oldest son Gordy has Autism. As a child I tried to understand what this meant, but it was confusing. Gordy doesn't speak, but every time he came over we would all say hello. Every year in the spring we would put on t-shirts that said "Gordy's Gang" on the front and had a big puzzle piece on the back. We would go down to the National Mall and go on a walk together with hundreds of other people wearing different t-shirts. Somehow this was supposed to help, but I didn't quite understand how. I knew that by walking we were raising money. One year Dara's family stopped going on the walk and so did we. I wondered why.

Autism Speaks is an advocacy organization that sponsors autism research. I now understand that when we participated in the walk each year, we donated money to the organization. I haven't thought about those walks in many years, but now I've begun to wonder about the reason that we, along with Dara's family stopped attending. Autism Speaks has received a lot of criticism by activists who are upset by the way the organization seeks to cure autism, when they see Autism as an identity rather than a disease. In his article for the *New York Times*, David Perry explains, "To me, the most important criticisms come from autistic individuals, who see the charity as "eliminationist" – seeking to eliminate autistic people... Some autistic bloggers condemn the "light it up blue" campaign for "autism awareness" that takes place every April, because they want acceptance, not awareness" (Perry). Perhaps Dara and

her family stopped organizing the walk each year because they believed in changing the language from that of a disease that needs a cure, to a language of acceptance.

Numbers

In middle school, I loved math class. Numbers just made sense to my brain, and I looked up to my math teachers as role models throughout the years. In sixth grade, my math teacher was an older man whose hands wouldn't stop shaking. My parents told me it was because he had Parkinson's disease. Sometimes his handwriting on the whiteboard was hard to read, but I didn't care because I loved the algebra we were learning and the math games that he taught the class. Students would often misbehave in his class, constantly pushing the limits. It seemed like they didn't respect his authority at all. I felt sad when I saw this, and I wondered if it had something to do with his shaking hands.

Today I still feel sad that my sixth-grade math teacher had so much trouble gaining the respect of my classmates. I didn't realize it at the time, but this was a clear example of academic ableism. Jay Dolmage discusses the inaccessibility of higher education and the ways that disability is constructed as the “inverse or opposite of higher education” (Dolmage 3). He writes, “academia powerfully mandates able-bodiedness and able-mindedness, as well as other forms of social and communicative hyperability, and this demand can best be defined as ableism” (Dolmage 7). Although we were in a middle school instead of a higher-education institution, the same type of academic ableism was present: although he was one of the smartest and most caring math teachers, the students weren't respecting this teacher as an academic because of his disability. I'm glad that the administrators had gotten past their academic ableism enough to hire this teacher, but the students needed to change their attitudes. My sixth grade math class is a

reminder that I need to constantly critique my education through a disability studies lens and strive to make academic institutions more accessible for everyone.

Dancing

Sixth grade was the year when everything became awkward. As part of our Spanish class, we were learning how to Salsa dance. The teachers assigned a partner for everyone, and we would practice dancing a few times a week. At the end, there was going to be a performance. Although this sounds a lot more fun than sitting in a classroom all day, the middle school hallways were rampant with cooties, and putting our hands on each other's shoulders and dancing was just about the most uncomfortable situation the teachers could have forced upon us. Sixth grade was also the year that I broke my ankle at soccer practice. I had to wear a big black boot, and I hobbled around on crutches for six weeks. The timeliness of my injury could not have been more perfect – I didn't have to participate in the Salsa dance, and I didn't have to put my hands on anyone's shoulders. I sat quietly on the steps, observing my classmates' dance moves week after week. I remember the teachers looking at me sympathetically, with pity on their faces. Some of them tried to chat with me and I'm sure that they thought they were cheering me up in my "sullen" state. Little did they know that I was overjoyed to be sitting quietly and observing a middle-schooler's worst nightmare from the safety of the stairs. Little did they know that I was laughing inside at what my classmates were being put through.

