I Am Here

How did I come to be an advocate for individuals with disabilities of any kind? Well, the answer lies in a story that has its origins at the end of 2002, when I was four years old. This was the year that my mother was diagnosed with a terminal form of lung cancer. Even at age twentyone, I have not learned the exact medical name for her specific cancer, but what I do know is that there were no known survivors at the time. I know if I knew the name, I would research it so much that I would surely convince myself I was going to expire as well. When she was diagnosed, they gave her less than a year, since she was already at stage four. Her only symptoms were a quiet cough every twenty minutes and extreme fatigue, but with two small children, I think she must have always been fatigued and didn't think much of it. My sister was always the good kid: she read books and stayed quiet. Then there's me: if I was ever quiet, it meant I was up to something. Whether it was coloring my dog completely green with a Sharpie, putting rocks in the toilet to see if they floated, or cutting my hair off with old, rusty scissors, I kept that woman on her toes. Her symptoms were simply hiding behind motherhood.

Along with raising two kids, my mother ran a dog rescue group called Another

Chance for English Setters (ACES), which she had been in charge of for about ten years. I grew
up on a five-acre farm in Waynesboro, Virginia, where everyone knew us as "those people with
all the misfit animals." My mom even ordered a hand-lettered sign that said "Strider Barn" on it.

She hung it right where the school bus picked my sister and me up every morning, directly
beside our mailbox that had pictures of dogs on it—as if she was asking for every stray animal to
come to our home. On our farm, we had sixteen rambunctious dogs of our own, from a petite

Chinese Crested named Timmy to a bulky hulky lab named Jake, with everything in between.

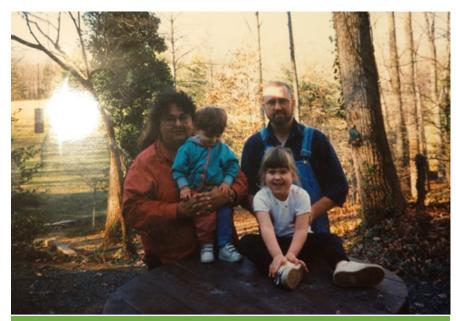
We also had donkeys, chickens, goats, a pot-bellied pig named Fatty, turkeys, birds, and every

neighborhood cat that my sister and I could scrummage into our home using only the finest of wet cat food (sorry dad.) It was one hell of a childhood. I mean, what kid wouldn't want an entire farm of sweet rescue animals to play with every day? One birthday, my mother even bought me a

huge dog crate filled with baby chickens to raise.

Another year, for show-ntell, after all the other kids showed us their best dollies and dinosaur toys,

I was disheartened because my scattered child brain forgot to bring something. My teacher rounded us all up and



My mother, father, sister, and me in 2001 when I was three years old, before she was diagnosed with cancer. My pants are the best, and I still wear the shirt my mother is wearing all the time.

brought us outside; of course, my mother was there so proud, sitting in a small pen with one of our turkeys! Needless to say, I won show-n-tell that day.

Now, like I said, they only gave my mother one year to live once she was diagnosed. I didn't understand exactly what that meant, for death is a confusing thing. But my family insisted we make the best of those last months. I was going into first grade, a time where you learn to write your letters, do basic math, and sit in a chair for an absurd amount of time. I was not too keen on that. I never wanted to sit still, and who the hell wanted to learn to count? I guess my teachers felt bad for me, since for the rest of my K–12 life they would put "Special instructions: mother died on 8/5/2005 from cancer" on my report cards and class schedules so they all knew

to, perhaps, tread lightly. They decided at that time that my education wasn't that important, that it was best that I go home and be with my family since time was precious, and damn right it was. So that's what I did. I missed a lot of school that year and drove around with my mom to all her favorite stores, since now she had a shiny blue pass with a stick figure in a wheelchair so we could get the BEST parking spots. We would talk forever about what you're supposed to do in life and what you shouldn't do, or should do but don't tell your dad you did (again, sorry dad). This went on for about three months, until her hospital appointments got more frequent, and her exhaustion skyrocketed. We could only sit in bed and watch M*A*S*H until we passed out.

