Mirror, Mirror

An intimate look at what it means to have immense pride in yourself while
being completely vulnerable in an average-size world.

by

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Abstract

This thesis is written in the form of an autoethnography. The author explores the journey of finding Dwarf Pride despite having a complicated relationship with herself. The researcher discusses how loving yourself and being comfortable with who you are is not always easy when the world attempts to put boundaries on who you should be. The researcher discusses her journey in finding Dwarf Pride beginning with a discussion on the history of Little People, the impact that history has on today, the current state and what is needed for future change. This autoethnography is written sharing lived experiences and theory and answers the questions, how does one find pride within themselves when society views you with curiosity and disregard? Why is it appropriate for society to ridicule someone strictly based on their looks? How do we, as a society, change to truly be inclusive of all?

Acknowledgements

I would like to start by acknowledging that I am writing this autoethnography while situated on ancestral lands, Treaty 1 territory, traditional territory of the Anishinaabe, Cree, Oji-Cree, Dakota, and Dene Peoples, and on the National Homeland of the Red River Métis.

There are so many people that I would like to thank and who assisted me throughout this journey. Starting with my advisor Dr. Diane Driedger for her invaluable guidance and support. In addition, I would like to thank my committee Dr. Nancy Hansen and Dr. Charlotte Enns for their guidance as I would not have been able to complete this work without their incredible insight.

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Dedication

For Yale

Second chances are the best chances.

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I do love all I am by Samantha Rayburn-Trubyk
Love is a wonderous thing and self – love is even better.
Loving my whole self has been hard and the road has been more of
a marathon, not a sprint, but loving my whole self has been worth
it and the benefits outweigh the rocks on the journey.

Chapter I: Introduction

“The greatest sources of our suffering are the lies we tell ourselves” (Van der Kolk, 2015, p. 11).

My thesis explores my journey to finding Dwarf Pride and my complicated relationship with myself. I explore how loving yourself and being comfortable with who you are is not always easy when the world attempts to put boundaries on who you should and should not be. Finally, I explore how loving yourself does not equate to a perfect daily existence.

I discuss my journey finding Dwarf Pride starting with a discussion on the history of Little People in society and the impact this history has on today. I discuss the current state and what is needed for future change through an autoethnographic form of storytelling. I write this as an autoethnography about my lived experiences and use experiences that, according to Ellis (2004), “knock me for a loop and challenge the construction of meaning I have put together for myself” (p. 31).

This autoethnography was researched utilizing a variety of resources documented in the literature review. The literature review consists of articles, websites, documentaries, and books as well as a review of essays previously written by disabled researchers. The literature review reviews disabled authors, in addition to authors born with dwarfism.

This autoethnography is a personal story that forced me to be vulnerable. Personal stories, theory, and resources are added when sharing my journey to finding pride and self-love.

It is my journey and I hope it will inspire others to look inside and find their own sense of pride and self-love.

In the spring of 2022, my husband and I were enjoying a date night at a local lounge. On this night, we were playing VLT’s (Video Lottery Terminals) as we often like to do on our date nights. The machine that we were playing was located in an aisle between the bar and other machines. My husband was about to press the button to spin when I noticed someone standing close behind us. The person standing behind me was a white, able-bodied man approximately late 30’s and was holding a cell phone. The phone was angled in a way where it was obvious that I was the object of discussion. I was the conversation and the joke within it.

When you grow up as a dwarf, you are always keenly aware of your surroundings and the actions of others, always. Your mind is constantly racing and analyzing your viewpoints as you leave the safe zone that is your home. Ahead of time, you often think about whether you want to tackle that errand, that coffee with a friend, or that outing based on the pre-planning that must go into every venture out of your safe zone. There are often days where the emotional toll is not worth the outcome, and you choose another day to leave the house.

As a 41-year-old adult born with Achondroplasia, a form of dwarfism, who has experienced this type of incident more often than I can count, it takes a lot for me to become upset with these constant scenarios. This one was different. This one rocked me. This one made me feel particularly awful about myself. I have worked tirelessly for the past several years advocating for Little People and hoping that with each win, we would move the needle on public acceptance and less on the more common occurrence of public mocking or ridicule. This incident made me feel that all progress was lost. It was 2022, and I could not understand how these situations were still occurring despite the constant flow of information and knowledge that we have gained despite the wokeness that this world claims to have, and despite the political correctness that all are so keenly aware of. How are we still here? This is an autoethnography of how I set out to find the answer.

I was raised to be confident, comfortable in my own skin and to believe I could do anything. Despite my parents' strong influence, there were times when I became frustrated with who I was or bothered by my disability. I would love to say that I have overcome that frustration, but there are days where I have not. Through this autoethnography, I explore my journey towards self-love and becoming fully comfortable with who I am. I explore how I embraced my Dwarf Pride despite being knocked down or keenly aware of who the world wanted me to be, how I was expected to exist in society and where I am supposed to fit in today.

My journey to self-love and acceptance has been complicated. I was raised with supportive parents who instilled confidence and a can-do attitude; however, my own mindset was one mixed with pride, joy, doubt, confusion, and a feeling of never being good enough. What is perplexing to me is that I was raised to always feel that I was good enough, or better at certain things than others, that I was beautiful, and that I could do anything or be anything. My parents were incredible. My mother was a lawyer who served on the Immigration and Refugee Board and my father was a self-made entrepreneur who ultimately became a lamp manufacturer. Theirs was an exceptional story of opposites attracting. I was always made a priority for both, and they were my greatest advocates from the get-go.

