Unbound

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Abstract

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Creative Writing & Poetics

In the process of writing this memoir, I engaged with the following questions:

1. How did the perceptions of family members, friends, and teachers, shape my earliest self-perceptions? 2. How did these points of view help or hinder my development? 3. What has made me want not to resign myself to my limitations? 4. Where does the stigma surrounding disability come from and why? 5. What lives, real or fictional, are in dialogue with my experience of disability and sense of self?

Also, this memoir is a follow-up piece to my talk at TEDx Everett where I shared my life's story. It was a great experience, but I was unsatisfied with the wording I used to talk about myself, and the language of disability and self-representation. Then the language of disability became a main concern to address in my memoir.

I decided to go to the roots of my disability experience. I found that it was closely associated with the negative memory of being singled out as "disabled" (in second grade) when I was introduced to the book *Helen Keller* by Margaret Davidson. This is a moment that I describe in Part 1 of my memoir that left me with a sense that the most important thing about Keller was her disability. The only way I was going to get past my negative impression of her was to read her books and I read all of them.

My disability is something I often ignored, not to be frustrated by my body's inability to function as it should. I acknowledge that I have a disability, I use a wheelchair to move around, and I need technology to live my life as I want to. My technological devices are part of the way I move through the world. However, I consider these devices extensions of myself rather than as integral parts of my identity.

My identity as a person who happens to have a disability has changed over the years. In Part 4 of my memoir, I discuss the social aspects that come with having a disability, such as people's misconceptions of people with disabilities, discrimination, and ableism. To talk about these social issues, I explored disability theory culled from different sources, including videos like *Aimee Mullins on Today Show, The Aesthetics of Prosthetics: Aimee Mullins, Changing my legs—and my mindset, The opportunity of adversity,* and *My 12 pairs of legs.* These videos allowed me to understand the relationship that exists among the individual with a disability, the technology she/he uses to navigate in the world, and society.

In this memoir I have sought to find a new language with which to talk about disability, and this search for language led me to ask questions about the meanings and connotations of words and word orders. For example, I already knew about my preference for describing myself in terms of person-first language such as “I happen to have a disability,” but I didn’t know that some individuals liked to use disability-first language like “I am a disabled person.” The different ways of self-identification showed me that the language of disability can vary from person to person.

There is no fixed language for disability and disability identity. Each individual develops her or his identity and language. To further my understanding of disability-identity development, over the past year I joined a primarily online support group called Here and Now—Washington Paralysis Network. When I first joined the group, I asked the members what was the best way I could identify as a person with a disability. A member said that I should stop worrying about how to identify myself and just do it and try many ways and see what stuck. This answer lead me to understand that in the community of people with disabilities there is a spectrum of identities that one can explore and be at any one time. In my early life, for instance, I was labeled as “disabled” by other people, but now I define myself as a “person who happens to have a disability.” For now I am comfortable with this identity.

In my memoir, I am telling a story about understanding myself as a person who happens to have a disability, and at the same time I am showing the reader contemporary arguments surrounding disability identity development. To do this I watched several videos about the topic that I have listed in the bibliography. Although I haven’t referenced them in my memoir directly, these videos have provided me with many perspectives about disability. By watching them, I came to understand that whatever language people with disabilities use to talk about themselves, we all aim to do the same: present ourselves on our own terms. We aim to let our voices be heard and be appreciated for who we are.

I hope that I have been able to narrate my life experience as a person who happens to have a disability, as a person who faces ableism, as a person who uses technology to augment her capacity, and as a person who is finding her way in society. I am proud to say that I am one voice among many others that seek to break the silence about disability. I feel that my memoir has freed me from the fear of writing about my disability experience. *Unbound* is a narrative about my disability experience, and it has also given me power over my story, something I didn't have before I wrote it.

Unbound

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Poetry is man’s rebellion against being what he is.

— James Branch Cabell

Tomorrow and tomorrow and tomorrow I want to endure
Desiring this man’s art that is yours
Time does waste me, days do chase me
The flesh goes pasty and still I ain’t found greatness
What meat and did they feed this Caesar
I want to taste the milk even if it is gall
Your mortal coil sprang back unbounded

—Akala, “This Gives Life to Thee”

According to society I am disabled
BUT
I am in constant rebellion against labels

—Cristina Cortez

PART I

Formation

Picture this: a baby girl has just been born at the twenty-six week mark of her mother's pregnancy, by C-section. She is shown to her father, then to her mother, and taken to the Neonatal Intensive Care Unit, NICU. Her lungs are underdeveloped and she cannot breathe. It's uncertain whether she will survive the night, but she does.

A year passes, but she is not developing as she should.

The doctor gives the diagnosis: Cerebral Palsy.

Being diagnosed with Cerebral Palsy has shaped my life, but it doesn't define me. Occasionally people ask me, what happened to you? Or, why are you in a wheelchair?

I have come up with different answers: BECAUSE I was born prematurely at twenty-six weeks of my mother's pregnancy. BECAUSE I have Cerebral Palsy. BECAUSE I can't walk. Or I was born this way. None of these answers explain my situation, but they are the *best* I have.

My body is a collection of cells that divide to form the organs, the muscles, the skeleton, and the skin. My body also carries my brain around. My brain is the command center that sends out signals via synapses to tell my body what to do. For most people this process of communication is seamless; there is no delay between a command and its execution. But in my case some of these signals are misfired and mixed-up. My body ceases to be an eloquent machine and becomes a sputtering collection of parts, housing my inner self. My body is a shell. I seek to live a life where physical limitations play no part. My body might be in a "cage," but my mind is unfettered.

At home I was never singled out, treated as disabled, special needs, or different. My parents and my brother cared for me with love. To my family, my Cerebral Palsy was just a fact. It was built-in. They learned how to manage and deal with it.

I am not saying that my parents and my brother didn’t have “why us?” moments. I am sure they faced denial. But they didn’t let a diagnosis get in their way of seeing me as their daughter and sister.

My family wanted me and accepted me as I was. Doctors suggested to them that I could benefit from therapy and I received it. I was always playing with toys to develop my fine motor skills, surrounded by songs and stories.

When I was three years old I went to a school for kids with physical disabilities and stayed there until second grade. The principal of my school eventually introduced my mother to the concept of mainstream education. My parents then found out it was an option for me, and they explored the possibility of making the transition.

In Pre-K I knew my colors, shapes, numbers, and letters. I was able to read three-letter words. But at the end of those three years at that school, I was not reading as I should have been for a first grader.

Before second grade my life was secure. Everything was adapted for my use and my needs. The transition into mainstream education was not easy. Much of the year was about leveling the playing field for my academic performance. All the adjustments in my new school were made so I could succeed in class along with the other students. I was part of the inclusive education initiative that stipulates children with special needs should learn the same curriculum with students who don’t have disabilities.

The biggest challenge of this transition was how I would cope and keep up with the other students. My fine and gross motor skills were underdeveloped. I couldn’t hold a pencil, or a book, or move on my own, or write or read independently. That is when technology became part of my life.

Finding the right technology was a fight. This technology ranged from bifocals to more importantly my first wheelchair.

2000

was the year when the eyepatch was taken off
was the year of the pink, thin-framed, bifocal glasses
was the year of learning to use a #2 pencil with a pink
        gripper made of putty
        to steady a shaky hand
was the year of the first attempt at penmanship—chicken-scratch
was the year of having no desk
        one was built—at the back of the classroom
        I was row number six: party of one
was the year of the first label-maker-typewriter, Brother PT-M95. Yes!
was the year of the first desktop PC, YES!
was the year of the first black electric wheelchair with
        a metal on/off switch.
I was free, free to roam, free to be me.
I was the only 2nd grader in the WHOLE school with a *car*!

My electric power wheelchair gave me a new way of life. It was a sturdy frame for my spastic and unbalanced body. The wheelchair had everything to keep me in place.

For the first time in my life I was free to move where I wanted to on my own. But before I could be free to get around with my wheelchair in school, I had to take my “driver’s test.”

I was practicing my driving on the white floors of the empty hallways of my school. There was a set of orange cones in rows so I could learn how to drive in between them, and another set was aligned so I could move in a zigzag motion.

My black engine started, and I bumped into all the cones.

Over the next few days I drove through the cones again and again, until I passed the test.

My teaching assistant (TA) gave me a laminated license that said:

Cristina Cortez,

Driver License

80 Lipton Lane

Williston Park NY 11596

Expiration date: NEVER

The expiration date was written emphatically, with capital letters and multiple colors. I spun around in victory.

Having an electric power wheelchair made my classmates curious, and they wanted to walk next to me because it was cool. It was like when you have a friendly dog—everyone wants to get to know you. My electric wheelchair made me more approachable.

For my classmates walking with me was a perk. Halfway down the hallway they would jump on the back of the chair and hitch a ride at top speed (7 mph). (When no hall monitors were around.) Because of the high demand of the students to walk with me the teacher created a raffle. She brought to the classroom a black hat with all the names of my classmates inside, and at the beginning of every class one name would be drawn from the hat and that student would be my walking partner for the day.

These happy interactions were the bright moments that I enjoyed in the sometimes dark experience I had of being the only one with a visible disability in class. I wasn't aware of and didn't know the meaning and the implications of having a disability.

Being different didn't hurt. But the dividing line between ability and disability was drawn by someone else, and that was hard to take.

One day in class the teacher said, "Today we are going to be reading a new book." She held it up with both hands and with her pink nail-polished nails lightly tapped the brand new cover. The new book was *Helen Keller,* by Margaret Davidson.

"Who was she?" One of the students asked.

"She was someone who couldn't see, hear, or speak. She did a lot for disabled people."

Another student asked, "What does *disabled* mean?"

"It means that someone can't see, hear, talk, or even sometimes can't walk, like Cristina."

I was startled when I heard my name. I looked up and saw that everyone in the class had turned to look at me.

At that moment I was socially labeled as disabled. I realized that I was like *someone* else but not like *everyone* else. My ticket to freedom (my wheelchair) had been transformed into a cage that set me apart. In my imagination, my wheelchair became a big, big cat with green, vicious, and glittering eyes that growled and pawed at me. I felt like I was huddled in a corner, hoping the big cat would swallow me.

The “can’t list” started to grow: I can’t do math, I can’t do science, and I can’t do geography…I can’t walk….

After a while everyone in class scrambled to get their copy of the book. I waited for my TA to bring me my copy.

The cover had a portrait in profile of Helen Keller. She was dressed in a pale yellow dress with ruffled and puffed sleeves; her hands were on an open book with white pages. I stared at the image. I was happy that I was going to read about her, but at the same time, I was sad.

The idea of myself as free because of my wheelchair was now melting. I was dismayed because I had just been told that I was *disabled*—a malfunctioning person. I was mad because I had been lumped together and compared with someone supposedly like me. But I was hopeful too because I might find a wonderful story in it, but I didn’t want the comparison between myself and someone who I didn’t even know and who wasn’t even alive.

I didn’t want to be different. I wanted to be the same as my classmates.

I wished I could walk, I wished I could run, but I didn’t know if I ever would.

My dread of reading *that* book was increased after we had finished it.

On the last day of reading the teacher told the class to flip to the back cover of the book and “see” what it was like for a blind person to read.

Under each letter of the alphabet were the Braille raised dots that corresponded to it. The teacher made us spell our names, using the dots with our eyes closed. After some encouragement, we pretended to be blind like Helen Keller and felt the bumps that would have spelled our names. I asked, and still ask myself, why did I have to pretend to be blind and play a game to understand what it is like to be a person who has a disability? I was already *disabled*, as the teacher had said.

But no disability is like another.

Pretending to have a disability when you don't have it reinforces the idea that disability is what you cannot do.

The other students already saw me as different.

To be polite, no one ever said anything about my *disability* in class. Their awareness of my difference was in their silence and in their looks.

I learned "the look." The look that later I would see in people's eyes when out in public. My classmates' curiosity slowly turned into fear.

Naturally children are curious and when they see me they ask questions like why I am in a wheelchair. Their question doesn't hurt. What makes it uncomfortable is when parents yank them away from me and say, *Don't ask her that; that's rude*. I try to intervene saying it's okay, but the damage is done. Now the child looks down or looks away. Shy, scared, and nervous to ask or approach someone who is in a wheelchair or different.

Out of that one word, *disabled,* came a lot of names which I have been called. These words are seen as common and more respectful, but they are more discriminatory. They include: differently abled, handicapped, incapacitated, slow, spastic, special, disability sufferer, disability victim, physically challenged, and bound (as in wheelchair-bound). The problem with these words is that they are often used to describe or define a person who happens to have a disability.

A person is a person no matter the skin color, the race, the gender, the sexuality, or the disability. Perhaps these labels, as I have come to understand them, should only and strictly be used in a medical context. In a social context however, these terms should be avoided since they serve as modifiers to an individual's personhood. These modifications of personhood classify an individual as other.

With the introduction to the story of Helen Keller and the-less-than delicately handled explanation of my disability, I had to adjust to my newly-ascribed social definition.

At this point, I began to deal with some of the psychological stages of my disability as outlined by the article, "The Psychological Stages of Disability" on disableworld.org. The stages are listed as shock, anxiety, bargaining, denial, mourning, depression, withdrawal, internalized anger, externalized aggression, acknowledgment, acceptance, and adjustment.

I don't remember the exact details of going through the stages, but I remember I dealt with them constantly. The moment I was labeled as *disabled* I was shocked into awareness of my pre-existent reality. This caused me to have immediate social anxiety of being physically inferior to others, and I threw myself into therapy routines. I was looking for a fix. I saw myself as other people saw me: incapable.

This moment of realization of myself as *disabled* was like being on a collision course with an out-of-control car—my emotions. I felt angry with myself because I was starting to think that I was disabled. I felt angry with teachers who said I was slow, couldn't write well by hand, or type. It was true that I couldn't do those things as other kids could. I felt that the world was closed off to me, full of impossibilities.

I remember my struggle to read *Hellen Keller*. The print was small, I couldn't see it very well, but I didn't say anything to my TA. Neither did I ask her to turn the pages. I just stared at the page I was on, pretending to read. I didn't want to admit that I couldn't read the book myself and that I needed help to read. Since I was smart enough to pass the comprehension test, I thought that by pretending I could pass as literate.

It wasn't until we read *The Lion, the Witch, and the Wardrobe*, by C. S. Lewis that I gave in to my inability to read. I began to pretend to read as I had done before, but this time my TA watched me closely and noticed that I didn't turn the page for a while and asked me, "Do you want me to turn the page for you?"

I answered, "No."

After sometime she asked again and I refused saying, "No, I'm not done with this page."

Once again she offered to help me and I had to admit that I could not read it, nor could I turn the page. At that time I was not able to read linearly, but I understood what I was reading because I caught on to key words that helped me to stitch the story together. I was caught.

With this incident, I had to admit that my disability was impeding my performance in class. My secret was out: I couldn't see well, couldn't read well, and I couldn't turn the pages.

After a few days I was reading a large xerox copy of *The Lion, the Witch, and the Wardrobe.* This way of reading was recommended for me after I took a series of tests conducted by the special education department of my school, and it was prescribed that the appropriate font and size of print for me was Times New Roman, 26 pt.

I read one sheet at a time. Each page took most of the space of my desk. I not only had a bulky wheelchair and a bulky desk, but now I had the bulky facsimile of a book.

The large print of the blown up copy was an assault on my eyes. My eyes blurred at the size of the letters, but after sometime my sight began to clear, and I was able to read. Slowly, but I could read.

I kept reading, and soon I encountered the question of the White Witch at the end of chapter three, “And what pray are you?”

This question was asked of Edmond Pevensie when he wanders into Narnia, but I felt that this question was asked of me too.

In my thoughts I answered her, “I…I don’t know.”

In the text she asked again, “BUT what are you?”

Slowly and barely finding my voice I said, “Disabled.”

After reading that part of the book, I realized how I felt about the idea of being disabled. My disability made me into an object defined by other people.

What I was was the same as who I was. My disability then became merged with my identity and I saw myself as a disabled person rather than a person who happens to have a disability.

That identity crushed my real self that had yet to emerge, but then it was the only truth that I was able to see in myself.

I believed that for so long that now it has become a scar that I have to force down to keep myself from spinning into that way of thinking again. That way of thinking had its consequences. I got bad grades to the point that I was two and a half years behind my supposed grade level.

Self-understanding was still a long way away, but in time I would learn that I had the power to define myself. My inner confidence and personal power would soon emerge and block out my negative way of thinking.

PART II

Forging an Able Mind

In elementary school, my reality was summed up in the word *disability*. The word boxed me in.

In the box of *disability* I fell into a regime of therapeutic routines and evaluations. It was a regime in which my parents and I were looking for the slightest sliver of hope that I would be somehow "fixed" or "cured." These routines sucked time out of my days and consumed me inside and out. My only thought was to work hard to make myself an able body, while at school I was slipping behind further and further in my grades; almost to the point that I got saddled with two other labels: dyslexia and learning disability.