My ankle injury had me only temporarily disabled, and I was out of the boot and off the crutches in about six weeks. I wasn't someone who was living with disability as part of my identity for a lifetime, yet this situation taught me what it feels like to have everyone around you stare at your crutches and look down at you with pity. I was sometimes sad that I couldn't play

soccer, participate in gym class, or keep up with the pace my friends were walking, but I had no use for anybody's pity. In his book, *Exile and Pride*, writer and activist, Eli Clare repeatedly says, "I am not asking for pity" (Clare 6, 7). He also describes one of his favorite shirts: "The slogan on one of my favorite T-shirts, black cotton inked with big fluorescent pink letters, one word per line, reads PISS ON PITY" (Clare 3). Instead of pity, Clare asks for acceptance of his identity. During those six weeks of sixth grade, I probably would have been better off if my teachers had accepted that I was injured and found some other way for me to contribute to the Salsa dance. Perhaps I could have designed programs or costumes, or controlled the music instead of sitting on the stairs, laughing at my classmates and avoiding my teachers' pitied faces.

Lines

That same year my family flew to Orlando to visit my grandmother for spring break. I always enjoyed being in Florida, at the house my mother grew up in, with the beautiful lake, the warm weather and the theme parks. One day my family decided to go to Disney's Epcot. I was still on crutches, so navigating the hoards of Mickey-Mouse-eared tourists was going to be difficult. My parents had me use one of the wheelchairs provided by the park and they took turns pushing me around. This meant that we waited in a separate line for every ride, and there was almost never a wait. We waited for 5 minutes to get on rides that had a 3-hour line. My siblings were delighted. I was frustrated. I felt bad that my parents had to push me around all day. I felt like people kept looking at me, and I wondered if they were annoyed that we were skipping the lines. Perhaps my ankle was broken, but my patience was intact.

Maybe I should have been grateful that there was a way for me to access the rides while I had a broken ankle, allowing me to still come to the theme park with my family, but instead I felt

singled-out and given unnecessary special treatment. Years later, my explanation for that feeling was that accessing the rides through shorter lines lacked any sort of access intimacy for me at the time. In her blog, disability activist Mia Mingus describes access intimacy: “Access intimacy is not just the action of access or “helping” someone. We have all experienced access that has left us feeling like a burden, violated or just plain shitty. Many of us have experienced obligatory access where there is no intimacy, just a stoic counting down of the seconds until it is over. This is not access intimacy” (Mingus). I certainly don’t know what it feels like to be permanently disabled, but in that moment I found out what it felt like to be a burden.

Inspiration

My middle school was not known for our athletics. Most of us were rather small, nerdy teenagers who seemed extraordinarily lacking in hand-eye coordination and athletic strength. But we were all hard workers, and in eighth grade, everything fell into place, so that our soccer team rarely lost. We had an unstoppable defense, a quick midfield and powerful attack. One fall afternoon, we were playing against a neighboring school in a very evenly matched game. The other team was talented, and could easily match our team’s success. Their power was guided by a talented player who led her team with determination and aggression towards the goal. It was difficult not to notice that this player only had one arm, but she barely seemed to notice at all. When she took a throw-in, she could throw the ball further than any player on her team, and she could steal the ball from the best of my team’s players and move gracefully towards goal. I don’t remember the outcome of that game, but I do remember what happened afterwards. The parent spectators for our team could not stop talking about “the girl with one arm.”

“She was amazing!” someone exclaimed.

“So inspiring!” chimed in another.

“Imagine having one arm and being that good of a player. She must have worked really hard.” And just like that, even though she was on the opposing team, she became a nameless icon for our fan-base.

I wonder how that player would have reacted if she had heard the comments from the parents on our team. Would she have been angry to be seen as the “supercrip” or the object of their inspiration? In her Ted Talk, activist Stella Young argues that “We’ve been sold this lie that disability makes you exceptional, and it honestly doesn’t... I want to live in a world where we value genuine achievement for disabled people” (Young). The parents on the sidelines of that soccer game were using that player for what Young calls “inspiration porn” – they were objectifying her disability for their own inspiration. They should have been noticing her achievements as a genuinely talented soccer player and not as an exceptional as a result of her disability.

Hearts

One of my best friends from my hometown wore a heart-shaped charm on a bracelet that she never took off. When she was four years old she had a heart transplant. As long as I’ve known her, she has travelled to Pittsburg each year for a “heart checkup” where the best of doctors make sure that her body isn’t rejecting her heart. I remember noticing how cautious she was sometimes. She would never share food or drinks with anyone, and if she had even the slightest tingle in her throat, she would stay home from school. This was because she will always take immunosuppressant drugs – drugs that reduce the strength of her immune system, so that her body doesn’t reject her heart. Although it seems like a hassle, Allie has no choice, and she finds a lot of joy in the transplant world. She celebrates her heart anniversary each year, and

even met the family whose son she got her heart from. She travels to compete in the Transplant Games every year where she meets thousands of others who have had organ transplants.