What I saw in the mirror did not always match that belief that my parents tried to instill in me. What I saw in the mirror was a girl that mostly compared herself to others. I saw a girl who liked herself but always felt that she was never as good as the average – height girls. I saw a girl who was beautiful but would be more beautiful if born average – size. I saw a girl who was never as skinny as the average-height girls. I saw someone who loved fashion but could not wear the latest fashions as well as the average-height girls. I did not see what I was supposed to see, and I did not feel what I was supposed to feel.

In the mirror, what I still experience is complicated despite hours and hours of internal work. From one viewpoint, I see a strong confident woman but turn slightly and I see someone who struggles with depression and feelings of unworthiness. I see someone who is in a great relationship, but at any point, any average height girl could come and lure her husband away. My complicated relationship with myself often surfaces high-functioning depression by being someone who works too much, and at times, can shop too much. I love and have compassion for myself, but I also struggle with love and compassion for myself.

Research Questions

The main research question for this autoethnography is, how do you find pride within yourself when society views you with curiosity and disregard? The sub questions will explore the question, why is it appropriate for society to ridicule someone strictly based on their looks? Also, how do we as a society change to truly be inclusive of all?

Definitions

Throughout this autoethnography there are multiple terms that will be used and referenced. I deem it important to define the terms to assist the reader in understanding what it means to be a disabled person seeking to find their pride; “the language we use influences and reflects our understanding of the social world” (Barnes & Mercer, 2010, p. 11). These definitions will align with my journey and argument and assist in describing my lived experience.

Disability Pride

Disability pride is taking pride in your whole self, finding community, celebrating the existence of disability, and using it to further progress towards acceptance.

> Distinct from self-worth, pride refers to being proud of one's identity and, in the process, acknowledging possession of a socially devalued quality, such as a mental or a physical disability. Pride encourages people with disabilities to "claim" rather than deny, mask, or hide disability and to adopt the perspective that physical or mental impairments are normative within humanity. (Dunn & Burcaw, 2013, p. 150)

Disability Pride, Crip Theory and Dwarf Pride will be used extensively in my discussion as the subject of this autoethnography is finding pride in myself when the world is against you.

Dwarf Pride

Through my own adversity, I have become a strong advocate for myself and others. I have a much deeper appreciation for myself and what I have accomplished. I know that I am fortunate to live the life I live partly because of my dwarfism and for that, I am grateful. I have an immense sense of Dwarf Pride, but its discovery will be discussed in depth in this autoethnography. Therefore, Dwarf Pride is defined as "where being a Little Person is a unique trait to be celebrated, not a problem in need of a cure" (Solomon, 2020, para. 4). To me, Dwarf Pride is ever changing – one minute it is loving your whole self, the next it is finding aspects that you are comfortable enough to share.

Crip Theory

Like disability or Dwarf Pride, crip theory can be used interchangeably. "Crip theory works to show the ways in which those with impairments can become proud of who they are and view themselves (and have others view them) as full and useful members of society" (Shaw, 2018, p. 31).

Discrimination

Discrimination is the unjust treatment of members of a marginalized group for no other reason than simply being from a marginalized group. Discrimination "entails awareness and recognition of an often-direct experience with the fact that people with disabilities are often the targets of biased, prejudiced, and unfair treatment within daily life" (Dunn & Burcaw, 2013, p. 150). I will discuss discrimination regarding treatment that I have received previously and how through adversity, I have lived and thrived through prejudice.

Inspiration Porn

Inspiration porn is being deemed incredible or inspiring for simply just being. Things that are typical for able-bodied people are deemed inspirational when a disabled person embarks on the same task. Therefore, "it's a portrayal of people with disabilities as one-dimensional saints who only exist to warm the hearts and open the minds of able-bodied people" (Weinberg, 2017, para. 10). I will discuss the impact that inspiration porn and the belief that someone is a Supercrip has on the disabled person, on society and on myself.

Supercrip

Like inspiration porn, the supercrip perspective deems someone as superhero-like for doing or simply for being – no expectations of that person otherwise. "The supercrip perspective is often lauded by nondisabled individuals, and frames individuals with disabilities as having 'overcome' their disability and as viewed as 'superhuman' because of achieving the unexpected" (Forber-Pratt et al., 2020, p. 8).

Medical Model of Disability

The medical model of disability defines the disabled person as the problem in need of a fix and makes no mention or consideration that it could potentially be the environment that is the issue, the environment that needs to change, or the attitudes of others that need an adjustment. Society, including the medical industry, generally subscribes to the medical model of disability. This model "focuses on the disadvantaging impact of physical or mental impairments rather that of the environment in which they operate. The impairments themselves are thought to be disabling" (Samaha, 2007, p. 1256). I will speak about this model of disability when discussing the concept of curing or fixing dwarfism.

Social Model of Disability

The social model of disability explains that the environment is what is disabling. For example, the counters at the bank are too high and need to be lowered, the elevator that must be installed in an old building rather than limiting someone to the use of the stairs or being excluded altogether, and any other such environmental adjustments. Those born with disabilities are marginalized in society due to the lack of accessibility of the built environment. Ultimately, breaking down the word 'disabled' to 'dis' and 'able' means 'not able.' This model "defines 'disability' as disadvantage caused by the confluence of (1) personal impairment and (2) a setting compromising architecture, economics, politics, culture, social norms, aesthetic values, and assumptions about ability" (Samaha, 2007, p. 1257). The social model of disability will be discussed at length in various aspects of my study and when comparing this model to the medical model of disability.