Her more frequent hospital visits, unbeknownst to me, were her beginning chemo. I know chemo still is not great even with more modern medicine, but 2002 chemo on a cancer that had not a single survivor was a totally different ballgame. I spent a lot of time in the hospital, which was kind of cool. I knew all the nurses and they'd slip me pudding cups, and my dad's entire side of the family were doctors at UVA, so at least I wasn't alone. Being at a hospital meant I was missing more and more school, but luckily for me it was almost summer, and the school decided to let me go on to second grade come August. My mom didn't want to do much, but one day she invited me to go get our hair done together. I hated haircuts because that meant my hair had to be brushed, which it probably hadn't been since my last haircut. But I had to be a good sport. I was ready to go through an entire bottle of detangler and hear the ladies whisper back and forth things like "Does this kid live in a barn?" and "Did a bird build this nest?" After about an hour, they finish with my hair, and I'm grumpy about it.

My reward, instead of a lollipop or ice cream, was my mom handing me clippers and telling me it was time to shave her hair off. She had the most beautiful curly black hair, but I hadn't been close enough recently to notice all the bald spots in her hair and how frail it was. At

the time I didn't understand that socially, women were conditioned to have long hair or whatever, so I was excited to do this! I thought it would look so cool! Maybe a mohawk, could we dye it green? Maybe purple, her favorite color? That didn't fly, but I still got to shave it all the way down and then we picked out wigs, and lots of them. It was so neat—she could be whoever she wanted with her new wigs, and I was enamored as I secretly tried them on and strutted around the house.

Three days later, my mom told me that things would change a little bit. They had found the tumor, and doctors were convinced that they could remove it during surgery. It was going to take three days at the hospital for recovery, which I was excited about because that's a lot of time for sneaking in pudding cups. They got her dressed in a blue gown from head to toe and she goes back, as brave as always, for thirteen doctors to open her up. Hours pass. I take naps and talk to the patients in the room beside ours about all the stuffed animals that I brought with me. Clocks move very slow during this time, but the main doctor finally reappears. Well, things didn't go as planned. I'm not good at medical jargon, but what my dad told me was that the doctors cut into her tumor when they tried to remove it, allowing the cancer cells to rush through her bloodstream. The cancer was originally only in her lungs, but at her appointment two weeks later, her CT scans showed cancer cells spreading into her hips, throat, brain, and left foot. I was told there would be another surgery soon, a sentence that got I got pretty familiar with.

So another summer comes to an end, and it's time for school to start. I was going into second grade, but my mother needed another major surgery. To say the least, school wasn't on my agenda. This surgery was to address her breathing issues, as a tumor had grown around her trachea, and they needed to remove it. It seems simple, but this meant they needed to take out her larynx. After that surgery I would never hear her voice again, so I talked and talked her ear off

through the hours of prep, as I always did. Normally when she came back from a surgery it was no big deal, but this time she came back and there was a hole in the center of her throat, about an inch and a half wide. She couldn't speak, eat, or drink normally. There were a lot of tubes, and, at the time, I thought it was really neat. I had to help her to eat and drink, clean the incision areas, and tell the nurses when she was uncomfortable or needed something, which I was very happy to do.

But an issue arose. I hadn't been at school, so I didn't know how to read and could hardly write. The only way my mother could talk to us was through writing, and she could only get our attention by ringing a cowbell, a noise that I became very used to hearing. She had a device, an electrolarynx, or as I called it, the robot voice maker, but it was too painful for her to use most days. I learned to read lips very well, mostly when she was angry because it was terrifying to see a woman say a million words with just her eyes and lips. I would have rather been yelled at, and I think my dad agrees. But anyways, here's the last photo of my mother and me together at



The last photo of my mother and me at my seventh birthday in July, 2005. She wore a wig and covered up her neck.

my seventh birthday in July of 2005.

Here is my mother: basically bedridden twenty-four seven, unable to eat or drink by herself very well, with a hole in her throat, and bald. A badass, if I say so myself.

Let me repeat: my mother was a badass. She was still working in the rescue, finding homes for hundreds of dogs while she was sick, and dealing with her own animals, and yes, that includes my sister and me. My dad worked a lot because cancer is extremely expensive, so he wasn't around much. Things calmed down a little bit during her last few months, as my mother did not have many more surgeries, and the number of hospital visits dwindled. It was almost 2004, and she had lived longer than any of the doctors had predicted. At that time, I didn't understand why the doctors were so attentive; I always just assumed she was superhuman and that no sickness could take her down. One day when she was walking to the bathroom after chemo, she fell, and I couldn't help her get up. She was stuck on the floor in her bedroom, and I sat there with her and told her that if she was ever going to die, she couldn't die yet, please not today.