I became immersed in a self-imposed isolation.

My "imperfections" grew. These feelings are captured in my poem "The Cement Block":

Can't do math without mistakes in each problem every time
Can't do science without getting the clouds mixed up
Can't do writing logs without grammar mistakes corrected in red ink
Can't do geography without labeling a map wrong
Can't walk, can't run, I'm stuck

I am overweight
Too many strings like Pinocchio
I can't do anything without help…always making mistakes
I am shrinking in the cracked mirror
I gain speed in the wheelchair, but I can't keep up in class

I am always using extra time

But, I watch and listen to what others do
I am on the sidelines
…keep to myself

Recess time. I watch the other kids play

I am on a cement block next to a wall,
with a putty ball in my left hand
Some times some kids start to come over and talk a bit

The recognition of myself as set apart from others brought along with it a skewed way of thinking. Under this skewed lens, every imperfection was seen as evidence that I was someone incomplete, someone that needed to be “fixed and repaired.”

I was surrounded by a collection of devices: braces for my feet, standing frame for my whole body, and clinical furniture, benches, balancing balls for therapy…

All these devices were a component of my personhood that made me whole or gave me the illusion of being whole. After years of trying to find a “solution,” through therapy and with my eyes gleaming with disappointment, I turned my back on the hope for a “fix.” There was nothing to fix.

I made the decision to leave that life behind. No more therapy. No more therapeutical devices, only my wheelchair. No more trying to fix myself.

Years later, reflecting on this phase of my life, I wrote “Hack It!”:

…my life has been an ongoing struggle for walking.
I tried therapies in different parts of the world.
Ukraine,
Poland,
Belgium,
Italy,
USA,

Conventional and non-conventional
kindling a flame of hope
…all failed

I have seen other cases of disability,
some have succeeded…
I have not.

I had blind hope…
and there is no point in struggling anymore

I made my choice of acceptance

to live with it

One by one my therapeutical devices were discarded, left to clutter in the basement. By refusing to use those devices, I unleashed a power within myself that later would allow me to embrace other realities. I would be the one in power with control over myself. I decided that nothing or no one would tell me how to live my life. I would not compromise myself to suit the image that society had of me. I wasn't going to be a "thing" to be fixed by the medical or educational community.

I would make myself again according to my own image.

I began to build my new identity by fostering a love for words. Learning became my pursuit. To bring forward my best self and have a strong foundation on which to stand throughout my life. The first blocks of my edifice were books.

I read "The Tyger," by William Blake, in fifth grade, and my teacher gave my class the assignment to find a poem that best defined each of us, and write an acrostic based on it. In "The Tyger" the strong sounds of the consonants and the repetitions sounded in my ears like a sword being forged on an anvil and being sharpened for use.

The Tyger

Tyger Tyger, burning bright,
In the forests of the night;
What immortal hand or eye,
Could frame thy fearful symmetry?
In what distant deeps or skies.
Burnt the fire of thine eyes?
On what wings dare he aspire?

What the hand, dare seize the fire?

And what shoulder, & what art,
Could twist the sinews of thy heart?
And when thy heart began to beat,
What dread hand? & what dread feet?

What the hammer? what the chain,
In what furnace was thy brain?
What the anvil? what dread grasp,
Dare its deadly terrors clasp!

When the stars threw down their spears
And water’d heaven with their tears:
Did he smile his work to see?
Did he who made the Lamb make thee?

Tyger Tyger burning bright,
In the forests of the night:
What immortal hand or eye,
Dare frame thy fearful symmetry?

The sword of my soul now lay on the supporting anvil of growing confidence. I would be stronger by edifying myself than by listening to others about what I should be. The hammer of will struck and struck again, as I repeated the poem in my mind. I had a habit of skipping the vowels and switching the placement of letters:

T g r T g r, b rn ng br ght,
 n th f r sts f th n ght;
Wh t mm rt l h nd r y ,
C   ld fr m thy f rful symm try?

 n wh t d st nt d   ps r sk s.
B rnt th f r   f th n   y s?
  n wh t w ngs d r h   sp r ?
Wh t th h nd, d r s z th f r ?

  nd wh t sh   ld r, & wh t rt,
C   ld tw st th s n ws f thy h   rt?
  nd wh n thy h   rt b g n t b   t,

Wh t dr   d h nd? & wh t dr   d f   t?

Wh t th   h mm r? wh t th   ch   n,
 n wh t furn c   w s thy br   n?
Wh t th   nv l? wh t dr   d gr sp,
D r   ts d   dly t rr rs cl sp!

Wh n th   st rs thr w d wn th   r sp   rs
  nd w t r’d h   v n w th th   r t   rs:
D d h   sm l   h s w rk t   s   ?
D d h   wh   m d   th   L mb m k   th   ?

Tyg r Tyg r b rn ng br ght,
 n th   f r sts   f th   n ght:
Wh t mm rt l h nd   r y ,
D r   fr m   thy f   rf l symm try?

Experiencing the poem in this way, I thought about the sound of the words and what they brought out in me. I began to see myself not as *disabled*, but as a burning able mind. After my immersion in the feeling of the words, I wrote my acrostic:

The Birth of the New ME

Creative

Resilient

Inquisitive

Smart

“**T**yger, tyger burning bright.”

Imagination

Nifty

Artistic

The words and books I used to build the edifice of myself were found quickly. I discovered books and authors. Each one of them was a layer inside me.

Fifth grade was a turning point in my life. I began to find myself again and left behind the wishing to fix myself by abandoning my self-pity and the view of myself as incomplete. I left formal education and went into homeschooling for self-directed learning.

Going on this new path, my parents and I became part of a home-based program called The Intensive Treatment Program (ITP) from The Institutes for the Achievement of Human Potential in Philadelphia, Pennsylvania. The program is founded on the precept that "the brain has enormous potential and that this potential could be fully realized, giving brain-injured children a chance to be whatever they wanted to be and to be and achieve the highest level of excellence they could," as said on the website.

The objective of the ITP was to allow me to achieve physical and intellectual growth. It was also designed to give me maximum stimulation and opportunity for improvement.

The physical therapy component of the program demanded high levels of physical exercise. During that time, I was able to do four-hundred laps of crawling across the wooden living and dining room floor of our cape style house. The program was round the clock. It was rigorous to the point that I had no days off. I got callouses on my hands and often got swollen knees, but no pain stopped me, I was committed to improving my physical performance while also improving my intellectual abilities. According to the program, as the body improves the mind improves because increased physical activity delivers more oxygen to the brain.

The intellectual component of the program consisted of presenting me with all school subjects at a level higher than my grade level. This meant that since I was at the age for middle school I had to learn at the high school level. No testing was required. I was just learning and not attempting to retain information to demonstrate my comprehension and competency.

Under the guidance of this approach, I went where my inclinations and interest led me. I engaged fully with literature and history. I simply enjoyed the narrative of humankind as a story. History filled me with fascination. A fascination that allowed me to discover the human chronicle contained in the nature of humankind. My engagement in science was more enjoyable, because I learned from the biographies of scientists and did science experiments, rather than from meticulous studies of terminology. However, math was a pain.

My approach to language was not through repetition, grammar, or memorization, but through the written word and films in English, Spanish, and Italian. Language, literature, history, and the rest of the Humanities vitalized me.

Gone were the tethers of the physical world and I entered into the world of the mind.

Reading was the same as inhaling air, and writing as exhaling the air I had taken in.

What follows are bits of significant encounters with the worlds of words that allowed me to reconstruct my sense of self. The authors and books I encountered became part of what I can best call a mental library of passages that inspired me to write. The following piece is a responses to some of the works I read.

“Mi ser” is a poem responding to Hans Christian Anderson’s *The Little Mermaid*, Louisa May Alcott’s *Little Women*, Isabel Allende’s *La ciudad de las bestias*, Maya Angelou’s poem “I Rise,” Marion Zimmer Bradley’s *The Fall of Atlantis*, Jorge Luis Borges’ *El Aleph*, Henry James’ *The Turn of the Screw*, Jorge Luis Borges’ “La Biblioteca”, Gabriel García Marquez’ *Cien años* *de soledad*, Gerard Martin's *Gabriel Garcia Marquez: A Life*, and William Shakespeare's *Hamlet*.

Mi ser

pain is the price
I have to pay for underworked and stiffened muscles
broken glass cuts into me—with every movement

my body doesn't measure up
but my mind is within my control
knowledge is my fuel

my castle in the air
holds my dreams
and I have the key
it's a small golden one,
with a sapphire in the center
I'll get it out of that cluttered drawer
and open the double latched door and go inside

in that world
I'll embrace my dreams

in that world

I'll unlock my future

full of possibilities

achievement will spur me on as I go, and
the more I do, the more my life will be a burst of color
and I will live in a world of my own making:
creating and acting and making it happen

nothing will work for me unless I do
I may not control all the events that happen to me, but I can decide not to
be reduced by them.
I can't walk, so I turn my back on what can't be

pain? I'll endure
I turn my back on the shame, the teasing, the low expectations,
the disappointment, and the failures that came with false hopes

I'll shove these dark memories into the black hole
of forgotten things and turn to the sun and do

I am walking on a path that is all my own
other footsteps have come before me,
their faded imprints are my foothold on this road of life
I must be firm and move forward
strengthen myself up quickly and dare to defy obstacles

life can be summed up in a moment of decision…

turning the screws of fate
that twist and turn into tortured flesh

I must move in the world as if the life I am building
is not built with stone but with sand
acting in a quick, decisive motion to set the sands of my time in place

it is not true that people stop pursuing dreams because they grow old
they grow old because they stop pursuing dreams

there is no life worth living without the pursuit of dreams
I live my life by following them and not sitting around,
while life goes on
I act and chase them down

I grab them

to dream and to achieve is the right of every individual
despite the arrows of challenges
to act is a duty to myself at a pace I uphold

There is one world with which I am identified and that world is *Frankenstein* by Mary Shelley. I was sixteen when I first read the 1831 edition. I engaged with the voice of the author. She was a young woman, bursting with the thoughts of creation. That voice yearned to bring her creation into the light, out of the darkness of her mind. This edition is preceded by a preface written by Mary Shelley that scholars contend Percy Bysshe Shelley helped her write. She gives an account of the genesis of *Frankenstein* and how she imagined herself as an author at an early age.

Shelley's life as an author began "with a castle in the air, where imagination runs rampant and vivid." She describes how her impressions of Scotland's landscapes, with the majesty of its hills and glens, were matched by the mountainous heights of her fantasies.

I felt as if she was speaking to me. My life was full of learning from books and some traveling. To Shelley and me, dreaming was a refuge and a great pleasure where we were free from the constraints of our lives—she from the quotidian duties as a daughter and me from a wheelchair-bound existence.

Looking back on this first encounter with Shelley and *Frankenstein*, I see how her fascination with Scotland was mirrored by my later fascination for Ireland. The experience of reading Shelley's account of the creation of *Frankenstein* and her early life left me feeling that I could and would pursue the life of an author. *Frankenstein* would become the wellspring that propelled my creative endeavors, spurring my need to create through writing.

Creativity gave me a way to pursue my dreams despite impediments. In dreams, I am free. And, as Langston Hughes once wrote,

> Hold fast to dreams
> For if dreams die
> Life is a broken-winged bird
> That cannot fly.

Dreams have allowed me to surpass the boundaries that life has inflicted on me. I wrote a homage to dreams in response to W. B. Yeats's "The Clothes of Heaven."

Dreams

Dreams are the clothes in which I dress my mind,
and I strengthen the luster of my dreams
with the flame of constant thought and action.

I protect my dreams from the wear and tear of daily life.
I tend them because they are woven together
with delicate threads
and I take them up
before the world
for they will be mine.

PART III

Back to School

Three years of self-directed education and homeschooling passed, and I wasn't making any significant improvement with the rehab portion of my ITP. But now I was two and a half years ahead of my grade level. My mind outran my body's ability.

Faced with this reality, I decided to go back to mainstream education for high school to see if I could achieve and maintain an outstanding performance alongside fellow students. During this period I was less concerned with my disability as a negative part of my life and instead I focused on what I could do.

Starting high school was rocky because I needed a TA, and my first one was difficult. Soon I had to request her removal.

This nerve-racking time was short. My first TA and I couldn't develop a useful system of communication and understanding. She was not skilled at note-taking. She wrote the notes for me in cursive, and I couldn't read them.

She also disregarded my needs. One day in class, I had an itch on the side of my arm. I asked her to scratch it.

"Do it yourself," she said.

That same morning during a break period, I requested an appointment with my contact teacher, Ms. Olson. She had volunteered to be my liaison to the Special Education Department to help me adapt to the education system again, and make sure that I had all the accommodations and services I needed to perform well in class.

I told her, "I need a TA who actually wants to do the work and not someone who is just sitting next to me, pretending to do the job. Her notes are illegible and unusable for me."

"I'll find someone." Ms. Olson said.

Two painful weeks later my parents and I met with my new assistant teacher, Ms. Guga. She opened the conversation by saying, “I know that there have been a lot of kinks in your start here at high school, but I promise that we will iron all of them out and make an easy transition from this tough time. I want you to know that this arrangement between us is permanent for your four years at school and we will make them successful years.”

Ms. Guga kept her promise to the end!

With Ms. Guga’s help I was able to excel in the classroom, and over the years, we created seamless communication. I didn’t have to worry about telling her to write notes for class, turn to the next page of a book, hand-in assignments to teachers, or keep track of time during tests. Ms. Guga would often complete my request for her to do something for me, without me having to ask her twice. Most of the time she even anticipated my requests.

She created a three-way relationship between herself, me, and my mother, who was my “assistant” at home. Ms. Guga passed on assistant techniques to my mother who soon became indispensable as my assistant. My later college success with my mother as my assistant would have been impossible without the formative presence and teaching of Ms. Guga.

Part IV

Disabled, What’s in a Word?

It is not only physical limitations that restrict us to our homes and those whom we know. It is the knowledge that each entry into the public world will be dominated by stares, by condescension, by pity, and by hostility.

—Jenny Morris

Wheelchairs have been a constant in my life, and from device to device, my relationship with them has changed, sometimes for the better and sometimes for the worse. Since my first wheelchair, my life has been dominated by a negotiation between freedom and restriction. My wheelchair gave me freedom but set me apart.

Disability is a socially constructed category to separate people into two groups: the able and the disabled. Separation leads to difference, and difference to discrimination, and discrimination to otherness.

Otherness is the ideological construction that a given individual—in this case, a person with a disability—is by nature inferior. This otherness is part of my experience as a person who navigates the world in a power wheelchair. Also, disability is often equated with mobility and mental ability, and by extension, the wheelchair is synonymous with inability.

Then an able-bodied person sees the wheelchair rather than the individual who uses it, and that person is disregarded. The wheelchair immediately implies the user is disabled, handicapped, passive, and dependent.

My power wheelchair cannot be hidden from view of others and gives the message of a permanent disability. My wheelchair is an object of nervousness and fear for others, and their fear follows me as I move through the world. That fear manifests itself as the stares I get in public, the avoidance of eye contact, or in the hesitation to talk to me directly. I shove off these uncomfortable moments, but those moments are reminders that in the outside world I am my disability.

In my early life, people told me *I was disabled.* People told me that *something was wrong with me*. People told me that *I was broken*. That *I needed to be fixed*. That *I was a person, who needed the help of others to be normal and to live a good life*.

For a while, I believed them. My disability became an excuse. I began to say and act as if I couldn't do this or that because I had a disability. But later, I fought against other people's judgements of me. I was capable despite my impediments.

Using a wheelchair and getting accustomed to how I fit in society was part of my learning curve. The wheelchair made my disability apparent to others and I had to confront and deal with other people's conceptions that seek to explain why and how I am disabled.

In social situations when I am with another able person, and someone else wants to get to know me, instead of addressing me directly, the person asks my companion. At these moments my presence is circumvented, and I become irrelevant.

I assert myself answering the person's question, but it often happens that I'm overlooked, and it takes up to three times for me to change this three-way dynamic. Eventually, the connection between the able body person asking about me and me is created, and a one to one conversation is established.

Going out is always a risk. Accessibility is one problem. But I also feel like I get thrown into a wrestling arena where I am on the defensive, knowing that at any moment someone is going to hit me with some variation of the question, *what happened to you*?

Someone often does.

Before I answer I ask myself, *do I want to get to know this person better*? The answer is often, *no*. To not be rude, I answer the question: I was born this way, or I have Cerebral Palsy.

Many of the reactions to my answer often sound like, “Oh I’m so sorry, may God console you and be your comfort,” or “Oh that’s too bad,” or “Oooh, I’m sorry I asked.”