Feminist Theory

Feminist theory often analyzes gender inequality through various themes from discrimination and sexual objectification to patriarchal foundations of society. “Feminism is the search to render visible and to explain patterns of injustice in organizations, behavior, and normative values that systemically manifest themselves in gender-differentiated ways” (Ackerly & True, 2010, p. 464). I will discuss aspects of feminist theory when discussing my own incidents involving inequities due to gender and disability.

Dwarfism / Dwarf

Dwarfism is a medical condition that results in an adult height of 4’10 or shorter. There are over 400 types of dwarfism and 80% of those born with dwarfism are born to average-size parents with no history of dwarfism in their family (Little People of America Online, n.d.). Dwarfism can result in a person being proportionate or disproportionate depending on the type. “The term ‘dwarf’ is the most common term used both medically and socially when referring to someone with dwarfism” (Pritchard, 2022a, p. 7).

Achondroplasia

The most common form of dwarfism 70% of Little People are born with this form of skeletal dysplasia (Little People of America Online, n.d.). Achondroplasia is a form of disproportionate dwarfism where limbs are shorter in comparison to one’s torso size. It is estimated that approx. 1 in 40,000 births result in this form of dwarfism (Little People of America Online, n.d.). Although both of my parents were average-size, I was born with Achondroplasia, and I passed the gene onto my son. As stated by Dr. Erin Pritchard in *Dwarfism, Spatiality and disabling Experiences*,

> [M]y Achondroplasia does not only cause short stature but has a number of other secondary impairments, including spinal stenosis which causes both pain and mobility impairments However, I find that the biggest obstacles that I encounter are related to society's response to my short stature. (Pritchard, 2022a, p. 5)

Average-size person (also referred to as average – height person)

Someone who is taller than 4' 10 and does not have dwarfism or any form of skeletal dysplasia.

Midget

Considered highly offensive in the Little Person community by most. This word is derived from the word "midge," a tiny fly that spreads disease (Rayburn-Trubyk, 2021a, p. 309). This word is considered a derogatory slur and is the most common word used to degrade Little People in public. It was popularized by P.T. Barnum during the Freak Show era to label Little People (Little People of America Online, n.d.).

Chapter II: Literature Review

At the outset of my research journey, I started by searching the University of Manitoba libraries database and found no articles written on Dwarf Pride and few articles written by Little People. Most journal articles were written from the perspective of the medical model and from the medical industry. It was rare when the articles were written from a social model perspective.

Little People of America (LPA), the largest support organization for Little People (LP) in the world, has a resource page on their website. This page includes articles, essays, books, and documentaries written by Little People and average height people who are connected to Little People. The resources offered are minimal and there are no documents regarding the meaning of Dwarf Pride or finding identity when living with or being born with dwarfism. On the Little People of America website, www.lpaonline.org, (Little People of America) there is one master's thesis titled, *Rethinking Repair* by Monica Rentfrow. Rentfrow's thesis includes a collection of poetry on the "effects a body with dwarfism has had on an individual" (Rentfrow, 2018, p. 2), and discusses the effects dwarfism has on a given situation. There are no studies or autoethnographies that have been completed on the topic of Dwarf Pride referenced on the Little People of America website.

There is a lack of literature from the perspective of Dwarf Pride or becoming comfortable with one's dwarf identity, and none written from an autoethnographic perspective. My thesis aims to detail the experience of Dwarf Pride and how one finds it through the sharing of storytelling and the utilization of literature. The literature review is a collection of books, articles, and websites that I have used to accompany my story of finding pride with my disability.

Recently, I read a book authored by Dr. Erin Pritchard also born with Achondroplasia. In her book titled *Dwarfism, Spatiality and Disabling Experiences*, published in 2022, Dr. Pritchard discusses several interesting concepts such as dwarfism as a disabling experience, how dwarfism is not considered a disability by some, social discrimination and the disablism that can occur, and how current cultural representation and stereotypes influences the treatment of Little People in society. Many of Dr. Pritchard’s experiences that she discusses in her book are like mine. Her interpretation of said instances, however, have been enlightening and will be discussed in relation to my autoethnography.

I reviewed the article “The theory of planned behaviour: Self-identity, social identity, and group norms” (Terry et al., 1999). Although this article does not directly speak to disability, I deem it important due to the theories discussed and the conversation around performing a role. The theories will be used in my autoethnography and will discuss the role of a disabled person specifically, the role we play to ourselves and others and how that impacts our disability identity. Disability identity is fluid and has aspects of all models of disability theories when finding and living one’s identity. The disability identity model is as important as the social and medical models of disability. It allows for disabled people to be viewed as having a significant impact on the world, beyond just existing. The disability identity model must be embraced, taught, and evaluated on a consistent basis. Disability identity will be different for everyone depending on how one defines one’s own identity, however the model in which we explore our disabled identity should be foundational. “Theoretically, the link between self-identity and behavioural intentions is predicated on the basis of identity theory which conceives of the self not as a distinct psychological entity, but as a social construct specifically” (Terry et al., 1999, p. 226).

The theory will be grounded in the Factors Scale as developed and discussed by Forber-Pratt et al. (2020). Using their definition, “disability identity is considered a unique phenomenon that shapes the way individuals' look at themselves, their bodies, and how they interact with the world" (Forber-Pratt, et al., 2020, p. 3).

The factors identified in the disability identity model will be integrated as part of the theory that I will use as the foundation for finding my identity. The factors within disability identity that I will link my autoethnography to are how one feels about their own disability, the anger and/or frustration one might feel towards their disability, advocacy, and connection to the disabled to community, and any other contribution given to the disabled community from mentoring to fundraising, among others (Forber-Pratt, et al., 2020, p. 7).