When I turned 16, I started learning how to drive. Getting behind the wheel was a scary thing, and there was a lot of responsibility that came with it. After months of practice, I finally got my drivers license. I excitedly signed up to be an organ donor, something I knew that my friend spent many long hours advocating for. When my license came in the mail, it had a shiny red heart in the corner. I showed it to Allie, who smiled.

I am still friends with Allie today, and she knows exactly how to be disabled. Yes, her transplant has made life for her and her family difficult at times, but through her transplant she has found an identity, culture, and community that she will carry with her for her entire life. As Rosemarie Garland Thompson writes, “Becoming disabled means moving from isolation to community, from ignorance to knowledge about who we are, from exclusion to access, and from shame to pride (Thompson). As I remember the heart shaped charm dangling from my friend Allie’s wrist, I realize that she has a lot of pride in her identity as a transplant recipient – she has genuinely “become disabled.”

Lab

At the end of my sophomore year of college, I declared a chemistry major. Science was something that was endlessly new and exciting to me, and each day in the lab felt like a new adventure. Over that summer I remained on campus and did research in a chemistry lab. The project I was working on involved designing syntheses for a series of target molecules that had shown potential against the devastating malaria parasite. I remember thinking that the work I was doing felt so real and important. I was helping to develop treatments and cures for a terrible

disease. I moved effortlessly around the lab, day after day, mixing chemicals together, analyzing data, and trying new methods. I loved chemistry more than ever before.

As college student who thinks about science every day of my life, I've begun to question the way I see disease, disability, and cure. Many disabled people who have come to find pride in their disabilities feel that the concept of "cure" contradicts their sense of pride. Cure attempts to eliminate their identity. For example, Ben Mattlin wrote an opinion piece for *The New York Times*, discussing his spinal muscular atrophy and his thoughts about curing it. He feels that the drug, "while giving hope, and perhaps a stronger and longer life, to some, may also release a torrent of self-doubt, of pent-up insecurity about our inexorable dependence and emaciated bodies. In some ways, it could make it harder for many of us to live with this type of disability" (Mattlin). When I think about the lab work I did last summer, I ask myself where I should draw the line between harmful diseases that should be cured and disabilities that should be accepted as personal identity. I've realized that there is no clear line. This is a question I need to keep asking myself wherever my love for science takes me.

Runners

Running is hard. Racing is harder. As a runner, day after day, I push my body to its physical limits, running in circles to try to beat numbers on a clock. Most of the time my body protests, and I spend each day at practice training my mind to say "yes" when my body says "no." Because of the demands track athletes place on their bodies day in and day out, a few of my teammates are injured at any given time. Earlier this year, my coach was holding time trials on the indoor track. As he usually does before a team event, he sent out an email explaining the logistics of the day. He needed the people who were injured to help with timing the events. In his

email, he wrote that “the lame” would help with the timing. This language made most of the team unhappy.

One of my teammates quickly emailed him back, telling him that the term was wrong, and asking him not to use it again in the future. He sent out a follow up email to the entire team, writing “I was corrected for using the term “lame” in my last e-mail, and I am sorry if I offended anyone. It was meant to be a joke and not in the context of demeaning anyone. Again, I am sorry and stand corrected.” This made me realize that in a sport where we ask our bodies to do so much, there is often a lot of judgment surrounding bodies – judgment about what we put into them, about what we can and cannot force them to do, and about how each body is built. Nevertheless, my life as a runner has also taught me to appreciate my own body for all that it can do.

Every human body is different. Everyone can push their bodies in some way or another. Everyone should love their body for what it can do. Disability really is all around us once we notice it. I hope that in reflecting on encounters with disability we can all learn something about disability justice, and about identity and culture. I hope we can all learn how to critique and change the inaccessible world in which we live rather than the people who live in it because we will all encounter disability someday. We will encounter it in strangers, in the people we care about, in the places we love, and at some point or another, in ourselves.

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