Internally, I cringe at this comment and take a deep breath. Then I give an answer that will deflect the focus of the conversation from my disability. “No, it isn’t. I live a full life and I just graduated from college.” An expression of awe comes over the person’s face, and the conversation stops there. I hate having to explain myself to people, but it is a part of my life as a person with a disability.

Back in high school, I began to socially identify myself as a person with a disability, and I started to feel comfortable telling my story to others. This was my way of taking control of my story, and I began to explain the nature of my disability at the beginning of every school year. I was like an “ambassador for difference and understanding.” The difficult part of this new role I took on was describing myself. I didn’t know what words I would be comfortable using, such as disabled, handicapped, special needs, etc.

Ironically by having power over my story, I began to use the very same labels that others used to define me. Spreading awareness about disability, difference, and understanding was my attempt to allow others to understand me as an individual with a disability, but I was able only to encourage tolerance of disability rather than social acceptance of the person with a disability.

To be clear. I don't mind answering people's questions about me. I just wish they didn't have to be the same questions all the time. Every time I answer them, it feels like I only have one chance to influence the way people perceive me and my disability.

Answering the questions fills me with a sense of pride but soon this feeling evaporates, and instead I feel I just fed the flames of misunderstanding about disability.

On the receiving end of these statements of my accomplishments, the person asking about my disability probably gets the idea that I am a "supercrip."

Anna Hamilton, in an article on bitchmedia.org titled "The Transcontinental Disability Choir: Disability Archetypes: Supercrip," defines the supercrip as an archetype:

> Supercrip [is] sunny, kind, overachieving, [and] possesses a "can-do" attitude, and does AMAZING! and INSPIRING! things and can thus "overcome" [her or his] disability, but above all, Supercrip's main function is to serve as inspiring to the majority while reinforcing the things that make this majority feel awesome about itself. Supercrip cannot just be human; she or he must be superhuman and surpass not only [her/his] disability, but the realms of "normal" human achievement. Supercrip [s/he] is disabled, and [s/he] is doing amazing things in spite of those limitations!…Never mind whatever anger, rage, sadness, or less-than-positive thoughts you may have; if you are a person with a disability, you are expected to be just a canvas onto which non-disabled people can project their need for "inspiration."

As a "supercrip," I am supposed to be "inspirational" for the things I do and accomplish. This doesn't make sense because many other people (able-bodies) are expected to go to college, have a job, and build a life.

For people with disabilities these ordinary expectations become extraordinary achievements and the individuals are elevated to the status of symbols.

I would like to set the record straight when it comes to me: I am kind to everyone I meet. I do possess a “can-do” attitude. I am a person with a disability, but I don’t want to be a site for non-disabled people’s “inspiration.”

I have accomplished many things. But they are not amazing things in and of themselves. For instance, many people are expected to go to college and graduate. The amazing part about having gone to college, in my case, would be the dedication I had put into getting Highest Honors, and not the fact that I graduated.

As a person, I want to be seen not for what I am, but for who I am. I don’t want people to see me as “amazing” or “inspirational” because of my disability, but for how I live my life: always looking at the road ahead of me.

Even though I live with a disability, I do not seek to overcome disability as if it is the biggest adversary that I have to defeat so that I can move ahead. Disability is just a part of my life, because even if I didn’t have a disability, I would seek to live my life despite its challenges.

I have a disability but it doesn’t stop me from doing what I want to do. I commit to the goals I set myself, regardless. I surpass my limitations and seek to be exceptional for myself, not because I have a disability but because I want to be the best version of myself.

Being in a wheelchair means that my life is tied to technology. My wheelchair is a piece of technology and the lifetime on average is five years. A couple days before my High School graduation, I learned that technology could backfire on me.

The motor of my wheelchair began to work inefficiently. I was alerted to the problem by a constant creaking when the chair was moving. A couple of times the motor just stopped working, and my TA had to turn on the emergency brake at the back of the chair by the back wheels to break the power connection. By doing this, the motor was reactivated, but the chair moved very slowly. At home, my parents called the providers to see if they could repair the motor in time for graduation. But the earliest repair time would take two weeks.

I didn't want to walk for my graduation ceremony, but my family and school faculty were hoping that they could share that moment with me. They wanted to see me walk and celebrate my graduation, so the problem of the motor of my chair was thwarting their plans.

My mother, along with Mrs Gigiante, the school guidance counsellor, decided that she would walk with me in case that my chair broke down in the middle of the ceremony. If it happened, she would push the wheelchair so my mother could enjoy being part of the audience.

The day of the ceremony came, and when my name was called, I turned on the wheelchair but found that the chair moved at an excruciatingly slow pace. Because of this people didn't understand what was wrong. Probably they thought, I was nervous, and as a form of encouragement more than 500 people in the gym clapped.

After graduation I got a new wheelchair, just in time to go to college. The new wheelchair allows me to move around and gives me the ability to change my body position. I can recline the back of the chair. I can tilt the seat back until I am in a horizontal position. I can extend my legs, and I can elevate my seat. The wheelchair's sophistication allows me to adjust my body at will, and this gives me a greater control of how I maneuver in the world. The wheelchair can manage many terrains, however, because of all its sophistication the chair is heavy. The heaviness of the wheelchair is not a problem when I am in accessible locations, but it became a problem when I decided to study abroad in Ireland, during my junior year of college.

To maneuver in Ireland easily, my parents and I decided that I needed a light weight electric wheelchair and we started looking for one.

In 2014, EMMA entered into my life.

I got an Electrical Mechanical Manual Assist wheelchair, EMMA. It has the capabilities of a power wheelchair, it’s not heavy to push when it’s turned into a manual, it works nicely on a variety of terrains, it is small enough to navigate in small places, and it has a 10-year functional lifespan. On top of that, it only weighs less than 100 pounds and can be easily carried or disassembled.

This wheelchair makes me feel more visible, and for this reason, I named it Emma. Emma then is not just a device, because it has a name. She is Emma.

Emma makes me feel more confident, more approachable, and less restricted because I can easily navigate in inaccessible and small places. The freedom and maneuverability I feel I have with Emma gives me an increased sense of humanity, probably because it has less metal. Emma represents a different and more intimate relationship with technology than my other wheelchairs have.

I searched for the meaning and history of Emma’s name on behindthename.com. Emma comes from the Germanic root *Ermen*, meaning whole and universal. It is no wonder then that Emma makes me feel more human. With her, I feel I have a wholeness that I have never experienced before, because in her I feel less boxed in.

With Emma, I have come to understand myself as a person who is not definable in terms of disability. I am an individual for whom disability is an afterthought. Disability comes later in my self-description. I don't say I am disabled. I say, "I happen to have a disability."

The word "disability," as I have come to understand it, is an umbrella term for the inability or inabilities of a person, and it is a word that is used to refer to a spectrum of categories. These categories serve to identify the inability of a person into a diagnosis and a diagnosis into a condition, making the person an open territory for labels. Labels reduce a person. Labels generalize the experience of disability as one of lack.

No matter what disability a person has, no label applies to the wholeness of the individual or can lessen it. I have had to ignore the labels and the fear of others to go on with my life, and not be dragged down by feelings of inadequacy or abnormality.

I looked up synonyms in Word's thesaurus for "disable" and these came up: incapacitate, restrict, inactive, deactivate, spike, put out of action, immobilized, stop.

Disabled is an adjective meant to describe a person, that is "deprived of the power to perform one or more natural bodily activities." This definition is precise and correct. It says what disability is, but when it is used as a verb, there's a problem with the word "disabled." The problem is the social implications of the extended definition and its synonyms or related words.

If taken apart, dis-abled means not able and negates ability.

Society defines me as "disabled," because I can't perform some activities without devices like my wheelchair to move around, or computer programs with synthesizers to read and write.

Many people grapple with disability, understand it, accept it (there's no other option).

People with disabilities have the option to use words to empower or limit themselves. Stephen Hawking once said, "Concentrate on things your disability doesn't prevent you from doing well and don't regret the things it interferes with. Don't be disabled in spirit as well as physically."

Words can define me, but what matters is how I define myself.

I might be defined as *incapacitated* because I can't walk, but I move from place to place with my wheelchair.

I might be defined as *restricted* because I'm wheelchair-bound, but I go anywhere, and everywhere I choose.

I might be defined as *inactive*, but I live an active and productive life.

I might be defined as *deactivated*, but I'm full of energy.

I might be defined as a *spike* in the side of those next to me because of my bulky wheelchair, but I'm not.

I might be defined as *put out of action* and that implies being benched from participating in life, but I don't stay put. I move from project to project and always achieve.

I might be defined as *immobilized*, but I mobilize people to go after their dreams.

I might be defined as *stopped*, but I'm unstoppable.

Disability is a condition that is not faced by many people, but there are some who have to deal with it. In the Merrrian Webster Dictionary online, disability is defined as "a physical, mental, cognitive, developmental condition that impairs, interferer's with, or limits a person's ability to engage in certain tasks or actions or participate in typical daily activities and interactions.” The meaning of disability goes beyond the definition, common knowledge, and society’s prejudiced assumptions.

Disability is a slippery category that quickly goes into social territory where a person is determined by her or his capacity or ability.

This way of thinking that prizes ability is known as ableism. In the Oxford English Dictionary, ableism is defined as, “Discrimination in favor of able-bodied people; prejudice against or disregard of the needs of disabled people.”

From the definition, as suggested by the Disable Feminist Blog, “What is Ableism?” it follows that ableism is a “systematic oppression of a group of people because of what they can or cannot do with their bodies or minds and is the result of…ignorance,” on the part of individuals.

Ableism in its social context is experienced by people with disabilities when they are either talked down to by others or ignored entirely. In this case, the companion is thought of as the mouthpiece or even the thinking-piece of the person with the disability, whether or not the individual with a disability is capable of carrying on a conversation by her or himself.

Ableism also appears in the form of the extra lengths that people with disabilities have to go to access certain public spaces. Accessibility entrances are sometimes located in the back of buildings used for dumpsters.

Despite having to navigate these obstacles, people with disabilities pursue lives where society would see their merit and not their ability or lack of it. People with disabilities should not live life by secondhand with others conveying their experiences to them, but by experiencing life for themselves first hand. In this way, we will be the protagonists of our stories and the designers of our lives.

In the past, many people with disabilities were shut away from public view and clustered together in asylums and wards or left alone at home living inconsequential lives. But some people have fought the odds and stood against the opinions of others, and have left great legacies.

Stephen Hawking, Franklin Delano Roosevelt, and Helen Keller are only a few. These individuals stepped out of the margins of disability and became central figures not only of disable history but of human history. As Douglas C. Baynton said, “It is time to bring disability from the margins to the center of historical inquiry.”

Stephen Hawking once called upon people with disabilities to concentrate on the things we can do well and not on the things that our disabilities can interfere with. He had what his sister Mary called “a stubborn will to live.” She believed that Hawking carried on because of this “stubbornness” until his death. This stubborn will to live is what keeps many people with disabilities pushing on day after day.

Franklin Delano Roosevelt left us with the idea that, “There is nothing to fear but fear itself.” Fear is what holds us back from getting what we want out of life. People with disabilities must put aside fear and go forward in spite of the obstacles around us.

Helen Keller in *The Open Door* wrote:

> Sometimes, it is true, a sense of isolation enfolds me like a cold mist as I sit alone and wait at life’s shut gate. Beyond there is light, and music, and sweet companionship; but I may not enter. Fate, silent, pitiless, bars the way…Silence sits immense upon my soul. Then comes hope with a smile and whispers, ‘there is joy [in] self-forgetfulness.’ So I try

> to make the light in others' eyes my sun, the music in others; ears my symphony, the smile on others' lips my happiness.

Life with a disability is sometimes made up of more solitude than one would like, but to live by disregarding our impediments must be our outlook if we are to live our lives as others do. Sitting alone at "life's shut gate" is not the answer, we must burst open the bars and make our way through. Living with the abilities we have and not mourning the abilities we don't have. We must let our voices be heard and not let others speak for us.

For me, examples of other individuals with disabilities have been a constant source of reflection and strength. Disability is as specific to each individual as a fingerprint, but the experience of disability in society is a constant repeating pattern across the life experiences of the individuals.

The disability experience then creates a collective unity among people with disabilities across time. In the following poems, I have responded to what President George Bush said when he signed the Americans with Disabilities Act into law, "Let the shameful wall of exclusion finally come crumbling down."

I

outsider

different

segregation

equality

struggle

Institution

Integration

Inclusion

The verdict

labels

Open Ground

What's the problem with giving assistance to someone who needs it?

Why pity someone who is in need?

Why ease conscience with *charity*?

Helping people is not charity.

Helping people is being human.

inhumanity

limitation

isolation

oblivion

Why do you fear disability?

…a constant reminder, it can happen to you

segregation.

integration.

inclusion.

keeps otherness at arm's-length

only dealt with when necessary

accommodations?

only when necessary

Let's make the world open ground for everyone!

Declaration Against "Disabled"

JULIET

What's in a [word]?

…doff [that word],

    for that [word], which is no part of [me]

[I would be] all myself.

ROMEO

Had I it written, I would tear the word.

—*Romeo and Juliet:* Act 2, Scene 2

I Speak Out for Myself: Spelling Disability

Dream, face your reality and you'll be better off

I might not be independent of body, but it is in dreams that I'm free

Special? No, I'm not I'm just different

Art makes my metal frame melt away. I

Believe in being boundless

Imagination gives a world to those who watch it sitting on a windowsill

Live a life were limitations have no bearing on who you are but only on what you are

Inspiration comes during work, rather than before it—Madeleine L'Engle

Time and tenacity make accomplishment possible

Inspirational? Calling me "inspirational" robs me of any talent—Aimee Mullins

Ever, never tell me what I can't do. I

Speak for myself

I Am

NICU, June 7, 1993, Manhasset, NY:
lights blare
EEGs beep

Born.
Voiceless.
Incubated.
Molded.

Surgeries:
eyes, tonsils, muscles, legs

wheelchairs

MY LIFE:
I am bound for a lifetime
with a weak body-mind connection
flesh and steel are one
with knots and bolts for support
I am plugged-in to life

Mind:

limitless

I am, I live

I live, I am

Part V

The Road to Ireland

Going to college is often thought of as a life-changing experience. College supposedly gives the student the opportunity to explore independence while living away from home. This was not the case with me. I applied to five universities and two schools accepted me: Santa Clara University in California and Hofstra University in New York.

When it came time to choose, I had to weigh many things, most importantly the financial package and living circumstances. The financial packages both offered were compelling, but I saw that accepting Santa Clara would involve making a cross-country move, while by accepting Hofstra I could still live at home within driving distance.

Moving away to California would put me in a very vulnerable situation, one that I was not ready to face.

Moving away from home would mean that I had to depend on aides around the clock to help me with my physical needs.

As soon as I wake up, my routine of dependency starts. I need someone to get me out of bed, give me a shower, dress me, and transfer me to my wheelchair so I can move on my own. When ready someone has to prepare my breakfast and brush my teeth. Someone has to drive me to school. I need also someone to be my assistant not only to take notes in class, but to help me navigate around campus since I have a disorderly sense of direction. At best, my sense of direction is that of the duckling following its mother. My assistant also has to be strong enough to take me to the bathroom. I need someone to drive me back home, assist me with the chores of the house, homework, and getting ready for dinner, brushing teeth, and bed.

For 18 years, my parents, with the help of someone else, have been my primary aids. My parents have been the only reliable aids that don’t call in sick or come in late because of traffic.

The best option for me to go to college in California was that my mother move with me to Santa Clara. My father would have to go as well.

Seeing all the changes I would have to make in my life, and that I would be tearing up the roots of our life in New York, I decided on Hofstra University. I thought back to the guided university tour I took to get to know the school and remembered that the tour guide had said that Hofstra was "The most accessibility-friendly private university in New York." I turned down Santa Clara and accepted Hofstra University.

The first semester at Hofstra went smoothly. One of the introductory classes was a history course, "Inhuman Race." It was focused around situating texts in their historical context. One of the books was the 1818 edition of *Frankenstein*, which I hadn't read before. We read the text through the lens of seeing how it dealt with other kinds of humanness. The use of this lens allowed us to see the creature as a human being based on his desires and not as different because of his circumstances.

This idea of humanness based on desire interested me to the point that I wrote a paper on it, and because of this paper at the end of the semester, my professor called me into his office and said that my performance in class was outstanding. He also stated that he would like to recommend me to the Honors College. I didn't know what the Honors College was. He explained that it was a higher level of academic instruction and that it demanded a higher level of class involvement of which he thought I was capable.

My professor said, "In my experience, there are two types of students, those who are at the bottom and try hard to get to the top, and those who are at the top who want simply to excel at what they do. Your work has been top notch, and you have shown that you are the latter."