As discussed in Betty Adelson's book, *The Lives of Dwarfs,* the history of Little People whether in the media, as court jesters, in folklore, or in freakshows, was a crucial factor in finding my identity. The history of Little People has dictated how Little People are treated by the public. There is much information about dwarfs as pets, dwarfs in the freakshows and dwarfs in the media historically that needs to be discussed for a full understanding of how we got here (Adelson, 2005b). When discussing our identity, being the punch line and making it acceptable for public mocking, "the ramifications of human beings transmogrified, by the stigma of disability or celebrity into objects of cultural fascination, and to begin to define the consequences of this process for both the human object and the culture doing the objectifying" (Gordon, 2020, p. 232). Little People have been objectified and treated as less than for centuries. History has played a key role in this and has provided a public acceptance for this to be allowable without consequence.

As Betty Adelson explains in her book, "the best of times for dwarfs have been the earliest period recorded – the ancient Egyptian kingdoms – and the most recent era in some Western democracies. The worst of times was the Nazi era" (Adelson, 2005b, p. 3). Starting with court dwarfs, these were dwarfs that were employed by the wealthy for exploitation, curiosity, amusement and furthermore, the prestige of owning a dwarf was considered a symbol of wealth. Like any commodity, dwarfs were treated as such, at times traded and presented as gifts.

> [T]his status – the combination of being highly prized, but also the property of an owner – was the defining characteristic of dwarfs' lives throughout the nearly five thousand years that they are known to have been present in the courts of Africa, Asia, and Europe. (Adelson, 2005b, p. 5)

Depending on the location of the court, dwarfs were treated in a multitude of ways. From Egypt to Russia, court dwarfs were treated as something that was sacred or an animal or pet and everything in between. Throughout the time where court dwarfs gained popularity, several themes emerged regardless of country where they were employed. Court dwarfs were loyal and considered "heroic warriors" (Adelson, 2005b, p. 19) to their masters and mistresses. Furthermore, "all could be indulged, abused, or ignored at the master's or mistress's pleasure" (Adelson, 2005b, p. 21).

In Egypt, dwarfs were considered sacred. They often worked for royalty and high officials, "often acting as personal attendants, keepers of linen, nurses, animal tenders, jewelers, and entertainers" (Adelson, 2005b, p. 5). The oldest reference to a dwarf in court is "a letter sent on behalf of the eight-year-old pharaoh Pepi II, or Neferkare, to Harkhuf, a leader of the caravants, during the sixth dynasty in Egypt, 2825-2631 B.C.E." (Adelson, 2005b, p. 4). The letter describes the dwarf having value to the young pharaoh as the belief was that this dwarf "seemed like the reincarnated image of their ancestral gods" (Adelson, 2005b, p. 4). Finally, in Egypt "dwarfs are depicted in more than fifty tombs of high officials and royalty" (Adelson, 2005b, p. 5). In Spain, "dwarfs were showered with gifts of jewelry, gold and silver, elegant clothing and furs, saddles, and the funds to pay for their weddings" (Adelson, 2005b, p. 13). According to Adelson, "there were few courts as welcoming to dwarfs of those of the British" (Adelson, 2005b, p. 15). Often partnered with royalty, dwarfs in England enjoyed a lavish life, though a controlled life.

In Ancient Greece, dwarfs were viewed as less than, unlike Egyptians who "seemed to hold tolerant views of disability" (Adelson, 2005b, p. 5). Grecians did not hold the same view. "Both Plato and Aristotle believed that the ideal state must ensure the existence of physically and mentally fit offspring, to produce a strong elite" (Adelson, 2005b, p. 7). In China, the courts "are a study of contrasts" (Adelson, 2005b, p. 9). There are a wide range of historical dwarfs, from You Zan, a "dwarf actor in the court of the First Emperor of Quin" (Adelson, 2005b, p. 9) who enjoyed a lavish life to dwarfs who were exploited in the courts to dwarfs who performed in freak shows and beyond, Adelson discusses the range in her book *The Lives of Dwarfs*. As Adelson (2005b) describes, "emperor Hsuan-Tsung created a palace harem called the Resting Place for Desirable Monsters, which included a number of dwarfs" (p. 9). In Rome, courts "collected dwarfs as oddities who could be exploited at their masters' whim" (Adelson, 2005b, p. 11). Additionally, dwarfs would serve as gladiators and "wealthy women observed the dwarf gladiators during training and selected some to take home for a day or two to participate in erotic games" (Adelson, 2005b, p. 11). Interestingly, "the Romans were also credited with initiating the practice of artificially crippling young children in order to stunt their growth and increase their value as freak commodities" (Adelson, 2005b, p. 11).

In Italy, dwarfs were valuable gifts for the wealthy. Dwarfs were sent for amusement to provide levity for those who were sick. In one instance, outlined by Betty Adelson in her book, *The Lives of Dwarfs*, Isabella D'Este, marchioness of Mantua was "interested in breeding dwarfs" (Adelson, 2005b, p. 11) after her gift of a dwarf was received with enthusiasm. In France, dwarfs were treated like that of Italian dwarfs. According to Adelson (2005b), "the court dwarf phenomenon had largely disappeared with the decline of monarchy" (p. 21).