Years later, I found that my mother wrote in her journal about how my sister and I pushed her to always keep fighting. Although my mom was a fighter, some days were better than others, and when she was feeling up to it, she would go out and do whatever she could with my sister and me. One morning, my elementary school had an event for "Pancakes with Parents," where families can come and eat breakfast with their kids. My mom and dad happily came, and I was so proud that I told all of my friends, although I didn't have many because I was never at school. When she walked in, trying to be as energetic as she could, my friends kept asking me questions: "What's wrong with her?" and "Why doesn't she have hair?" and "Isn't that hole in her neck disgusting?" I had never thought about any of these questions. That was just who my mom was: we rolled with the punches and made the best of an extremely shitty situation every day.

A year or so later, I was about to turn seven, and my mom's prognosis was not very good. She didn't leave her bed for two months straight and lost so much weight. You see, my mom had seven kids, and only two of us lived. My mother was one of those women who wanted nothing more than to be a mom, to watch her children grow and teach them whatever she had to offer in any given situation. Her first child was terminated at seven months, due to complications that left the child growing on the side of her vaginal wall. Doctors pushed her through a round of extreme radiation that terminated the child before my mother could bleed out on the table. Doctors think that round of radiation might have been the root of her cancer, but at the time it was radiation or death. My mother then had my sister, the only easy birth. Then triplets. They were all born prematurely and only lived for three days. Doctors feared if they would have survived, they would have dealt with lifelong complications, since their brains were all severely underdeveloped. Then came twins, of which I was one. My brother did not survive, and I caused my mother another trip way too close to death's doorstep. As I said before, I always kept that woman on her toes. With this, she gained a lot of weight, and she never wanted to lose it: she was happy because it was from her children, and she loved what she had worked for.

Now, she had started to lose an alarming amount of weight; her skin fell upon her bones like an old sheet at the end of a bed. What she had worked so hard for was fading away more and more every day. We all knew she didn't have much longer, so my family decided to throw me the best birthday party ever. Everyone came, except for the ones who stopped talking to my mother once they found out she was sick. It seems like a lot of people preferred to pity her or ignore her once they found out she wouldn't survive. I think many people shield themselves from situations that challenge them, acting like it's not happening by not facing the situation, something that is common with a lot of disabilities. Nonetheless, we had candy, cake, the best

snacks, and a huge piñata, and all my pets were dressed up in their best garb by yours truly. It was a day just for me, and I'm pretty sure the world stopped spinning for at least a couple hours. It was a day I will never forget. After that, my mother never got out of bed again, and I never heard her cowbell ring again. She died peacefully with all of us around her a month later. It was another day I'll never forget, but I don't dwell on that one, much, anymore.

So you ask about disabilities. The first time it really came home for me was when those kids asked all those questions about my mother. That's when I first realized, without knowing the real-life implications at that time, that people don't understand anyone with a disability and that they seem to fear what they don't understand. I left school that day with my family and refused to go back for the rest of the week. The second time was when I went back to school at the end of my second-grade year. I hadn't been at school, so I didn't know how to read and could hardly write, and understandably, they held me back to redo that year. I didn't know how to write, spell, nor understand basic math skills, and I was seven years old. Once the dust settled and my motherless wound had healed a bit, they decided to put me in "special education" classes to get the "special attention" that I needed. In these classes I was treated like a toddler, talked down to, and completely misunderstood. I wasn't dumb or whatever they thought I was; I was capable of doing these things. I just needed to be taught like everyone else. These classes were separated from my peers, one-on-one, like I was going to rub my stupidity off on them or something. It was as if what I had endured had made me a weaker human being. I'm pretty sure I even started to believe that it did.

Sadly, I believe these feelings radiate in classrooms all around the country. Children who can't abide by the "normal" classroom rules are singled out by teachers who most likely haven't taken classes on disabilities and if they have, it was most likely a special education class that in

the name itself creates two categories: this child is either normal or they are different. After my

second-grade year, I
moved to West
Virginia to my family's
farm. I think my dad
needed to get away. He
was trying to figure out
how to manage a life
with two confused and
grieving children while
working ten-hour days
to keep us afloat. I



My father, sister, and me with our first Chinese Crested— Timmy—in 2006 in Highland County, West Virginia, one year after my mother passed.

spent a lot of time at the babysitters, who could only do so much to comfort us. We sold all our animals except for two dogs, three cats, four donkeys, and three goats.