I said that I wasn't sure if I wanted to go into the Honors College. My mother poked my footrest, hinting to me not to turn down this opportunity, so I said yes.

My professor added, "Well, that's good because I already set up your appointment with the dean next week. It looks like we might be seeing more of each other because, aside from being Chair of the History Department, I am also part of the Honors College."

Dr. Louis J. Kern Chair of the History Department was a Distinguished Professor of Hofstra University.

This appointment with Professor Kern would put me on a one to one relationship with Dr. Warren G. Frisina, Dean of the Hofstra University Honors College (HUHC). Dr. Frisina became my primary advisor and mentor for the rest of my time at Hofstra University.

When Dr. Kern recommended me to the Honors College, he set in motion a life-changing experience. I was able to delve deeper into the humanities, particularly history, literature, and cultural studies by making almost all my courses Honors Options for more academic credit.

On record, I was part of the English, History, and Latin American and Caribbean Studies Departments. Off the record, I was also part of the Irish Studies Department. Ultimately I was ranked as a High Honors with Distinction student.

Eventually, I took part in the Hofstra in Ireland Study Abroad Program and it became the crux of my university experience. In Ireland, all my academic background accumulated over the last three years found real-life expression and application. I completely immersed myself in the program, in the classroom, and beyond. During my time in Ireland, I wrote a blog that captured the degree of my involvement in the program.

The road to Ireland wasn't smooth. Ableism got in my way.

I learned about the Study Abroad in Ireland program from a poster. It had an Irish castle that said in emerald green letters, “Study Abroad in Ireland 2014, this castle can be your classroom.” That semester I was taking a course on Anglo-Irish Literature, as an Honors Option. I asked my mother to take a brochure.

On the brochure was a tall, gray medieval castle on a field with Ireland’s bright green grass. Across the castle, in diagonal print, were the words “Ireland, the isle of poets, scholars, and song” in gold letters, with a rainbow in the background.

That December afternoon, I told my parents, “I want to study abroad in Ireland, during the next summer session.”

“That’s great that you want to do that, but..,” my father said.

“There are no *buts* about it,” I declared “What matters is how we are going to make this happen.”

I went to my study room and asked my mother to take down my dream board that was hanging on the wall in front of my desk. I asked her to cut out the castle on the poster and put it in the center. I looked at my board at the jaguar leaping onto the black winding road stretching across the board and into the distance. That jaguar was the projection of my spirit self. I looked from the jaguar to the blue flag with the letter E on it. “E” meant education.

Education was my goal, and Ireland was the next step in that direction.

My dream board also had clippings I had put on it during the previous semester. One of them said, “Novelist and poet in training.” It was pasted next to a picture of a graduation cap and a diploma with my graduation date under it. I had the clear goal to graduate in four years in May

2015. The next clippings on the dream board were portraits of W. B. Yeats, James Joyce, and Seamus Heaney. These portraits looked at me every time I was at my desk.

I live and breathe language. The words of other writers mix with my own to create my own world. I cannot physically go into the world as much as I would like, so knowledge and literature are my vehicles to experience life. The portraits of these Irish writers were pasted alongside the picture of the bookcase with the names of Shakespeare, Percy and Mary Shelley, Lord Byron, and William Wordsworth. Below this literary corner of my dream board was a cartoon-drawn typewriter that had one page sticking out of its lip, and had the words "my first novel" on it.

In the center of the board was also a miniature-sized print of the poster from the *Michael Collins* film with Stephen Rea. It represented the long road of Irish history marked by the Irish Literary Revival and the Easter Rising of 1916. I asked my mom to pin the brochure of Hofstra University's Ireland Study Abroad Program in the lower right corner of my dream board, so it would stick out as if to say, "Notice me."

All I wanted to accomplish in my life, up to that point, was on that board.

This trip to Ireland would help me find my writer's voice. Having finished designing my dream board, I said to myself, "Now, it is ready to be accomplished."

I sent my first email to the director of the Irish Study Abroad Program on September 9, 2013, expressing my interest in the program and explaining that I am a student with a physical disability, restricted to a wheelchair. I requested an appointment with her to discuss the logistics of my participation in the program and the strategy I would use to make the trip as accessible as possible. After three weeks she still hadn't answered.

Why hadn't she answered me yet?

I sifted through reasons why she could not answer: too much work. Email locked. No access to Hofstra account. Sick.

Maybe my email hadn't been clear enough about my special needs. Maybe she just skimmed the email. For regular students there is no rush for discussion. Deadlines suffice.

I logged out of my Hofstra account and finished up the last poem I had to write to complete a set of Petrarchan sonnets I had to present for my poetry class.

During my daily email check, on October 29, 2013, I received an email from the Irish Study Abroad program Director. In the email, she said, "Sorry for the delay in response. I am just putting the program together now and will be in touch with you shortly."

I went over the email twice to make sure of what I was reading. I was looking for a thread of conversation that will start our talks about my accommodations I would need. I needed to know how I would manage my life in another country for a month. As a student with a physical disability I needed to plan ahead.

I decided to check the first email that I sent introducing myself. I opened the sent mailbox and read it over again. I had written:

> Dear Professor:
>
> My name is Cristina Cortez. I am a Junior-level student at Hofstra University, and I am majoring in English Creative Writing and History. I want to set up an appointment with you to discuss the requirements for the Ireland Study Abroad Program. What day and time would be most convenient for you?

"Damn it!" I screamed aloud, slapping my palms on the desk.

“Are you all right?” my mother asked from another room.

“I’m all right,” I screamed back, but she came in anyway. She knew that I didn’t make those kinds of noises or have those kinds of outbursts.

“I made a mistake, that’s all,” I explained.

“And just because of a mistake you’re *hurting* your desk?”

“I sent an email to the director of the Study Abroad Program, asking her about the trip to Ireland, and I forgot to tell her that I am a student with a physical disability. Maybe because of that she is not giving me the appointment I need to discuss my participation in the program ahead of time.” I showed her the email.

After looking over the email, my mother said, “There is nothing that justifies a professor’s lack of responsiveness. Sure, you didn’t mention you have a disability. But she knows you already. Don’t you remember you introduced yourself to her at the Faculty Research Day and said that you would email her requesting an appointment? And you talked to her a couple of times in the halls. Anyway, how could she not know you have a physical disability? Your chair is hard to miss.”

“But in the email, I didn’t tell her about my physical disability. How was she supposed to know I need to plan ahead of time?” I said with frustration.

“Cristina, she has been a professor for so long. I’m sure that she must have had students with disabilities in the past. Hofstra University is the most accessible college in the state. That’s why you are there.”

I said to my mother, “Forget it. I’ll figure this out for myself.”

My mother left.

As a person with quadriplegic Cerebral Palsy, I have to take into account that every daily task, no matter how simple, takes me twice as long. I want and need to be a person with as much of an ordinary life as possible. To have that life, I have to anticipate challenges ahead of time.

I wanted to make the best of this trip to Ireland. Going to Ireland was about expanding my horizons and connecting with the artistic culture of the country. After all, it is called by its own people as “the isle of poetry, inspiration, and song.”

On top of this, the trip was another challenge for me to tackle, I would need someone along with me to help with my physical needs, and this means extra expenses.

I needed to plan one semester in advance, but that semester in advance was halfway gone. November was around the corner.

I knew I would go to Ireland and that I would be dealing, for a month, with a professor who ignored my situation. Once in Ireland, she would have to take my situation into consideration and help me navigate in the country. That kind of support is in the job description of any director of a study abroad program. She couldn’t avoid it, but she wasn’t open to discussion about these issues.

I decided to talk with her in person during her office hours. I looked up her office hours on the faculty directory page and found that they were on Tuesday and Thursday at 2:10 to 3:45 P.M. If I went myself, I would be late for my Renaissance Europe history class on Tuesday. So I asked my mother to go instead. She later told me that their conversation went something like this.

My mother went to speak to the director and caught her in the hallway on her way out to a meeting.

My mother said, “Professor, do you have a moment? I need to talk to you.”

“I can’t talk now, I don’t have much time.”

“It will only take you five minutes or so,” my mother added.

“I guess I can make some time,” she said, stopping.

“My daughter, Cristina Cortez, is interested in the study abroad program in Ireland and she thinks we should set aside some time to talk as soon as possible about the logistics of the trip, since she moves around in a wheelchair.”

“Yes, I’ll get on it as soon as I have an idea of how the program is going to be laid out,” she said hastily.

“I know you are busy doing that, but we need to have a general idea of what Cristina is going to get into before we make travel plans. We need to know how accessible Ireland is and about problems that she might face while there.”

“Ireland like most of Europe,” the director said, “isn’t as accessible as the United States.”

“I understand that it is not as accessible as here. We’ve traveled to Europe many times including England, Belgium, Italy, Poland, and Ukraine. We assume that Ireland will be similar to any European country, and in anticipation of that we just bought a lighter motorized wheelchair that will allow Cristina to have more mobility in less accessible places.”

“We are going to be constantly moving around. The course doesn’t take place in just one location and during the time that we will be traveling, Ireland goes through brisk changes in weather, there’s a lot of rain. Some students even get sick.”

“Cristina has optimal health. She has never missed a class because of illness.”

“Ireland is a very rural place,” the director said. “She might have problems navigating.”

“There are problems everywhere she goes, but we deal with them. We need to sit down and talk as soon as possible.”

“We’ll figure something out,” she said as they parted ways.

At home, I opened up my Hofstra email account to check if I had any new messages. Among the most recent emails was one from the director. The email’s subject was “Hofstra in Ireland: organizational meeting.”

In the email, the director gave the eight recipients of the message a general idea of what would be discussed at the meeting and promised that there would be time to share experiences and stories about past trips. The meeting was on January 22. The email as a bulk message was not a problem, but there was no hint of discussion for accommodations of any kind that I had been requesting since the last semester.

In the meeting, the director delivered what her email promised, but there was nothing said about the accommodation arrangements I had been asking for. At the end of the meeting, my mother and I left, feeling that nothing would be accomplished with her.

I browsed around in my computer for the Services for Students with Disabilities (SSD) site. I click on the link to the “Faculty Syllabi Statement” which outlines the arrangements that must be made to accommodate the students with disabilities in accordance with Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. The syllabi statement said that I was entitled to any accommodations that would facilitate my participation in *any* academic program.

With the right to accommodations reaffirmed, I visited the Director of the SSD office and the Dean of the Honors College. I told them I was pursuing my goal to participate in the Ireland Study Abroad Program and I needed their support.

Soon I received an email from the director of the Study Abroad Program in Ireland inviting me to discuss my plan for the trip. The meeting would be at the office of the SSD Director, scheduled for March 22 at 2:00 P.M.

I went to the meeting. Ms. Yindra, the director of the SSD office, was ready for the discussion sitting behind her desk finishing up an email. “So are you ready for Ireland?”

“Yes,” I said, “I’m looking forward to it.”

“You must be really excited, I would be.” Ms. Yindra said with a wink.

“I can’t wait to go. I have been waiting for this trip since I was a freshman. I want to get this planning and conversation underway.”

“I’m sure the Study Abroad Program Director will be here shortly, I just sent her an email in reply to the one that she sent me letting me know that she would be a little late.”

“Ok, I guess we can wait a little longer.” I watched the second hand of the clock on the wall.

Ms. Yindra said, “If you don’t know already Ireland is really, *really* green.” She put an emphasis in the second “really” and continued, “The fields look like emeralds all in a row, so when the plane is landing you get a great view.”

“I’ll look out for that,” I said, but I felt a little anxious.

Ten minutes later the director rushed into the office with her purse slung over her shoulder and sat in the empty chair saying, “Sorry I’m late, I lost track of time,” as she took out a pen and notebook from her purse. Her bracelets jingled.

“Well, Professor, now that you are here, we can start with this discussion.” Ms. Yindra said, “As we all know, we are here to try to help Cristina figure out the logistics of what it will take for her to travel while she is in Ireland, so her trip is a successful one. Here in the states, she has her own means of transportation, but abroad is another question entirely. Would you tell me, Professor, what kinds of events she will be expected to attend during the program so we can arrange the proper type of transportation?”

“All the students in the program would be expected to attend at least ten cultural events that will take place at different times throughout the day before and or after class.”

The conversation was a rerun of the organizational meeting that all the applicants had gone to.

I interrupted saying that my greatest concerns were accessibility, transportation, and the cost of bringing someone to assist me (that would mean bringing my parents along).

After I laid out my concerns Ms. Yindra said, “Now that you have voiced your specific needs for this trip, Cristina, we need to figure out a way to provide you with a means of transportation to attend the cultural events and do errands.”

The Study Abroad Director warned, “For transportation, I will have to make some calls to find out what are Ireland’s disability provisions. Then I will arrange a suitable mode transportation to accommodate you and your companions, but *it is going to be very expensive*.”

Ms. Yindra interjected, “The cost of the transportation will be covered by the SSD, and for the charges incurred by your parents I believe that the study abroad program office will give you a summary and breakdown of the costs involved. Once you register for your course, you will get the financial details.”

“I will be sure to register in the coming weeks,” I replied.

Slapping her hands down on her desk in a lively manner, Ms. Yindra closed the conversation between the director and us saying, “I think we are all set.” Addressing the Director she said, “You will be in contact with me about the transportation arrangements for Cristina and her parents. As for you Cristina, keep up the good work in your class during the study abroad program, and most of all have fun.”

I grinned.

At home I couldn’t wipe the smile off my face. I went to the bookshelf and took out my copy of *The Collected Poems of W. B. Yeats*. I opened the book and by chance opened to “The Lake Isle of Innisfree.” I read the opening line: “I will arise and go now, and go to Innisfree.” I closed the book.

“I will arise and go now, and go to Innisfree” took on new meaning for me. It became a declaration of victory. “I shall go to Ireland, the isle of scholars, poets, inspiration, and song.”

As I fused the lines “I will arise and go now, and go to Innisfree” and “I shall go to Ireland, the isle of scholars, poets, inspiration, and song,” I knew my dream of going to Ireland was in the making.

As the journey to Ireland got closer, I began to make arrangements for my Study Abroad participation to count as an honors credit class. I soon had a conversation with Dr. Frisina, and he gave me this piece of advice: “If you want to make the most out of this trip and make it count for honors you have to immerse yourself in the experience and make a record of it. Talk to Dr. Neil H. Donahue about it, he created the Study Abroad Honors Option for the programs.”

As I left the dean’s office, he added, “While you are in Ireland be sure to spend time at The Crane Bar. That is one of the best pubs in Galway.”

I went to Dr. Donahue’s office which was the next door down from the dean’s office, and we talked about what I wanted to get out of the trip. I talked about my interest in the literature, history, and folk traditions of Ireland.

“Well,” he said, “you should have a lot to write about, and for your Honors Option I will be the one evaluating your work. I think it will be interesting for you to write a journal about your time there.”

“Can I write a blog?”

“Sure, just send me the link.”

I began my blog, “Travel on Wheels: An Irish Adventure.”

Part VI

Groundling to Starling

When everyone says you can’t, determination says, “YES YOU CAN.”

—Robert M. Hensel

I finally arrived in Ireland. From Shannon Airport we went to Doonmacfelim House B&B, where our program would begin. I hit the sack and took a catnap that lasted two hours.

Reenergized, I went out to discover Doolin. In the sprinkling rain, my parents and I walked downtown to the pier near by. I passed limestone walls that stretched along the length of separate plots of land. There were no sidewalks, so cars and pedestrians shared the winding roads making space for each other.

Doolin is known for its delightful farm animals, such as cows, horses, and sheep. These "gracious lawnmowers" keep the green pasture lands, scything and chomping—working all day long.

Ultimately, the stone walls converged at a ledge and I sat there for a while overlooking the rolling Atlantic Ocean, blending into the overcast silver skyline. That moment on the ledge would not have been possible without my small but sturdy Emma that had taken me down the rough way to the pier rattling along the way. Neither would it have been possible without the audacity and commitment of my parents. They lifted me out of my wheelchair and carried me across the rocky shoreline.

Looking out at the seascape, I saw where the sea and the sky converged at the horizon line, and as I looked the full realization that I was in Ireland hit me. I had traveled across the Atlantic Ocean that Irishman had crossed to find a new life in the United States, but in the opposite direction to find myself as a writer.

This trip was about engaging with the same places that had inspired the many writers of the country I admired. This trip was about getting to know the land, the people, the culture, and its past and present.

One of the first excursions planned for my Study Abroad group was to Inishmore, one of Aran Isles. Instead, I ended up going to Inisheer and to the Cliffs of Moher. I used the tour services of Garrihy's Doolin 2 Aran Ferries.

After a long waiting-line for the ferry, I got on the motorized boat, "Happy Hooker," that zipped through the blue black waters showing off her curves as she pitched and rolled along the way. My parents were sitting in front of me and each one of them was holding down one leg of my wheelchair to keep it steady. The ship soon docked, and I got off ready to start feeling my way around the island.