The history of Little People dates to ancient Egypt and ancient Greece. Dwarfs were treated as gods and were often protected in these cultures (Adelson, 2005a). Although the experience in Egypt and Ancient Greece was mostly positive for Little People, their experiences in Ancient Rome were different: "the Roman courts collected dwarfs as oddities who could be exploited at their masters' whim." (Adelson, 2005b, p. 11). Dwarfs were collected and used for amusement:

> Owners would intentionally malnourish their slaves so they would sell for a higher price. In ancient Greece, dwarfs were associated in a menacing and lurid way with the rituals of the Dyonisian cult; art from that period shows them as bald men with out-sized penises lusting after averaged-sized women. This same pattern of reverence and bondage also appears in China and West Africa, where LPs were so often servants of the king. A 17th-century author wrote that the Yoruba people in West Africa believed dwarfs to be "uncanny in some rather undefined way, having form similar to certain potent spirits who carry out the will of the gods." And out of a similar reverence for their stature, the courts of China employed dwarfs as entertainers and court jesters. Here there also may have been a level of fetishism; Emperor Hsuan-Tsung kept dwarf slaves in the harem he called the Resting Palace for Desirable Monsters. (Lenz, 2015, para. 7)

From the Middle Ages to the mid-1800's dwarfs were kept as court jesters and pets for the wealthy. Except for ancient Egypt, dwarfs were not respected (Adelson, 2005b). The history of Little People has been marked with continuous disregard, disrespect, and disdain.

There are many accounts of, and resources written about the horror of the Holocaust. The Nazi era for dwarfs was deadly and excruciating. Dwarfs were treated as medical experiments and forced to endure painful procedures and tolerate pain that would often result in death. Within the literature, there are several stories about a family of dwarfs from Romania. As explained in the book *In Our Hearts We were Giants: The Remarkable Story of the Lilliput Troupe: A Dwarf Family's Survival of the Holocaust*. The Ovitz family from Rozavlea, Romania was a family of dwarfs and average-size siblings who mostly survived and detailed their account of the atrocities that they endured.

This group of ten siblings formed a musical troupe called the Lilliput Troupe. As the musical group gained popularity in Europe, the family grew. The siblings began to marry and with each marriage their spouses would join the group and move into the shared family home. All members of the family participated in the family business; "while the dwarf siblings were the stage stars, the average height family members worked behind the curtains" (Koren & Negev, 2013, p. 33). While on tour, The Lilliput Troupe began to hear rumours of the German army invasion. They were away from their village at the time and urgently needing to get home, they boarded a crowded train, and set forth to return home cancelling all their shows outside the vicinity of their village.

On Friday, April 7, 1944, at the start of the Jewish holiday, Passover, a decree was signed ordering the ghettoization of all Hungarian Jews. Seven days later the Ovitz's were ordered to pack their things and move into the synagogue. In May 1944, they were ordered to travel nine hours by foot and were crammed into cattle cars for a destination unknown. The excruciating train ride lasted for several days. The ride was mostly without light, food, and minimal water.

This was accompanied by a heavy smell of urine and feces. Upon reaching their destination, the cattle doors opened. They believed they had landed in Auschwitz but had landed in Birkenau.

Josef Mengele, a Bavarian doctor, had a PhD in anthropology and a medical license allowing him to practice and perform human experiments in Auschwitz-Birkenau. His focus was on twins, dwarfs, and other people with various disabilities. The literature states that "a primary goal of his research was to prove that the race of Jews was disintegrating into deformed beings – not unlike dwarfs, he thought – to further validate killing them off" (Kelly, 2017, p. 21). Under Mengele's 'care,' "inmates were exposed to every medical examination that could be performed on human beings. Blood tests, lumbar punctures, exchanges of blood between twin brothers, numerous examinations, all fatiguing, and depressing" (Koren & Negev, 2013, p. 106). Although evil, Mengele was described as "a beautiful beast. Among ourselves we always asked how a man like that could become a Nazi" (Koren & Negev, 2013, p. 146). Josef Mengele conducted horrific and painful experiments on humans. These human test subjects were to be kept alive and avoided the gas chambers. They were housed in more humane conditions than others who were killed or used as slave-labour.

Mengele was intrigued by eugenics and "was particularly fascinated by the genetics of dominant abnormalities" (Koren & Negev, 2013, p. 71). In 1937, Mengele joined the Nazi Party and later applied for a position at Auschwitz where he could progress his research and have a "continual access to an unlimited supply of human specimens" (Koren & Negev, 2013, p. 72). Mengele started his position as chief physician of the Gypsy family camp at Birkenau in 1942 despite applying at Auschwitz. "Auschwitz was no longer large enough to deal with the mass of racially undesirable peoples" (Koren & Negev, 2013, p. 72). Mengele quickly distinguished himself from the other camp doctors,

> Mengele was collecting twins, but was also using his long, diligent shifts on the ramp to select unusual and striking human mutations. Like a demonic impresario casting the ultimate freak show, he plucked out from the masses hunchbacks, pinheads, hermaphrodites, giants, dwarfs, extraordinarily obese men, grotesquely corpulent women and anyone else suffering from a growth disorder. (Koren & Negev, 2013, p. 73)

Mengele was alerted to the Ovitzs' arrival and quickly removed the family from any potential of going to the gas chambers. In the time between landing in Birkenau and when Mengele had become alerted to their arrival, the Ovitz family had grown while awaiting further direction. The Slomoowitz family, neighbours in Rozavlea, had been placed on the same train as the Ovitz's. Upon realizing that the Ovitz family was being singled out and possibly 'saved,' they quickly identified themselves as siblings. The newly formed large family was taken to a disinfectant area and told to strip. They were disinfected and shuttled into the 'family camp' where others who were deemed oddities were imprisoned. The family, like the other prisoners, was tattooed with identifying numbers on their arms. Throughout their time at Birkenau, the Ovitz family was subjected to some of the most horrific human experiments,