Upon entering my new school system, teachers read my special instructions note, and I was put into special education classes again. There was no evaluation or questioning. I was disgruntled and thought I would never achieve. But was it me or was it the school system structure? There was no need for my teachers to separate me from my peers, to lower their expectations, to think that singling me out would push me to become like all the "normal" students. Where had the system gone wrong, and why did these teachers think that they knew what was best for me, without ever asking for my opinion?

Elementary school finally finished, and nothing had changed. I was in and out of different special education classes, and I was treated as if they were just getting me through the K-12

system to say they did, not thinking that I could amount to much. Finally, I was on to middle school. Once I was immersed with new teachers, it was as if I magically became "smart." The teachers didn't know my background, and I started embracing my special instructions. Who cares about my past? I'm here now! I was regarded as any other student, and before I knew it, I was in honors classes and in high school, all AP courses. I started college during my senior year at Shepherd University; it was as if I had done a complete turnaround.

I lived in a small town, so when it came to senior graduations, almost every teacher from elementary school to high school came to show their support. I began to walk across the stage, wobbling in heels that I wore no more than once a year, embarrassed because they pronounced my name wrong, but ecstatic that I was finally here and going to JMU in the fall. I looked out in the seats, and there was the teacher who taught me all the "special education," and she looked strangely proud of me. It was at that moment that I wished my mother could be there, to see how much I had grown and to know the person I was hoping to be. I wondered how different things would be if she never passed: I figured I would be better off, that I would have been smarter throughout life. But why do I feel this way?

When I got into JMU, I was a biology major. I do not know why. I hate math, and math hates me, but unfortunately it lies in bed with biology. After my first exam, I knew I was in the wrong major. I tried psychology, but who hasn't? By my sophomore year, I knew I needed to find what clicked with me. One night my roommate who, bless her heart, snored like a freight train, was doing what she did best, and I just couldn't sleep. I decided to pick up the JMU catalogue and look around at what majors JMU offered. After four hours, I had read absolutely every major and minor. I told myself I would put a bookmark on the majors I was interested in, hoping to help narrow them down. Luckily, I'm picky and had only one bookmarked: Justice

Studies. As class enrollment came around, I clicked my laptop keys furiously, making sure I got into JUST 200: Introduction to Justice Studies. Disability Studies stuck with me as we read about everything this major had to offer. I even went and researched external information, which is something that no other major had enticed me to do.

So here I am. This is why I am taking Disability and Justice. People with disabilities and the ones who love them dearly: that is what led me here. Society is unsure and sometimes unwilling to confront human diversity; my friends didn't need to ask about my mother, and my teachers didn't need to give me special treatment, but it was what they were accustomed to do. I want to be able to teach people to be open, to try and understand what people with disabilities go through and what we can do to build a better world for everyone. Disabilities do not just come from within a person. They are also created and stigmatized by a world that was not created with them in mind. A world that never asks their opinion. A world that acts like everyone is the same, and if you don't fit this mold, it's your fault. Everyone will experience a time in which they are disabled, so the time is now to understand how to combat criticism and misunderstanding. My mother never got to tell her story, so I will live my life studying the ways to best portray what it must have felt like to be in her shoes.

I am here for my mother who experienced the hardships of cancer through absurd medical bills to people staring at the hole in her throat, my sister who deals with bipolar disorder, my pop-pop who lives with dementia, my grandmother whose frail body is giving out at the age of ninety-three, my dad who has horrible knees, and the millions of others that live in this diverse group. I am here to speak about taboo subjects such as debilitating reproductive disabilities in women, to let everyone know their voice deserves to be heard, and that change must happen in terms of inclusion and accessibility. I am here to encourage teachers to challenge their training

and to try and gain insights on what they can do to help *every* student. I am here to challenge individuals' perceptions of people with disabilities and to remind them that we will all become disabled at one point in our lives, so why not start advocating for change now? I am here to be a pissed off advocate who demands change and who cannot and will not be silenced. I am here for younger me and future me. I am here.