There are many ways to get around in Inisheer: by the modern tourist truck, the classy eighteenth-century horse-drawn carriage, bike, or just walking. At a leisurely pace, I moved around looking out at the large green "chessboard" of plots of land sectioned off by stone walls on the hilly island.

Inisheer greeted me with a warm sun, but on my way to the Cliffs of Moher, in the motorized boat "Discovery," the sky became overcast and threatened to bring down a drizzle of rain. In Ireland, the weather is a bit moody. Rain began to fall, accompanied by a cold brisk wind. My diligent parents put me in a plastic parka that made me look like an overgrown lemon drop. I was dry and warm, but I felt ridiculous.

The weather changed back again and through the remnants of rain and a sunny blue sky, I saw the stags. The rock pillars were jutting out of the ocean standing like Celtic warriors guarding the Cliffs of Moher and its natural inhabitants.

Later on land, I was ready to go back to Doonmacfelim House B&B and before I left, an athletic and tall Irishman, Donnie Garrhy, the director of the Garrihy's Doolin 2 Aran Ferries, introduced himself to me and thanked me for using his services. As a gesture of goodwill, he gave me a memorabilia of my excursion, a signed postcard with a picture of a puffin on the front, and underneath the bill was typed, “Hi from the Cliffs.”

Richard Casey, my taxi driver, told me that Donnie had an accident and became paralyzed for five years. Listening to this story reminded me that disability can happen to anyone and that it is always unexpected. Ireland, like any country in the world, has inaccessible and accessible locations. While society is still not as ready as it should be, a person with a disability has two choices: either be resigned to it, or cope and/or overcome it. I choose the second.

That night was the first Communal Dinner with my Study Abroad group, and my parents and I were running late. Quickly we got ready to leave and I turned on my wheelchair. I waited for the pale green screen, on the controller, to blink to life. My father held the door of our room open as my mother, and I drove out into the hallway and we all left to head down to Gus O’Connor’s Pub.

The wheels of my chair rattled as they took me down through the makeshift sidewalk, hardly distinguishable from the road. Ahead of me were a row of colorful and vibrant little houses on one side, and on the other were simple stone wall fences.

The houses were built in the Georgian style with two chimneys, one on either side of the roofs. The chimneys topped off perfect squares and symmetry was at every angle of the façades. Each of the houses had a front door and rectangular windows surrounded by deep fruit color walls of red, yellow, and orange. The sequence of colors broke off with white Georgian houses flanking a thatched cottage style house that stood out. The walls of the magenta cottage seemed as if they wanted to be noticed, disrupting the symmetry created by the other houses. The thatch looked worn, a remnant of Ireland's peasant life. I imagined that a family of eight or maybe fourteen might have lived in that hut in the past.

Ireland was telling me fragments of its history.

This is what I came for. I couldn't wait to share my thoughts and hear about the experiences of the others in my group.

The gray stone walls on the other side of the path caught my attention. They reminded me of the larger stone walls that the fading Roman Empire had built when it had gained a fleeting foothold in Ireland. Back then the walls were a protective structure and now, in the twenty-first century, they were downgraded to the status of agrarian property divisions.

My wheelchair kept rattling as I drove down the sidewalk. I changed its speed from high to low, trying to find the right velocity for these roads to prevent the bumps and gravel on the sidewalk from throwing me off balance and maybe from flinging me out of the wheelchair altogether. I struggled to keep my balance. Good thing my seatbelt was fastened.

Soon enough, I stopped in front of Gus O'Connor's Pub that had stood in the rural town of Doolin since 1832.

I was ready to have fun with my Study Abroad group.

I wheeled my way inside the pub and looked around for my group. Inside I saw three tables put together, family style. My group was sitting down with the professor at the head of the table. I looked at the periphery of the table, expecting to see empty spots available for me and for my parents. I approached the table and said, "Hi, everyone."

They echoed my greeting and I waited to see if anyone would make room for me. No one did.

Here I was, wanting to eat my dinner after a long good day and chat with my peers about the experiences of our first few days in Ireland. This was supposed to be our first Communal Dinner, and there was no space for us at the family style table.

Rather than picking a fight, I politely excused myself and looked for another table.

Now I was sitting at a table near the exit door. My parents and I ordered our dinner: burgers. While waiting for food they tried to make small talk with me about the day we already had. I heard them, but I wasn't listening. My parents' voices sounded like revving trains in the distance.

This trip was supposed to be a cultural immersion experience. Ireland is "an extension of the classroom," as claimed on the Study Abroad brochure.

I had signed up for the class 20th Century Anglo-Irish Drama, and all the texts were plays having to deal with the theme of characters being trapped. Some of the characters in the plays had disabilities, like Billy Claven from *The Cripple of Inishmaan* by Martin McDonagh. In these plays, disability is a metaphor for how the Irish people are stuck in their ways of life.

I was stuck in a group headed by a professor without disability-sensitive-etiquette. Able-bodied people don't know what is like having a physical disability and being restricted to a wheelchair. Some people hear the word "disability, " and they imagine a stereotype, someone not physically competent. Entirely dependent. Someone with catheters that can't control their physiological needs. Someone who gets sick all the time. Someone not able to communicate or even have thoughts or feelings. But, even if those stereotypes are true, does that justify excluding people with disabilities from life experiences? As one character in the film *The Other Side of the Mountain* says, “The outside world [often] assumes that if your toes have gone numb, your brains have gone numb, too.”

Food came. Burgers and French fries were laid out on a middle-sized plate. We ate, not talking. The meat was dry and tasteless. I chewed my food like the cows. The fries were soggy, pale, and yellow like the hide of the cows that I saw earlier by the window of our room at the B&B.

I hadn’t gotten a good view of the cows where I was, all I could see were their rear ends. Their bony tails moved back and forth, fanning away the flies swarming around them. The tails reminded me of the fan used by the woman in Amedeo Clemente Modigliani’s *Portrait Lunia Czechowska with a Fan*. The woman, in the portrait, is sitting down, fanning herself and trying to cool down from the heat. Her pale yellow skin is the color of the cows’ hides, a cheap imitation of the gold gown that she wears. Her angular pale face is expressionless. Her downcast and disinterested eyes fail to make contact with the viewer. The painting is a tribute to boredom and emptiness.

I had looked forward to my time in Ireland, but my experience, so far, had been solitary.

Just the day before, the professor of my Study Abroad Group told me, “We are all scheduled to go to Inishmore, one of the Aran Isles.”

“Great, at what time should I get ready to leave?” I asked.

“Oh,” the professor answered as if she had forgotten something. “I don’t know how accessible this excursion is going to be for you. I already bought the tickets. We are going to reimburse your payment. You are free to arrange your own private trip.”

“I can make my own way, you don’t have to worry about me getting around. My parents are here to help.”

“Yeah, you will have a good time.”

After this conversation, I went to the tourist information office. I found out that all visitors to the Aran Isles needed to take a ferry, and the representative told me that I should go to Inisheer. According to her, it was the easiest isle to navigate through.

I bought the tickets and went to Inisheer. If there were any problems along the way, I would deal with them. I wasn’t going to miss out on an excursion like this. I wasn’t going to be stuck.

Coming out of my thoughts, I noticed that local people and tourists were coming into Gus O’Connor’s Pub. The quiet place was changing into a boisterous hub of chatter, punctuated by thick Irish accents. The local music performance was about to start.

Someone touched me on my shoulder. I look up to see who it was. It was the professor and she asked, “Having a good dinner?”

“Yes,” I said, careful not to reveal my frustrated mood.

“We are going back to the B&B, but you can stay here and enjoy the traditional Irish music performance. It’s wonderful; I heard it many times before.”

"OK, I might do that," I answered trying to brighten up a bit.

"Before I forget," she added, "how was your day?"

"Great! I went to Inisheer, since Inishmore was inaccessible, as you said, and I took a walk around the isle."

Kenni, a classmate of mine standing behind the professor, got into the conversation and stopped texting, saying in an exuberant voice, "Really, that's funny we went there too."

"Really," I echoed back, "I didn't see any one of you guys."

"We must have gone in a different time and different direction," Kenni said.

Kenni told me that they had gone to the highest point of elevation on the isle to see the larger expanse of stone walls that Inisheer offered.

I had gone there too and had some time alone to myself. I just enjoyed the silence, looking at the plots of green grass that seemed endless. They looked like a chessboard and I remember the first and last stanzas of the poem "Chess" by Jorge Luis Borges:

> In their solemn corner, the players move
> The slow pieces. The board detains them
> Until the dawn in its severe world
> In which two colors hate each other.
>
> God moves the player, and he, the piece.
> Which god behind God begets the plot
> Of dust and time and dream and agonies?

Kenni’s voice still rambled on and pulled me out of my thoughts. I said to her, “It was interesting to see the plots of land surrounded by stone walls, wasn’t it?”

“Yeah,” she chimed in. Then she added, “Too bad we didn’t meet up.”

“Well,” I said, trying to stay positive. “We’re going to have loads of fun over the next month, and I’m looking forward to spending some time with you guys,” I said this, referring to my other fellow students, who were nearby. Then I added, “I’m on Facebook, how about you? Let’s get connected.”

“Sure, that’s fantastic,” Kenni said.

The conversation ended, and they left.

My father requested the check and I turned on my wheelchair to make my way to the bar section of the pub were I let the lively music of Ireland delight my ears.

Going back to the B&B in the darkening night frustration filled me again. Frustration at not being included in the excursion that ended up in the same place, anyway. Frustration at not being included in the Communal Dinner.

In my mind, I run through the dichotomies that rule my life.

Mind and Body.

Able and Disabled.

Inclusion and Exclusion.

Friendship and Solitude.

Connected and Disconnected.

I know these opposites. I deal with them every day. I hate them, because they emphasize difference—parts of life that never meet. These dichotomies divide and division is not the principle by which I want to live my life.

Connecting with others isn't hard for me and I want to be close to others. But the reality of my life is that no matter how much I want to be close to others something or someone excludes me. At school I consciously position myself in the front of the room (when I can) to prevent exclusion. But in social activities I am always lagging behind or catching up or on another path.

In my room at the B&B I parked my chair next to the outlet where the wheelchair charger was ready for use. On the desk in front of me was my computer in "sleep mode." I pressed the power button to wake it up. My Facebook profile appeared on the screen. The Friends logo had a red number one next to it. I clicked, and the automatic message for a friend request appeared: Kenni O'Donnell has sent you a friend request. With a slight smile, I clicked confirm.

Before bed, I talked to my parents and expressed my frustration about what had happened during the day and I said to them: "I don't want to feel that I am at the mercy of someone to have a full experience in Ireland. I'll attend class, do the coursework, connect with the other students. But outside of class we're on our on own. I want to be in control of my experience, and I want to plan out all the places that I want to go to while I am here."

As I fell sleep I thought about my Anglo-Irish drama class that was starting soon, and I dwelled on how plays would have been put on in Shakespearean times. The audience of a play would be made up of different social classes. The wealthy and the poor. The wealthy would have sat in box seats while the poor would have had to stand near the stage to see the performance. The poor were often called groundlings, people of inferior taste and intelligence.

In situations when I am socially excluded, I feel like a groundling, omitted and non-consequential. Normally I don't allow these feelings to affect me or stay in my head. I mentally delete these emotions and instead I opt to be solitary, because in solitude I am in control of my experiences in the outer world and in my inner world.

In trying to control these moments of discrimination and negative feelings, I have found pleasure in creating a world of the mind. I am constantly experiencing the world through travel and the gaining of knowledge. Knowledge is my way of going beyond the limits of my physical body and living a life full of meaning.

Groundling to Starling

I am no groundling
craning my neck
to see the world.

I am a starling
flying high
in silver skies.

I planned the rest of my excursions through Ireland.

I visited the Cliffs of Moher again, this time on land. I wheeled my way around on the limestone paths that have been around since Neolithic times, 5,000 years ago. As I looked out on the range of the cliffs, the green layer of grass dips into the distant blue ocean. Wind and sun beat down on my face, and in a moment of silence, the soft and sweet notes of a harp reached my ears. I knew I could get closer to the sound and listen to the harp, but this tranquil moment was better left undisturbed.

I soon left the majestic Cliffs of Moher behind and Richard drove me down to the Burren. The Burren is a region formed out of limestone where there grows a rich variety of flora and fauna. The Irish historian, Sean Spellissy, in his book *A History of a County*, recorded the presence of 569 plants and thirteen seaweeds. More than 400 of the plants are medicinal, and the others are used for culinary, decorative, dyeing, grazing, poisoning and, yet, unknown purposes.

In this unique and fertile environment, stands the largest monument to the work of humans in Ireland of ancient times: the dolmen. The dolmen at Kilnefora, County Clare, is called Poulnabrone. This dolmen is known to many as a portal tomb. Archeologists have confirmed that underneath the dolmen are the remnants of bones of men, women, and children dated from about the fifth century. This was a glimpse into Ireland's past, and this excursion can surely be called "a walk through time."

After three days spent in Doolin, my Study Abroad group and I set out for Galway City, the home of the National University of Ireland, Galway (NUIG), where our "studying" would take place. I couldn't wait to see my updated accessible accommodations. I hadn't had a shower since I arrived. The shower at the B&B was too small. To take a shower, I need a bath bench, and someone else has to bathe me. The B&B bathroom was to small and it didn't have a bath bench. I had to take bed-baths. This was one of the hurdles that I had to overcome during my time in Ireland so far.

Richard drove me through the Burren, but this time near the coast, and I enjoyed the landscape left behind by the last Ice Age. There were layers of rock where grass and plans grew, in between the stones. I just watched from the car window as the long-left-behind landscape of Doolin changed into the urban one of Galway.

In NUIG I found accommodations galore!

I was now in my accessible dorm, it was comfortable, and big enough to accommodate my parents and me. I freely wheeled myself around the dorm. But first I needed a shower, a long one.

Up to this point, I had not found any significant barriers to my mobility with Emma. But I am not used to sleeping in twin beds, and on this first night in my dorm, I fell onto the floor in my sleep.

Navigating on campus at NUIG was easy, but off campus accessibility was problematic. I faced one of these situations when I visited the Crane Bar, recommended to me by Dr. Warren G. Frisina.

Since the Middle Ages, the Irish pubs were a center of social, political, and economic exchange, run by monastic orders. The pubs were also well-known for the revelry, dancing, and storytelling. In the eighteenth century, Ireland was dotted with pubs. In the present day, the pubs still keep their role as social and artistic centers, but many of them are closing down.

The Crane Bar is hard to miss because it takes up the whole corner. It's painted in emerald green, one of Ireland's national colors. The pub was vibrant with the sounds of traditional music and started right on the dot at 10:30 P.M. and went on until 4:00 A.M. the next morning.

The Crane Bar is a two-floor building—it's true to its name because cranes naturally nest in high places. But the seventeen-step staircase would not stop me from having a good time. I know the exact number of stairs because my father counted them. He carried me up. On the landing of the second floor, I sat down on a wooden stool while waiting for Emma to be brought up. Once Emma had been carried up the stairs, I had to push people out of the way so I could make room for myself.

As part of the crowd, I looked around at the audience and saw that the entire floor was packed with people: keeping time and drinking ale, wine, and beer to the music. The exchange among the people was continuous chitchat in different languages. The many voices on this floor gave the bar a lively and rounded atmosphere complemented by strands of Irish Folk music.

The group playing was made up of musicians based in Galway who represented different cultures. The first fiddler was of Asian descent. I thought that the racial diversity within the musical group and the audience was an interesting part of the cultural event.

Halfway through the improvised performance, a woman playing second fiddle join in, creating harmony between the two fiddlers as well as a musical competition.

After my night out at the Crane Bar, I dealt with the risks that come with traveling in a wheelchair, especially when it is electric. Emma's charger had stopped charging. My parents had to push the chair around for me to get to class and navigate. The brand of the charger was

INVACARE and in Galway there wasn't one in stock. The closest INVACARE outlet was in Dublin. Luckily we had plans to go there on the weekend.

Meanwhile, my father disconnected Emma's battery. He disassembled it and reassembled it, and connected it again thinking that something was misaligned. He hoped that it would be fixed by this point, but the battery was not charging. He also texted my brother, back in the United States, to see if he could find out if the guarantee on my chair could be applied so that when we got back home, I would have a functioning charger.

My father found out that the manufacturing company was based in Germany and if we ordered one it would take more than a week to get to us. I couldn't wait that long. So, he contacted the INVACARE outlet in Dublin and asked if they could sell a charger to him, but Lisa Wogan, the representative, said that they didn't sell them at retail. My father explained the emergency situation, and Lisa said that she would try to find one, but that she wasn't making any promises.