> Every few days the doctors drew blood. The night before, we had to fast. It was a big syringe, the amount they took was enormous and being feeble from hunger, we often fainted. That didn't stop Mengele. He had us lie down, and when we came to our senses, they resumed siphoning our blood. The nurses and doctors were prisoners too, but they didn't make it easier on us. They punctured us carelessly and blood spurted. We often felt nauseous and vomited a lot. When we returned to our barrack, we would slump on the

> wooden tier, but before we had time to recover, we would be summoned for a new cycle. (Koren & Negev, 2013, p. 93)

At the request of Dr. Mengele, the Ovitz siblings were often summoned for x-rays and provided with strong laxatives in each instance. As described, the x-ray sessions could last for hours. Drops were put into their eyes that would blind them, healthy teeth were removed, eyelashes were plucked out, hair was extracted, and painful tests occurred on their brain, nose, and mouth. The female siblings were subjected to evasive gynecological testing that included injections into their uterus (Kelly, 2017). The dwarfs were paraded around naked, poked, and prodded endlessly. All parts of their bodies were exposed to endless measuring. There were interrogated for hours and repeatedly asked about their family history to ensure consistency in their origin story. They went through extensive psychological testing to determine intelligence. They were asked uncomfortable and personal questions about their sex life and paraded endlessly in public partaking in humiliating public experiments.

Josef Mengele will forever be known as the “angel of death” (Hawiger, 2019, p. 112). The torture that Mengele inflicted on the Ovitz family was excruciating and humiliating, but Mengele seemed to have a liking for the dwarfs. During one exam, Mengele informed the dwarfs that he was a fan of the Grimm Brothers, *Snow White and the Seven Dwarfs;* “never though had he imagined such a real-life encounter” (Koren & Negev, 2013, p. 148). Disney’s newest fairytale was created, their first full-length animated film, and became extraordinarily successful in Hitler’s Germany. It is possible that based on Mengele’s affinity for fairytales that he equated the dwarfs to be of similar mystique. There are accounts in the literature where it was reported that Mengele would come to see what was referred to as ‘his’ dwarfs in their quarters and would laugh and joke with them. He would give the female dwarf siblings compliments about their looks and have an overall pleasant attitude with them during his visits. What is astounding is that all members of the Lilliput Troupe and their neighbours survived the Holocaust.

Josef Mengele was a complicated figure. In one respect, he treated the Ovitz family as a science experiment, putting them through horrifying, inhumane, painful procedures. However, he also appeared to have affinity for the dwarfs in this group due to the impact that Disney's Snow White and the Seven Dwarfs had on him. Different from how he treated the other people with disabilities, he did keep them somewhat sheltered from how the others lived.

The article "Writing Celebrity as Disability: Las Menias, Performing Dwarfs, and Michael Jackson Fan Day" does not seem like something that would link to my topic, I found many aspects within it that do. Like celebrity, someone being born with dwarfism can feel the burden at times, living life publicly, like celebrity. Although without the glitz and glamour, living with dwarfism requires a certain amount of public spectacle and vulnerability when subjugating and opening themselves up for ridicule when out in public spaces. This autoethnography discusses the similarities between living with celebrity (intended to be considered as something that could be perceived as a burden*)* and living with dwarfism. This article compares performing dwarfs and the contemporary treatment of celebrity and how both shape their self-identity. I will discuss this article and link it to the creation of my self-identity.

The public perception of Little People or disabled people at times can be viewed in terms of witnessing a live 'monster' in the real world. There is much information on the idea that disability is considered 'freakish' or 'monstrous' simply based on historical accounts. "Monstrosity is referred to as something 'irregular, enormous, excessive,' out of natural proportion, a definition that implies a moral contrast with the neoclassical values of balance, decorum, and symmetry" (Gordon, 2020, p. 233). Furthermore, "monsters might be regarded as evidence of natural processes, particularly man's physical development, or as portents of man's moral decay" (Gordon, 2020, p. 233). History has shown dwarfism is no different and considered as good for public embarrassment and entertainment. Dwarfs were often treated as something that was grotesque, freakish, and monstrous. "Monstrosity in the case of the early modern court dwarf is described as 'both a biological condition and a social construct'" (Gordon, 2020, p. 233).

There is much to discuss about dwarfism history. Court dwarfs are a direct reflection on how society views dwarfism today and will be discussed in detail as the treatment of these Little People had a significant impact on the freakshow era as established by P.T. Barnum. Court dwarfs were often favoured due to their small, childlike stature. Often thought similarly to that of a family pet, they were thought of as safe escorts for princes and princesses due to their mature intelligence; "in regal court paintings, dwarfs are often found standing next to dogs or monkeys, stressing their similar roles as royal pets" (Gordon, 2020, pp. 234-235).

The impact media has had on how society views dwarfism cannot be understated. Much of the treatment we have received has a direct correlation to how dwarfism is portrayed in the media. Whether it be from reality shows to movies, society learns about Little People from these sources. How dwarfs are represented within these media outlets impact how the greater public treat people born with dwarfism. Much of the treatment I have received or that I am advocating against has a direct correlation with how Little People are represented in the media. Whether it is a discussion about The Munchkins in the *Wizard of Oz* (Fleming, 1939), The Oompa-Loompas in *Willy Wonka and the Chocolate Factory* (Stuart, 1971) or more recent movies such as *Willow* (Lucas, 1988), one cannot discuss how dwarfism is viewed in modern society without referencing the representation of Little People in the media.

I reviewed an article titled, *People Who Look Like Things: Representations of Disability in The Simpsons.* The popular television show *The Simpsons* discussed and how it relates to disability. In addition to having many of the characters written with disabilities, the creators/writers of this show depict disability as freakish, however the messaging evokes critical thinking towards objectifying disability and often the object of mockery in the media. At first this article appears to be irrelevant to my study. However, I would argue that the relevance that a popular show like *The Simpsons* has on mainstream society is enormous. The benefit to a popular show like *The Simpsons* discussing disability in ways that allow the audience to think in alternative ways beyond stereotypes allows for the broader society to become better at thinking of disability beyond its typical black and white boundaries. *The Simpsons* discusses disability in non-traditional ways and allows for such discussions to impact those with disabilities positively. *The Simpsons*, an influential show in modern society, depicts disability in various situations:

> [T]he series [*The Simpsons*] portrays a satirical mirror image of a society where the objectification of "freaks" has become a media commonplace. Through incorporating positions of "offensive humor" in its text, *The Simpsons* offers the potential for distanciation and thus provokes its audience to look beyond *The Simpsons*, to realize that disabled people are still often rendered as visual spectacles and objects of mockery in our media culture. (Fink, 2013, p. 268-269)

Dwarfism has often been the butt of jokes and I will use this autoethnography to discuss the ease in which someone can tell a midget joke without any thought of how it affects someone else. "[W]hat is accepted as a joke […] first has to be negotiated as a joke" (Fink, 2013, p. 268). I discuss the effect such a joke has, not only on the individual but also on society itself. This autoethnography will also segue into my discussion on the history of dwarfism in the circus, as a court jester and for entertainment value. The media has a significant impact on society's view of Little People resulting in how Little People are treated today. Whether it be through the gaze, through the idea of being considered 'normal,' or thinking that those born with dwarfism must be cured (or want to be cured), the media impacts all of it and that impacts one's identity. The media portrays disability with disregard and disgust, thus perpetuating stereotypes within society. Fighting through what society expects you to be is one of the hardest things for someone to do. "Disability identity is considered a unique phenomenon that shapes that way individuals' look at themselves, their bodies, and how they interact with the world" (Forber-Pratt et al., 2020, p. 3). Finding self-identity based on factors within yourself is key to having self-love and ultimately constructing our identity. Fighting through the belief that we are more than just 'freaks' is hard, and doing that while finding our identity and having pride for ourselves is even harder, especially because dwarfism is a "stigmatized condition" (Ablon, 1990, p. 879).

Based on history, the media has a significant impact on how Little People are treated today. The freak show era played a crucial role in not only the history of Little People but continues to impact our treatment today.

In 1881, Phineas T. Barnum, founder of Barnum and Bailey's circus act, popularized the word 'midget.'

> ["Midget" became] popular vernacular and used for almost anything smaller than usual. As a result, it became the word that most people learned and used. This meant that when people wanted to call attention to short stature and body differentness, midget was the first word to come to mind. (Ebert, 2005)

It is important to understand that midget, at the time,

> referred to Little People who were more “proportionate” in size, meaning their arms, legs, head, and torso were all in proportion to one another. And then everyone else who was “not proportional” were to be called “dwarfs,” which was thought to be less desirable though the 1950’s. There were layers of discrimination occurring. There is the first layer that Little People were discriminated against because they were physically different from those who were average height. And then there was the second layer of discrimination within the Little People community: those who were considered “midgets” versus those who were considered “dwarfs.” Those who were “midgets” – or those more proportional – were treated marginally better than those who were considered dwarfs – those not as proportional. For instance, both groups performed on stage at shows, but midgets were on display to “polite society” and were usually in a starring role. Dwarfs, on the other hand, were treated as “assistants” and were mainly used backstage or specifically in the freak shows, where they were judged and ridiculed. (Robledo, 2015, para. 13)

During the height of the freakshow era, Little People were put on display for amusement and “taken advantage of by agents and greedy brokers” (Lenz, 2015, para. 11). Animals and humans that were outside of the norm were exciting curiosities; different races, ethnicities, and disabilities were all billed as novel entertainment. At this point, medical curiosity toward Little People was prevalent and curiosity for subjective experiments took form: “for most of early history, the response of doctors to LPs was to measure everything—nose, hair, genitals. This meaningless collection of data is often accompanied by condescending notes on the appearance and intellect of the dwarf” (Lenz, 2015, para. 15). Prevention of dwarfism was a key motivation from the medical industry as a cure was not possible at that time.

> They believed that dwarfism was caused by the mother having seen another dwarf or animal. In fact, for most of medical history many disabilities and unexplained deformities were chalked up to maternal impressions. Consequently, pregnant women often sequestered themselves away from their communities, acting like they themselves had a disability. This isn't different from the modern approach to "curing" dwarfism. (Lenz, 2015, para. 18)

As described by Nicholas (2018), Little People were often associated as child-like and therefore, considered cute: "cute was then also linked to stature, and small size was associated with reduced status. In sum, cute was associated with non-dominant identities and things, which could be consumed, petted, and enjoyed through display" (p. 176). Furthermore,

> Performers were regularly described with terms like "perfectly formed." As such, more than body size connected midget shows with children. Their alleged innocence and perfection resonated with contemporary ideals about "the child." If widespread ideas of childhood were popularly dichotomized as "the protected child" and "the dangerous child," midgets and dwarfs were slotted into those existing categories. (Nicholas, 2018, p. 178)

Freak shows from that era were a profitable business for entertainment. 'Midget shows' were not any different, although the intent was as an alternative to the typical shows. As Nicholas (2018) explains,