With the hope of getting the replacement charger, we headed up to Dublin the next morning. We paid Richard for the weekend to make this excursion possible. The drive from Galway to Dublin was three hours and our first stop was the INVACARE warehouse.

At the outlet, Lisa Wogan told my father that they had found a charger, but that they couldn't sell it or rent it, but that they were willing to lend it to us. To our surprise, they didn't even ask for paperwork or credit card to ensure that we would return it.

With the replacement charger in hand I began my travels through Dublin after checking-in at the Radisson Hotel, and I was ready to set off and discover the city.

My travels through Dublin was like traveling through time. I tried to visit as many sites as possible, to be in touch with places that I had learned about in books. My first stop was at the National Library of Ireland for an exhibition titled, *YEATS: The Life and Works of William Butler Yeats.*

Yeats who helped shape the Literary Revival in Ireland during the twentieth century is one of my favorite poets. The exhibition explored the major episodes of Yeats's life, while relating his life to his works, and the socio-historical and political atmosphere of Ireland during his time. It included short films about different aspects of his life with commentary by scholars and poets like Seamus Heaney. Also, the display lead the viewer on an auditory journey through his *Collected Poems*. At the center of the exhibition was a cylinder shaped room with three all-around display screens showing texts of some of Yeats's major poems. I listened to someone reciting them, with great all-surround sound quality. This exhibition was one of the highlights of my first day in Dublin.

Also, I went to the National Museum of Archaeology and History and saw a series of displays titled: *Prehistoric Ireland, Ór—Ireland's Gold, Celtic Ireland, Viking Ireland, and Medieval Ireland*. This allowed me to get a glimpse of the early history of Ireland, one of my first loves. The series started off with a brief introduction to the pre-Celtic and pre-historic civilization of the Irish, the development of Irish culture, including the first Irish language script Ogham, which has twenty letters. The building blocks of Ogham script are a series of right side downward strokes, left side upward strokes, perpendicular strokes, and notches that represent vowels.

The maximum number of notches or strokes used to represent a single letter is five, suggesting that the primary measuring tool of that time would have been the human hand. Perhaps in future a simpler letter based alphabet will be used to reconstruct the faltering Irish Gaelic language, which is now dying. It is only spoken in the western parts of Ireland in Gaeltachts that I look forward to visiting soon.

Unfortunately, on the second floor the building didn’t have indoor lifts, so I couldn’t see the exhibition titled, *Clontarf 1014: Brian Boru and the Battle of Dublin.*

I also went to *The Dublin Lockout,* an exhibition sponsored by the National Library of Ireland. It mapped out the story of how Dublin’s industrial workers protested against the malpractices of their principal employer and factory owner, William Martin Murphy. The exhibition mainly shed light on this event in history that was largely unknown to most people.

My visit to Dublin was a sort of pilgrimage, as a creative writer and a historian of Irish studies.

On my second day, I visited the Abbey Church, colloquially known as “Findlater’s Church.” It has stood there for more than 150 years in Parnell Square. Its architecture combines the Gothic, Romanesque, and Baroque styles. Across from the Abbey church was the Garden of Remembrance, the home of the Irish Freedom Fighters commemorative statue.

The figure itself uses the mythological theme of the Children of Lir. The intertwined figures of swans and fallen men, rise up into sky. It refers to the story of the three daughters of Lir, the Irish sea god, and how they transformed into swans to protect the men of Ireland from future harm in the years to come. For me it is an emblem of personal freedom. The motif of flight is a sort of liberation from my body as a person who happens to have a physical disability. I am free and boundless when I fly with the power of knowledge.

Afterwards, I took a walk across the Samuel Beckett Bridge. One of the plays I read for class here in Ireland was Beckett's *Waiting for Godot*. The cable-stayed bridge has stretched across the South side of the River Liffey since December 2009.

As I crossed the bridge, I passed through the other end of the city, and soon the Jeanie Johnson Tall Ship loomed ahead of me. This replica of the original ship is a floating museum of the story of its namesake's trips across the ocean to United States and Canada.

The original ship is one of the many ships that carried Irish immigrants who were escaping from the Potato Famine of 1845-1849. These famine years were the worst times of this event in Irish history which peaked in 1847, Black '47.

As if the model of the Jeanie Johnson famine ship wasn't enough of a reminder of the hunger, nearby stands the Famine Memorial unveiled in 1997. The set of bronze statues crafted by Dublin sculptor, Rowan Gillespie, depict Ireland's poor looking vacantly in the distance or upward towards the sky. They seem as if they are imploring God or life itself to put an end to their suffering. Standing in front of these statues, the viewer seems small and insignificant, because of the pain and despair engraved in them.

In Dublin, I went to so many places. It was an overload of thrills. I encountered challenges of navigating with Emma, but they have a strange way of making me want more of what I cannot have or what is not easy to get. If I hadn't insisted on taking this trip, I wouldn't be having this Study Abroad experience. If I hadn't been confronted with discrimination at the beginning of the trip, I wouldn't have dared to proposed to my parent that I make my own way in Ireland.

I was comfortable with my choice to experience Ireland on my own. I was part of the Study Abroad program, at the price of being alone most of the time. If it were up to the professor, I might have not been there at all.

One day, I saw that the professor had change her Facebook Cover Photo with the latter-added comment, "My kids on the Study Abroad Trip in Ireland. The whole farm is here." The picture had the heard of cows in the background. All the students were in the picture, except me. I had been omitted from the group. The photo made seem as if there were two groups on the trip I and my parents were one group and the rest of the students with her were the other group. The two groups were and should be separate. This situation on the grounds of my disability was ableism and apartheid personified.

Solitude for anyone is difficult to bear. But, when I am alone I can learn, read, write, and achieve at my own pace. Alone, I am most free.

The Connemara region of Ireland is known for its green hills, mountains, marbles, and its castle, Aughnanure, built in the 16th century. The remains of the castle are three of the four watchtowers, one dome-shape armory, protective stone walls around the perimeter, and the front and west facades. Aughnanure is an impressive sight, and it testifies to the battles the Irish people fought against invaders, including England.

Henry VIII conquered Ireland, but Aughnanure was one of the last fortresses to be overtaken by the English forces. The Fall of Aughnanure is one of the tales of Ireland's past that captivated my imagination to the point that I didn't pay attention to a small incline that was right in front of me. I was “overtaken” by the force of gravity and pinned under the weight of my wheelchair. I couldn’t move at all, because I was strapped into it. For a moment, I couldn’t speak, because I was processing the fact that I had fallen. But the pointer puppy of the groundskeeper came to my side and bark for help.

In the last battle of Aughnanure, the people spilled their blood, and their morale was broken. I didn’t have an epic fall, only a split lip and a bruised arm. But I spilled my blood in Aughnanure and my morale was broken for a moment. After I had recovered and I was alone, the professor confronted me saying, “I warned you that something like this would happen. You should have stayed home.” This comment stung, but neither the fall or the comment would affect my experience of Ireland.

Days later, we left NUIG and headed for the last leg of our journey, a four-day stay at the Gaeltacht of Gleann Cholm Cille. Once there, I chose to wheel through the village to see the rural scenery and I made my way up to the hilly, winding, narrow road, without sidewalks, where the cliffs nestled Gleann Cholm Cille. On my last day in the village, I went to see the Sliabh Liag Cliffs, famed to be bigger than the Cliffs of Moher.

We drove up the hiking trail and I saw the Cliff of Sliabh Liag that loomed large, rising up to meet the foggy skyline. Rays of sun cut through the fog bringing patches of clear sky. Soon the fog was no longer in sight, and I saw the cliff range. The cliffs jutted out of the sapphire-blue seascape of foaming water below.

In that moment, I found myself connected to the works of Irish literature I had read and their characters. The characters were trapped by their homeland, losing themselves in the day to day and wandering aimlessly through their existence. Whereas they felt trap by the land, for me Ireland was freedom.

My trip to Ireland was an act of emancipation. Emancipation from the fear of other people's opinions of how to live my life. Emancipation of my right to pursue my dreams despite barriers, and emancipation from my body in a lasting metaphorical sense. I dealt with ableism, but made my own way, and like a starling I soared high in the silver skies of my dreams.

I left Gleann Cholm Cille behind and began the 5-hour-long drive back to Shannon, enjoying the scenery. I wanted to stop by a local restaurant to have lunch, and Richard suggested that the perfect place to eat would be Morans The Weir**.**

The name of the restaurant reminded me of the first play I read for my class in the Study Abroad program, *The Weir* by Conor McPherson. *The Weir* is a play about a conversation, in a small rural bar, between all five of its characters. It focuses on the role of the weir, a dam, in the lives of the people of the town that could either be Northwest Leitrim or Sligo. The role of the weir, in the play, is to function as a metaphor for the constant flux that goes on in an individual's life and the struggle that one has to cope with. In the Irish experience, this becomes the condition of being stuck: not being able to go forward in life and always looking back to the past.

At Morans The Weir, I requested a table inside despite the beautiful view outside because it was windy. After eating, I asked the waitress if she could tell me more about the history of the restaurant, because I noticed that the buildings cottages had roofs made of thatch. They are remnants of Ireland's rural past, and because of abandonment and pricing are disappearing.

The waitress said she'd better get the owner, Sheila Moran, to talk and meet with me. Sheila explained to me that the business of the restaurant is now in the hands of her daughter, Catherine Moran, the 7th generation of the family. The restaurant goes back more than 300 years.

The Morans were a notable fishing family, and the roots of the family business started out with the keeping of a pub that only served whiskey and Guinness, in the 1800's. Up until the 5th generation, the family business had been passed down to the first-born son, but the first-born of the six generation, Sheila's brother-in-law, died unexpectedly. Then, her husband Willie took over and his mother, Kathleen Moran, affectionately called, Kitty, brought new life into the pub. She made it into a restaurant by adding a signature recipe for Irish brown bread to the menu. The upper floor of the cottage is still a bakery.

After telling me the history of the restaurant, Sheila asked me what I was doing in Ireland and why I was there in her restaurant. I answered that I was with Hofstra University in a Study Abroad Program and I was heading back to Shannon and Richard had thought this restaurant might interest me. She also asked me what I was studying, and I said I was an English major.

Sheila engaged with me in a conversation about Seamus Heaney and she said that the restaurant had a connection to him. She said that Heaney had come to the restaurant ten days before his heart surgery and death, to have a coffee. For them, this moment represented Heaney's last good-bye to Ireland.

Years before Heaney had given the owner of the Morans The Weir a copy of his poem, "Oysters." The poem was in part inspired by the restaurant and Heaney copied out the poem in his own handwriting for them. This copy is framed and hanging on the wall of the restaurant. Morans The Weir was the perfect place to end my Irish adventure.

My room at the hotel near Shannon Airport was not reserved for accessibility by the director of the Study Abroad Program, so it didn’t have an accessible bathroom. My parents asked for a bathroom bench, but the Inn didn’t have one. My parents asked for any type of chair that would fit in the bathtub and/or a shower…There were none.

My father asked at the front desk if he could see a couple of rooms to see for himself what bathroom might be most practical for me. He came back, and we opted to take a room with a shower where he was able to fit the wooden desk chair that was in the room to make it serve as a bath bench.

When accommodated in the new room, my father got the chair in place through the top of the shower, because the door was too narrow. This shower turned out to be a “rocky” one. It was difficult to get in. There was only about an inch of space between my legs and the shower’s wall. When I tried to lean back in the chair, the wooden seat was only supported by three legs since the other leg was wobbling on the uneven shower floor. I was sitting on the chair, my mother was showering me, and my father was kneeling to hold the wobbling chair leg to prevent an accident. After the shower, I was ready to turn in and get rest for the next morning to go back home.

PART VII

On a New Frontier

My last year as an undergraduate student passed and I achieved what I wanted, graduating in four years, right on time. My experiences in undergraduate college carried me further than I had thought possible. My last days were full of preparation and ceremony, including ordering my diploma and its frame. The form asked me to list the majors I had achieved. I put them in without a thought, and to me, the preparations were over.

But a few days later as I made my way through the campus, I met Dr. Frisina along the way, and he greeted me saying, “Congratulations on your achievements.” I thanked him, thinking that he was referring to my graduation. He asked, “Have you received your invitation to the Phi Beta Kappa induction?”

“No,” I said, “ that sounds like something for someone in science.”

To this, he chuckled and said, “Check your emails you might be in for a pleasant surprise. Phi Beta Kappa is for the Liberal Arts which you have done in the English and History Departments.”

I checked my emails as soon as I got home and I found the invitation.

I was proud. From this moment on I was determined to make a mark on the world and lead a life of significance and purpose. How? I didn’t know yet.

I felt humbled and proud that I had reached such heights, but after the celebration came to an end, I felt empty and restless. Then I found out that for a creative writer, an undergraduate degree was not the end for academic possibilities. I discovered a Masters in Fine Arts in Creative Writing existed.

I decided to look around for programs in the country. Over the course of the year, I filled out the applications while enlisting the help of my top three professors and advisors. I applied to

The University of Iowa, University of Washington Bothell, New York University, and Sarah Lawrence College; I was accepted to UW Bothell, NYU, and Sarah Lawrence College. After much thought and compelling offers I decided to attend UW Bothell and persuaded my family to finally make a cross-country move.

A summer day in July 2016

The hammer comes down on the last bolt of the aluminum ramp that gives me access to the house, and the metal sheets fall to the ground. My dad wipes the sweat off his face on this hot day. I lie on a gym mat, in the backyard, looking at the house that is no longer my home. The door is open, revealing an empty kitchen. I smell the dust, and I can see the home remodeling supplies, paint, electric screwdrivers, and a ladder that takes up the empty living room space. Almost three months of sorting things into moving boxes and the Sundays of garage sales are over now. Twenty-three years of my life were spent in that house. All my life. My parents and I are moving to Washington State so I can pursue my Masters in Fine Arts in Creative Writing and Poetics at the University of Washington Bothell.

Many people around us asked why we are moving across the country when there are so many universities right here in New York. Close friends have even said to me that I'm so crazy to have turned down NYU.

A winter day in January 2016

I'm finalizing my applications to the graduate schools of the University of Iowa, University of Washington Bothell, New York University, and Sarah Lawrence College. All of them ask for the same information in the same order, but the real tough question for me is choosing my genre, only UW Bothell doesn't ask me to choose.

April 1, 2016: Decision Day

For my MFA I wanted to study at a place that helps me grow as a writer with a support group and community. I field-tested all the three universities that have accepted me into their programs, and I chose a West Coast school because the program will allow me to explore many writing styles without boxing myself in as a writer in a particular genre.

Metal bolt breaks
three lives are unbound
ready for new ground

I received an email from the graduate office of UW Bothell asking for my incoming student's profile, I wrote my profile but didn't send it.

This student profile tells me what I have done, but more importantly, it shows me a new path for my writing.

boxes and boxes
I can go anywhere with my pen:
Let me explore

Late July 2016

I load Disc 1 of *Call of the Wild* by Jack London, the audiobook edition I got from the library a few days ago. I'm revisiting this book to get myself into the Husky Spirit before I get to UW Bothell, and the best way I can think of is to read the books about sled-dogs and the explorations of Alaska.

Soon, a deep voice comes on through the speakers and reads, "*Call of the Wild* (pause) Chapter 1: INTO THE PRIMITIVE. My ears take in the words and my mind puts together the descriptions and actions of the plot into a mental movie. I'm inside the story, an unseen and silent spectator. When Buck the St. Bernard-Scotch Shepherd, the protagonist, is dognapped from his home in Santa Clara Valley and arrives in the Alaskan wild, the phone rings. I overheard my father on the phone. He interrupts my reading and says, "We got the apartment. We are set for August 8th."

I pause *Call of the Wild* and with my mother we celebrate with high fives.

The Call
A call
Bothell, WA—my new home

After our small celebration for this big moment, I go to the Google Chrome web browser and log into my free Pandora Radio account. I selected my Traditional Irish music station. A moment like this one for me calls for a good Irish reel. "Promontory" by Trevor Jones from *The Last Of The Mohicans: Original Motion Picture Soundtrack,* comes on and I slap my palms on the tabletop, following the music's leaping rhythms. When the track was over I go back to reading *Call of the Wild*. The voice keeps reading where I left off. I'm a spectator inside the story again. Buck is resisting the will of his captors to use him for their own purposes, but he has no alternative and learns to obey them. Now Buck learns the Laws of the Wild among the other dogs that were already mastered by the men.

Soon I'm listening to Chapter 6: FOR THE LOVE OF A MAN. Buck wins a $1,600 bet for his master, John Thornton, by pulling a sled loaded with a thousand pounds of flour. Buck is proving he'll do anything for his master. As Buck pulls the sled, in my mind, I become him, and I begin to feel determined to do the undoable. With new strength I know that I can pull "my own sled" in my new environment: Washington.

After reading this part of the book, I open the draft folder of my email account and press "send" to send the student profile that I have saved for a while.

Buck pulls the sled
I'm not bucking from my task anymore:
SENT

Another day in July 2016

On Facebook, I scroll through my News Feed and see that the UW commencement page has posted a photo of Dubs, the husky, the university mascot. He has a graduation cap on his head covering his ears. I smile and share it on my wall, thinking this will be me in two years. After hours of work, late nights, stress, achievements, and learning experiences, I know I will be at my own commencement in 2018. But before I get to have that moment, I have to get to Washington and go through the MFA program.

I can't get too ahead of myself, I need to relax by listening to the last chapter of *Call of the Wild*, Chapter 7: SOUND OF THE CALL. The voice starts reading, and I'm in the book again. Now Buck is hearing the Call of the Wild in his dreams, and in them he sees a caveman squatting by a fire. Over time the image becomes clearer, and he hears the distant howl of a wolf. This is the Call of the Wild. Buck reacts and leaves Thornton but not before spending one last night with him. Buck enters the wild accepting the call.

As *Call of the Wild* ends, I see that my parents are overseeing the last details while the movers are about to close the truck with all our things inside. The truck goes off Westbound as we stay behind in an empty house. The only things left for us to take are our luggage and laptops. Now with everything out of our hands, the move becomes real: I'm leaving. I'm accepting the call.

The call
I move forward
to a life filled with evergreens, mushing along

Last week of July 2016

Now without a house, we are in a hotel room in NY and I go to sleep to make this last night go faster. It doesn't work. I'm kept awake by dreams of making my own trails in the snow as a UW Husky.

Husky doesn't stand for anything at UW. It's not an acronym, but in my restless dreams, I make it one: Hope, Unity, Skill, Kindness, Yearning.

Huskies run in snow, always looking forward
the night of one life passes slowly for another to begin

August 8th, 2016

On the five hour flight to Seattle, WA, I watch the live-action remake of *The Jungle Book* to make the wait for my arrival bearable. I've never read the book version by Rudyard Kipling, but the scenes of nature in the movie are all I need to see right now.

The captain announces that in fifteen minutes we will arrive at SeaTac Airport. Everyone exits the plane except us. When we boarded (as we usually do), we requested for my electric wheelchair to be brought to the airway. But now that we landed, time passes, the cleaning staff cleans the plane, and my aisle chair assistants suggest that we exit and stay in the airway and wait for the wheelchair there. We accept reluctantly, and I'm strapped into the aisle chair, we wait, and wait, and wait…until one of the assistants gets notified via radio that my wheelchair is on its way, but the motor isn't working. Time passes. We are taken to the waiting area at the gate.

Later—

—I see two security guards pulling and pushing a large wooden cart with my wheelchair on it.

My dad tries to see how to solve the problem…there is no fix. The motor has to be replaced. I have no wheelchair for at least two weeks.

Good news: I land safe (my physical body)

Bad news: my wheelchair (my exoskeleton) is cracked

After a long trip and a broken wheelchair, we get the keys to our apartment. White walls, empty rooms, and the sounds of construction outside welcome us to our new home in Bothell. All these annoyances greet us, but we will build a foundation for new dreams on this new frontier.

Part VIII

Tethered to Technology

> This way of life is marked by an endless succession of material objects, yet it is a life that curiously seems to float beyond the terms of the real world.
>
> —Arthur & Marilousie Kroker, *Code Drift* (67)

Technology is anything humans use to make life easier and more productive. Technology is an integral part of my life. I use a power wheelchair and a computer.

Over the course of time, my technologies have changed from pencils with special rubber grips molded to my hand to advanced computer programs. My computer is an iMac, and it has third-party specialized software for reading and writing. The technologies in my Assistive Technology (AT), and the way that I interact with them, are in constant flux. At best my relationship with AT is like a stream of input and output with glitches. During these glitches I realize just how much control over my life I have because of my AT and how much control my AT has over me.

With my wheelchair, I can navigate the world at the touch of my fingertips, but sometimes the machinery acts as if it has a mind of its own and doesn't obey my commands. This give-and-take relationship gives me mobility in the outside world. My wheelchair gives me freedom.

My wheelchair has different speeds and settings. On the console there is a screen, and behind that screen is another screen, and behind that secondary screen is an emergency screen; the layers of screens give me an overview of the functionality of my wheelchair. On that console there is also a dial with a tortoise at the bottom and a rabbit on top, meaning low and high speed respectively. The dial lets me choose the speed up to 6.8 MPH, and my wheelchair weighs 329 pounds.

The freedom that my wheelchair gives me has its limits. I remember once during a winter afternoon during my undergraduate senior year at Hofstra University, I was running late to class, a poetry seminar. It was 2:40 P.M. and class started at 2:45.

Driving at high speed, I felt the wind blowing around me as it stung my face. My assistant, my mother, walked ahead of me to open the door of the building (there was no ADA automatic door switch).

Everything in the going-into-a-building scenario was okay. Then I heard the click-click-click of my chair alerting me that something was wrong. On that cold afternoon, my wheelchair simply stopped, revving like a truck stuck in the mud. My chair couldn't have picked the worse time and place to stop working.

I was half inside and half outside the building.

My chair console had a screen in the middle with the battery display that turned from green to red, meaning there was a problem. Only half an hour ago, I checked the screen, and it showed that my wheelchair was fully charged.

I turned the wheelchair off and on to restart it. The third screen appeared, it displayed the same fire-red light (indicating that something was OBVIOUSLY wrong), and at the bottom of the screen, a yellow warning sign appeared with the word "fault!" next to it.

I turned my wheelchair on and off repeatedly to reboot it.

The screen was the same.

My mother asked, "What's wrong?"

"My wheelchair is dead."

"Check the secondary functions."

I pressed the button in the middle of the console to activate the secondary screen, and four arrows appeared. I moved the joystick forward, and the chair tilted back slowly. I moved the joystick to the left and my legs elevated. I moved the joystick to the right, and my seat was raised. I moved the joystick backward and the back of the chair extended outward to put me in a laying down position. I did all the position adjustments in reverse and again tried to move the wheelchair forward, but nothing happened. The yellow warning was still there. I was stuck.

In silence, my mother put my wheelchair on manual and started to push 329 pounds of metal and 94 pounds of human. A five-minute walk down the hall turned into 20 minutes.

I thought to my wheelchair, *why can't you work when I need you to*? Sometimes I think I would be better off without a power wheelchair.

If I didn't have a power wheelchair, I would be as stranded in a manual wheelchair. I would have to ask the people around me to move me everywhere and go at their pace, and what if they didn't want to move me around, or were too tired to?

The fact, the fact, the FACT: I'm bound to a wheelchair, and this power wheelchair is the best that I have got so far.

My wheelchair allows me to engage with the world on my own terms. I don't have to ask people to push me to get from point A to point B. I can go at my own pace and not lag behind.

Am I that free?

I'm free to move with my power wheelchair for as long as the battery power allows. But my wheelchair seems to have come with an invisible contract:

> *This wheelchair ensures a long range of mobility for the user, with a variety of speeds to move with and bodily positions to be used at will.*

> *But the user should be aware that he or she is subject to the limits or constraints of the device, or its occasional bouts of unwillingness to obey the command of the joystick, that the user will utilize to operate the device.*
> *The user of this wheelchair must be mindful that it might cease to function at any given moment and it's her/his responsibility to resolve these technical issues.*

I don't remember signing on the dotted line of such a contract.

I do remember the fresh sense of freedom when I get a new wheelchair. Also, I remember after driving it a few times around the empty hallways of my wheelchair provider's center saying: "I'll take it!"

This wheelchair that I'm driving now is my third one, and each one was different. Each wheelchair had its own set of functions and challenges, only to be found out after an undefinable period of use.

The wheelchair gave me mobility and power over my own body, but, I often ignored the battery.

It's annoying to always have to remind myself that I'm tethered to a device underneath me that allows me to move, but puts a time limit on my freedom, usually eight hours, depending on the terrain and the temperature. Sometimes the battery life is unpredictable.

It took twenty minutes to get to the classroom. My mother knocked on the door, and a classmate opened it so we could come in.

As I was set in my spot at the discussion table, the professor stopped class for a moment and said in her customary cheery voice "You're here. Finally! What happened?"

"Its cold out, and the joystick of my chair got stuck: it froze."

"Joystick? Joystick?" she exclaimed wagging her finger at it. "That's no joystick. That's a *misery* stick!"

I laughed.

The *misery* stick incident taught me I'm not always going to be in control of the devices I use. My devices give me the power to move, but that power can be taken away when I least expect it. My wheelchair gives me freedom on a leash. Sometimes, I have a lot (eight hours), and sometimes I have a limited range.

Sometimes my wheelchair has a will of its own. This relationship is like a tug-of-war, where I control the wheelchair for a while, and then at the most inconvenient moments, the wheelchair refuses to obey me and I am neutralized.

When I'm in it, the wheelchair becomes an extension of me and, in return, I give the wheelchair a kind of humanity. If the wheelchair is left alone, it's just a chunk of metal, sitting around waiting to be used.

With my wheelchair, I'm a person of flesh and bone who happens to have an exoskeleton of metal. I'm like a snail. A snail has a shell fused to its back because of its biology, but the snail can discard one shell for another when one is damaged. My wheelchair and I become one unit, fused together by the belt that ties me into it and after five years it's replaced by another one.

Changing my wheelchair every five years is mandatory and every time I get a new one, I have new functions at my disposal. The new wheelchair becomes the new standard, enhancing my quality of life. But before every upgrade, I decide the aesthetics of my most important prosthetic.

I call my wheelchair a prosthetic because it is external to my physical body. If my wheelchair doesn't feel right for any reason, my wheelchair supplier and I won't make the final order.

Getting the right model takes time, but the adaptation and personalization stage is crucial. The whole day is taken up with tweaking. The seating. The footrests. The buckles. Speeds. Joystick commands. Secondary mobility functions…My wheelchair is almost ready to order. Except for one detail: the color.

After hours of work my wheelchair supplier says, “Well, now that we are putting the finishing touches on your first adult-sized power wheelchair how do you feel?”

“Great, I can’t wait to break it in.”

“Good. The more you use it, the more you’ll develop a working relationship with it.”

“Sure.”

“Maybe, you’ll give it a bit of *personality*.”

“How?”

“Change the color.”

“Why would I do that?”

“You’ll be *personalizing* it, taking more ownership of it.”

“We’ve just spent time adapting it to fit me, that’s all I need.”

She insisted on changing the color, and I replied, “If I change the color people will be more interested in the wheelchair than in me. I don’t want people to see the wheelchair, I want them to see me. I want it to be neutral. I choose black.” She insisted and I added, as Henry Ford said “It can be any color as long as it is black.”

I don’t consider my wheelchair an accessory to be changed on a whim, it’s a vital part of my life. My wheelchair is part of a large AT suite that gives me that ability to do what I want when I want. AT augments my capabilities.

Aimee Mullins, a fashion model who is a double amputee and a disability rights activist, champions the idea of “augmentation.” She argues that disability is no longer a state that needs to be compensated for with technology to increase the quality of life of an individual.

Technology isn’t then a sign of lacking functionality, but of augmentation of ability. In this sense I have the power to become the architect of my identity as a person that happens to use a wheelchair. My inability to walk is surpassed with my wheelchair and my disability itself becomes secondary. It is secondary in the sense that where there was once lack, there is now possibility for enhancement. My disability then becomes the realm of possibilities where I choose what and how to improve.

Technology is an integral part of my identity. I and my wheelchair become a unit, establishing and performing a bionic relationship. Technology is then like a supporting actor to the main character of the person in the play of life, and the device becomes a *second skin* that allows the person to exist as an agent in the world.

Augmentation allows a shift away from the absence of ability to the presence of potential through the use of technology. Technology is a means of edifying an empowered self that previously was locked inside a body that could not or wouldn’t respond to the will of the individual. Technology is a medium through which the individual proves that it’s not just deficiency that determines the value of a life, but it’s rather the willingness to improve life that reveals its worth.

This unimpeded self that emerges with technology is also subject to faults and glitches. Imagine that your car or your computer stops working. In the face of this setback, you have to backtrack to a previous form of technology, like a bus or a pen.

This backtracking brings a delay in productivity, but it also shows how dependent people have become on the technology they use. At this moment, the activity becomes difficult for us to proceed without the technology that we have just been using. With the absence of that technology we manage to do our task, showing the ability of adaptation that humans have.

From the beginning of evolution, people have relied on different tools to survive and build civilization. We have developed technology over time to facilitate tasks, but when those technologies fail, we continue life, having never lost our ability to adapt.

The ability to adapt in a world of digital technology is ever-present and is part of the evolution of our world. Humans have to constantly stay up-to-date.

Day to day technology is improving and with this improvement come updates that lead to software updates that in turn result in system-wide updates. These chains of updates are meant to create the very best technology available for use and efficiency.

But, even the very best of data has its own broken synapses, overloaded consciousness, flickering memory, software glitches as Arthur and Marilouise Kroker put it in *Cold Drift.* Then the moment of a technological breakdown affects our performance while revealing that we are used to the pattern of constantly updating our systems to keep up in life. Not updating technology can render our devices obsolete. This also applies to my wheelchair, if I don’t update it, my body becomes *obsolete*.

As technology develops we evolve, and as we evolve technology also develops. This type of evolution is what Stephen Hawking called not biological evolution but exponential evolution. “Exponential evolution” is what makes humans become integrated with technology from using it as a tool for work or as part of the self as a component of one’s identity.

In exponential evolution, new devices replace older ones in a very short time. Think about how many times we have to update the apps on our devices like telephone or computers. When it comes time to update we can either lag behind or keep up. Also, humans in this technological world can design their lives around technology or otherwise be absorbed by it; technology can be used to empower or overpower us.

In my physical and artistic life, technology is a tether that augments my capabilities. My wheelchair is a prosthetic that gives me functionality, while my computer-based AT enables me to read and write.

Most of the time that I've used computers, I've used a Dell PC laptop and it didn't matter what computer model I had or what operating system was integrated into it. A computer was meant to store a data file, that was all I cared about.

My PC had the best memory core and the best virus protection available, but one day while I was writing a final paper during my undergraduate senior year it crashed. Power was out in a flash. When I turned it on, I found that I lost my paper.

At that moment, I remembered an instant message conversation I had had with my brother where he tried to persuade me to switch from PC to iMac to resolve these crashing problems. He said that all my data would be saved in the cloud. My rejection was based on the fact that another operating system would mean having to go through a big learning curve.

Now with my iMac, a graduation present my brother gave in 2015, I realized he was mostly right. Along with the computer, he gave a year's pass for Apple classes to learn to use accessibility features on the Mac and make my work easier. I was looking for a way to enhance my reading and writing. I tried the standard suggestions of the technician, but I found that they lacked many features to fit my needs. I needed to add third-party programs.

The programs that I added to my iMac are TextExpander, that allows me to write quick notes; Kurzweil 3000 is text-to-speech, audiovisual, and reading software; and CoWriter Universal allows me to use fewer keystrokes to type.

I have found that sometimes technology is both an aid and a hindrance. Once I got these programs installed, my iMac was fully operational for my needs, but after some time working with this AT, my iMac suggested to update the operating system. I did. The system rebooted, but when I was ready to work with my computer, to my SURPRISE, I discovered that my third-party AT programs didn't work.

The new system had locked them down. I had to go to an Apple store and have a technician to reinstall the previous operating system, but in that process, I LOST MY AT, and I had to reinstall all the programs again and customize them. Installing the programs isn't a big deal. The challenge is customizing them once again.

With this experience I learned that I cannot update the operating system again at the risk of losing my AT.

I use my computer base AT programs by switching back and forth between them.

I've reached a point where I maximize their functionality by keeping them active as I work. In isolation, I can type my shorthand commands with TexExpander. I can upload a file, a book, or a document that I'm reading and a synthesized voice reads it to me with Kurzweil. CoWriter allows me to write a full-length ten-page document in a couple of days, whereas if I try to type it out just with my fingers, it would take me a couple of weeks if not months.

My AT programs work fine, but I can’t use them together; they seem to get jealous and don’t want to cooperate. I write using a succession of programs throughout the process. Learning to use my AT is a process of input and output with glitches. This process of writing is what I think of as writing with an invisible hand.

After moving to Bothell, I prepared for the writing phase of my MFA by signing up for the AT I would need. My AT has a set of built-in voices for auditory feedback.

Searching for the perfect set of technology took years of wishing for miracle solutions, finding that many of the programs didn’t stand up to the tasks that I needed them for. Dictation software was and is my biggest failed attempt to work efficiently and independently during my writing production. Text-to-Speech technology didn’t work for me because my voice often changes its pattern. So the only function that is close enough to dictation and doesn’t involve vocal input is transcription.

CoWriter is a program that I adapt to my visual and auditory needs. Visually, a bright surface bothers my vision, and with this program, I can choose and change my writing window screen background to a “calming” blue-green color. Also, I’m able to choose the writing unit size from three options: word by word, sentence by sentence, and paragraph by paragraph. I choose sentence by sentence because word by word seems choppy, and blocks of text augment my strabismus that makes me see double. The sentence by sentence mode allows me to focus on my writing, but is more like writing idea by idea. My sentences are the length of my thoughts. They are sometimes as short as a pair of words or sometimes as long as six lines.

For auditory accommodation, I chose the Australian female voice “Karen,” this voice is best for me since the American voices male or female are sharp for my ears and the standards synthetic ones are robotic.

I’m working with my disability to write, I’m not working against it.

While I’m writing with CoWriter, I type the first two or three letters of the words that I want to write, and immediately a numbered list from one to nine appears. From this list, I type the number of the word I want to use to build my sentence. Then I enter the ending punctuation to the sentence, and the sentence appears in my Pages document instantly as if written by an invisible hand.

To write: I write with letters and numbers.

The program comes with three basic dictionaries 6K words for beginning writers, 12K words for intermediate writers, and 40K words for advanced writers. I use the 40K dictionary because it allows me to write a variety of sentence structures and develop my style while growing my dictionary by adding new terminology.

CoWriter makes my writing easier in typing the words but it interferes when I try to input the mechanics of writing. My first draft is always full of omitted words, typos, missing punctuation, and grammatical errors. As I write I see the errors, but I choose not to correct them, because if I do CoWriter becomes slow in its transcription time and may delete the part of the sentence that follows the mistake. For people with efficient fine motor skills, these corrections are not a big deal, but I only use one finger. Inefficient as it is, it is the best I have. To deal with this problem, I opt for writing the idea down and produce a “messy draft.”

Once the ideas are down on paper, I require someone to read them to me and, as the person, reads I make corrections. During this phase of my writing process, I rely mostly on auditory feedback.

I don't mean to say that the way I work is the best way for other people with disabilities. Each person with the same disability might work differently with another AT program, I just mean to show how things are for me.

After all, all the AT in the world can't take away the making of mistakes. It's like practicing a dance for the first time. The beginning dancer steps on toes as she goes. AT, for me, just facilitates what my body can't do well, because of my limited fine motor skills. My hands along with CoWriter make what I write, but it's my mind that creates and builds the narratives I'm crafting.

With the use of AT, I might be more independent in my writing process but, like any other writer, I need readers to know if I'm conveying what I want to say. I'm co-dependent on other people and technology.

As technology improves and comes into my life in better forms, the experience of a life with technology and specifically AT will grow as well. This is because a life with technology is in a constant state of trial and error, and a stream of input and output with glitches. The faults of technology show me that life is dominated by constant evolution and the experience is far from over. The interaction between myself and AT from my wheelchair to my computer-based AT programs is in itself a world of pixels that has to be continuously adjusted and reassembled.

Part IX

Unbound

I choose to live a life full of the experiences gained from learning and traveling. These experiences expand my world, taking me beyond my body, my home, and my neighborhood. I am constantly pushing against my body's limitations, as a person who happens to have a disability navigating the world in a power wheelchair. Some people see me as a disabled person, but I don't let how they see me affect how I see myself.

I have come to understand that my body is the space I occupy in the world, but my mind is the territory that I claim for myself. My mind is the one muscle I have control over, and it has allowed me to fuel my unwavering drive for accomplishment.

I am a person who is used to going from project to project with confidence. But after getting my MFA degree, I am at a crossroads with many opportunities available to me and no set path.

A few days after graduation, I'm going to Mount Rainier for a residency at the Mineral School. After my residency, I am unsure about the road I will take. I could be traveling across the country on a road trip with my parents or I could fly to the East coast, live there for a year while looking for residencies or apply to Creative Writing PhD programs.

I have always faced challenges from the physical outside world and from social barriers. But when barriers get in my way, I have the urge to overcome them. Obstacles reaffirm my desire to prove I can accomplish what I want. I thrive on competition.

At this moment in my life, I'm just hovering in the air waiting for opportunities to come my way. I don't have obstacles to challenge me, and there is no fun in just drifting through life, waiting for it to happen.

I feel like I don’t have control over what is going to happen in the future, but I still have a dream. I have a dream of continuing to write and having my work published. I want to share with my readers my belief that the written word can transform lives through provoking thought and conversation.

I want to build a career as a writer, but I don’t see a clear path I can follow. There are no definite milestones that can assure me I am going in the right direction. But the mastery of any craft takes time and discipline.

The pursuit of my writing career has made me think that my life is like climbing a mountain. I am at the bottom and everything is daunting. I muster up courage, take a foothold and start to climb. With hope, I occupy my whole self with my dream, and I know I shall achieve: time allowing.

My determination to pursue my dream is firm, and it will demand labor. But like a sculptor who does not complain about the clay that is collected under her fingernails, or the dryness of her skin, or the dust that fills her workshop, I will not run from the inconveniences of my craft.

I know my dream of having a life as a writer will involve messy drafts, editing, revising, re-drafting, submissions, and many rejection letters. But the rejections will mean that I have not found the right home for my work. The submission forms that need to be filled out to find homes for my pieces in journals and publishing houses will come with waiting times. I am willing to wait, and endure the process of sending work and keep writing until I make my own path.

The dreamer in me is resolute like a miner in search of a vein of precious stones behind a rock wall. The miner has to strip away the rock and mud to get what she wants, while fighting the urge to quit. Rock is the only thing standing in between her and the precious stones.

The dream is there but at the same time just out of reach. In this in-between moment of success or failure, courage returns. Exhilaration passes through the body of the dreamer making a new woman, invigorated by the pleasure of achieving the dream knowing she will brake through the wall.

As I look ahead, I hold onto my optimism to see myself achieving my dreams. I am bound to the earth but I am unbound with my dreams. My mind is the vessel that will take me towards my future. I will not shy away from challenges. I will endure.

Finding My Language for Disability in *Unbound*

Disability is a part of my life, and to me the topic was too private to write about. But disability has found its way into my writing over the years. It was in my poems and in the blog of my Study Abroad trip in Ireland. During the first quarter of my MFA I wrote “New Trails” where I described the problems I had with my wheelchair when I first landed in Washington. The reaction of my cohort made me think it was time to tackle the challenge of writing about disability. So I wrote this memoir.

In the process of writing the memoir, I began by putting together all the pieces I had written about disability in my life, in poetry and prose. Afterwards when I met with my thesis adviser, Rebecca Brown, we talked about how I should take a look at contemporary memoirs about disability to get a sense of the genre. As per her suggestion, I read *Body Remember* and *The History of My Shoes And The Evolution of Darwin's Theory* by Kenny Fries, *Plain Text: Essays* by Nancy Mairs, *Planet of the Blind* by Stephen Kuusisto, and *One More Theory About Happiness* by Paul Guest.

In the memoirs, I found that the authors talked about their experiences with disability, particularly about the nature of the disabled body. I felt uncomfortable with the attention they gave to the physicality of their disabilities, and after some time of reflecting about my discomfort, I realized that I didn’t want to talk about my body as a physical object and the transfer of control that is inherent in my disability. Instead I wanted to focus on the development of my identity as a person who happens to have a disability. I wanted to share with the reader my growth as a person through learning. My memoir was going to be a window into my mind and process of thinking about disability. In the memoir, the reader finds how we are alike in the ways we think about ourselves, feel about the world around us, and dream about what the future holds.

I started to map out my disability experience by going back to my thesis proposal and my second-year plan. In my proposal, I stated that I intended to write a full-length memoir using poetry and prose. My memoir was going to be about my life as a person who happens to have a disability, while constantly encountering social barriers in the form of people's perceptions.

In the process of writing this memoir, I engaged with the following questions:

1. How did the perceptions of family members, friends, and teachers, shape my earliest self-perceptions?
2. How did these points of view help or hinder my development?
3. What has made me want not to resign myself to my limitations?
4. Where does the stigma surrounding disability come from and why?
5. What lives, real or fictional, are in dialogue with my experience of disability and sense of self?

Also, this memoir is a follow-up piece to my talk at TEDx Everett *Tearing Down Walls - Building Bridges* where I shared my life's story. It was a great experience, but I was unsatisfied with the wording I used to talk about myself, and the language of disability and self-representation. Then the language of disability became a main concern to address in my memoir.

I decided to go to the roots of my disability experience. I found that it was closely associated with the negative memory of being singled out as "disabled" (in second grade) when I was introduced to the book *Helen Keller* by Margaret Davidson. This is a moment that I describe in Part 1 of my memoir that left me with a sense that the most important thing about Keller was her disability. The only way I was going to get past my negative impression of her was to read her books and I read all of them.

For half of the summer before the second year of my MFA I read continuously about Hellen Keller and for the rest of the summer I read about the life of Stephen Hawking. After reading about Keller and Hawking, I put together the first draft of my thesis. When it comes to Keller's work, the most influential books on my memoir are *The Story of My Life* and *The World I Live In*. They showed how Keller gradually understood herself as a person in the world who was given independence through learning, a parallel to my own life experience.

In the writing of the memoir, I didn't realize that there was a direct connection between the books that I have read in my life and the development of my identity, as Rebecca Brown pointed out to me in one of her revision letters. Literature is synonymous with my freedom, because when I read or write my disability becomes irrelevant and my mind is what matters. In the many books about Stephen Hawking, I found that his disability changed the way he worked as a physicist but didn't stop him from doing it. For him, as for me, disability is just a fact of life.

In my memoir I mention my disability as something I often ignored, not to be frustrated by my body's inability to function as it should. I acknowledge that I have a disability, I use a wheelchair to move around, and I need technology to live my life as I want to. These devices are part of the way I move through the world. However, I consider these devices extensions of myself rather than as integral parts of my identity. To show this, I have consciously chosen to use phrases such as "I use a wheelchair" instead of "I am wheelchair-bound." The choice of this kind of language puts me as a person at the center of my work and not my disability.

My identity as a person who happens to have a disability has changed over the years. In Part 4 of my memoir, I discuss the social aspects that come with having a disability, such as people's misconceptions of people with disabilities, discrimination, and ableism. To talk about these social issues, I explored disability theory culled from different sources, including videos like *Aimee Mullins on Today Show, The Aesthetics of Prosthetics: Aimee Mullins, Changing my legs—and my mindset, The opportunity of adversity,* and *My 12 pairs of legs.* These videos allowed me to understand the relationship that exists among the individual with a disability, the technology she/he uses to navigate in the world, and society.

The hardest part of writing my memoir was the social critique of people's perceptions about disability. I narrate the experience of my life while making the reader aware of the social backdrop that surrounds me. In Parts 4 and 8, I talk about my relationship with my disability, and my sense of self as an individual in relation to technology. In terms of technology, I discuss my wheelchairs while also giving the reader a glimpse of how I read and write.

The title of my memoir is *Unbound*. I chose the title after much debate with myself. The title was inspired by the line "Your mortal coil sprang back unbounded" from the song "This Gives Life to Thee" by Akala, and the song, in turn, is based on William Shakespeare's canon of works. I chose *Unbound* to reflect my central theme of freedom, and because my work is in conversation with many writers I have read over the years. All those books have influenced my life.

During my MFA I have been exposed to the poetics of many thinkers like Lyn Hejinian and Fred Moten. From them, I have learned the importance of speaking or writing in a community and the reinvigoration of language. My understanding of these ideas came out of Professor Jeanne Heuving's class BCWRIT 510 Writing and Cultural Change.

Through my explorations of what poetics is, I have come to think of it in terms of Lyn Hejinian's definition:

> Poetics is always in an unbounded, excessive relationship to its art, which may in part account for the difficulty one has in defining the term. It is more than theory and more than practice; it is what identifies an artist's largest aspirations and discovers the ways those become manifest—the ways they are activated and provided with the manner in which the artist applies him—or herself to realizing those aspirations and, when lucky, something more besides—expanding, perhaps by virtue of their inherent contradictions, between affect and structure, materiality and sensibility, aspiration and patent failure, ostensibility and abstraction, assertion and silence. (From "An Art of Addition, an Eddic Return," unpublished paper given at first Fall Convergence.)

I have taken this interpretation of poetics to mean that a writer should explore the subjects that occupy her mind the most and these subjects must drive her to be compelled to write.

Poetics emerges through the writing; writing comes first and poetics follows. Through the act of writing, the writer's interests come up repeatedly and turn into "fascinations and/or obsessions" as Hejinian calls them. Fascinations and obsessions are then at the core of a writer's poetics. In my case the nature of disability on the personal and social levels has been the fascination at the center of my writing during the MFA.

As my poetics takes shape, I realize that poetics is an ongoing "process of becoming" as Tracy Morris said at the Fall Convergence. At this moment my poetics is to follow the lead of my fascinations as they assert themselves until others come to take their place. Then poetics is not made up of a fixed set of "fascinations and/or obsessions," rather a writer's poetics is ever-changing and in constant flux.

In the excerpt from *The Language of Inquiry* titled “Who Is Speaking?” Lyn Hejinian shows that writing is a form of communication that constructs the world that the reader is entering through reading. Language constructs the world and presents the predominant perspective of the society in which and for which it is being written. Consequently, language becomes a form of presentation and representation of a community and/or society.

As Hejinian states, writing is more than just a writer’s way of answering why and how we write through the practice of writing. In her discussion of poetics Hejinian outlines some of the questions that a writer may ask when writing or speaking:

1. Isn’t incumbent on me to break through others’ noise and my own silence so as to speak? If so, how so?
2. Having broken through into speech, what should I say and what should it sound like when I’m saying it?
3. Is it important to speak?
4. Is it necessary to do so?”

These questions have allowed me to understand why I am writing this memoir. I am writing it to get rid of the discomfort of talking about it to others unless I am asked, to understand how my relationship to disability has changed, and to develop a sense of the language used to talk about disability. My answers to these questions about poetics have made me realize that in the process of writing I had to repurpose the pre-existing language of disability. I took a look at Fred Moten’s theory of reinvigorating language.

In the video “The Touring Machine: Flesh Thought Inside Out” Fred Moten talks about the responsibility of the writer to write about a subject in a different way. This reflection on writing in a new way references the depiction of slavery in narratives, he states:

> I am not just interested in reciting the sad horrific common narrative of people whose personhood, body, souls, and spirits where reduced to flesh and to things or objects or commodities—it’s not that I am trying to say that story shouldn’t be told, what I am really trying to say is, that *that* story *can* be told. If you tell it, it has to be told in an amazingly distinctive way to take on the task of taking repossession of the language used to tell it, to cause a fundamental disruption of that language [to create a new language for a new view] (00:41:27-00:42:19).

From these remarks (that I have transcribed from the video), Moten is saying that it is ok to write about something that has already been written about with a new language and to create a new perspective for the readers to embrace the subject in the story.

Finding a new language with which to talk about disability launched me into asking questions about the meanings and connotations of words and word orders. For example, I already knew about my preference for describing myself in terms of person-first language such as “I happen to have a disability,” but I didn’t know that some individuals liked to use disability-first language like “I am a disabled person.” The different ways of self-identification showed me that the language of disability can vary from person to person.

There is no fixed language for disability and disability identity. Each individual develops her or his identity and language. To further my understanding of disability-identity development, over the past year I joined a primarily online support group called Here and Now—Washington Paralysis Network. When I first joined the group, I asked the members what was the best way I could identify as a person with a disability. A member said that I should stop worrying about how to identify myself and just do it and try many ways and see what stuck. This answer lead me to understand that in the community of people with disabilities there is a spectrum of identities that one can explore and be at any one time. In my early life, for instance, I was labeled as “disabled” by other people, but now I define myself as a “person who happens to have a disability.” For now I am comfortable with this identity.

In my memoir, I am telling a story about understanding myself as a person who happens to have a disability, and at the same time I am showing the reader contemporary arguments surrounding disability identity development.

To do this I watched several videos about the topic that I have listed in the bibliography of this thesis. Although I haven’t referenced them in my memoir directly, these videos have provided me with many perspectives about disability. By watching them, I came to understand that whatever language people with disabilities use to talk about themselves, we all aim to do the same: present ourselves on our own terms. We aim to let our voices be heard and be appreciated for who we are.

I hope that in the process of writing my memoir I have been able to narrate my life experience as a person who happens to have a disability, as a person who faces ableism, as a person who uses technology to augment her capacity, and as a person who is finding her way in society. I am proud to say that I am one voice among many others that seek to break the silence about disability. I feel that my memoir has freed me from the fear of writing about my disability experience. *Unbound* is a narrative about my disability experience, and it has also given me power over my story, something I didn’t have before I wrote it.

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Yours,

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