> [M]idget shows were informed using "cute" as a commodity aesthetic, and for people of small stature, their work on the sideshows was different from that of other freak performers […] Midget shows were about perfection of the small body, and what made them cute was their child-like size. (Nicholas, 2018, p. 178)

Midget show performers were “depicted in positive terms” (Nicholas, 2018, p. 200) and provided an alternative to the typical sideshow. “[O]ver time, ‘Little People’ were taken from the world of the bizarre to the realm of the innocent […] and such changes influenced sideshows in Canada as well” (Nicholas, 2018, p. 180). These shows grew in the twentieth century and cuteness became something that could be marketed. As Nicholas (2018) explains in *Canadian Carnival Freaks and the Extraordinary Body, 1900-1970’s,* midget shows were profitable due to the audiences being drawn in by the cuteness of the performers. In addition, audiences enjoyed how these small people played into the narrative of family and these small mothers and fathers “mimicked middle class or upper – class consumer and family patterns” (Nicholas, 2018, p. 183). Marketers looked to add an additional stream of revenue, and thus baby and then child shows emerged (Nicholas, 2018). A great example of a profitable progression from the cuteness provided in midget shows to profiting off children’s looks is actor Shirley Temple. In 1934, Temple’s career skyrocketed due to midget show performers and she, a child, profited off the cuteness that the midget performers also capitalized off (Nicholas, 2018).

It is relevant to explain the importance of cuteness when explaining the role of Little People in freakshows, as our entire history as Little People during this era can be traced back to the idea of being ‘cute.’ Cuteness became a “commercialized value associated with female maternal desire (longing) and a feminized sense of empathy” (Nicholas, 2018, p. 177). The midget shows were to highlight an almost doll-like, miniature version of the average-size person and their ‘normal’ world. These shows were not intended for comedy or for the performers to be to be laughed at but rather, the audience was to be in awe of the ‘cuteness,’ almost doll-like quality of the performers. The shows were intended for amusement but intended for Little People to be revered. These shows were different than other freak shows. The intent of these shows was not to laugh or to provide levity for the audience:

> The nexus of cute, childlike, and innocent in the midget shows worked to produce a level of respectability not afforded to others. These shows were especially important after the “cleaning up” of freak shows that happened in the 1920’s […] Midget shows could satisfy the demand for difference while not risking offence or sanctions. (Nicholas, 2018, p. 179)

The cuteness of these performers should not be understated and their relevance to future pop-culture is impactful. “[T]he freak was cutesified […] [O]ver time, ‘Little People’ were taken from the world of the bizarre to the realm of the innocent” (Nicholas, 2018, p. 179). The midget shows, and their ‘cuteness’ led to Walt Disney creating *Snow White and the Seven Dwarfs* in 1937, Disney’s first feature length cartoon. Furthermore, their ‘cuteness’ played an important role and was included in *The Wizard of Oz* in 1939. However large the impact of these movies was regarding pop culture, these movies helped to perpetuate the typecasting of Little People that we continue to see today. As mentioned in Canadian Carnival Freaks and the Extraordinary Body, writer Robert Marks states, “Most midgets have been compelled to earn their living in the carnival field or in show business, but many have special talents which if they were several feet taller would equip them from business or professions” (Nicholas, 2018, p. 181). Much of what he is saying still holds true today.

Regardless of what the show was, it was a business built on entertainment with the only requirement being to increase profits, as also discussed in the participant interviews and in the literature.

> [S]ex and graft were still part of some of the carnivals and sideshows, tension within the outdoor amusement business remained, with some operators, host venues, and performers wanting more "tasteful," less controversial reputations as part of the modern entertainment industry. (Nicholas, 2018, p. 179)

Many Little People would attempt to capitalize off the freak show after leaving the circus. In Canada, in 1925, the Nicol family, known as the Count, Countess, and Prince, decided to profit from their experience from the circus and create a version of what they experienced while performing. Having worked within the circus business in America, the family decided to continue to capitalize off their 'cuteness' and started a profitable business in Montreal: "working against the vision of their bodies as disabled or diseased, the Nicols drew instead from the familiar framework of the dime museum but created an altogether different type of tourist experience by rooting their exhibit in a home made entirely accessible for little people. (Lewis, 2009, p. 66).

At the age of three, Philippe Nicol started traveling with circus shows and continued until the age of 15. During his traveling circus days, he met his wife, Rose Dufresne, also born with dwarfism and a circus performer. The couple moved to Montreal from New Hampshire, USA in 1913 and started a business. In 1926, the couple and their newborn son Philippe Nicole Jr. moved into their newly constructed home known as 'The Midgets Palace.'

The Midgets Palace was a living museum where they exhibited their everyday life for a small fee. The Nicol family treated every aspect of their lives as a business and ran it like that of a modern-day reality show. "The Midgets Palace provides a domestic theatre that can reinforce certain normative values of class, gender, and family, but can also challenge, subvert and de-essentialize mainstream conceptions of the "normal" body" (Lewis, 2009, p. 68-69). Everything about this performative show made to feel miniature and mimicked what "normal" society would look like in that era. From the way the family dressed, their home and even the birth of their son, Philippe Nicol Jr.to

> [T]he success of his courtship with Rose Dufresne, whom Philippe met through a business associate, is framed through his "aptitude" and "fitness for business," and their wedding is likewise described as so important to the community that "many business houses as well as numerous factories closed their doors while the ceremony lasted" […] as might be expected, the family narrative hinges on the couple's reproduction of an "heir," a son who was "perfectly constituted, very lively and normal in every respect but size, just as his parents themselves." The young Philippe, then, serves to articulate the family's apparently "normal" qualities, in particular the value placed on masculinity […] An analysis of The Midgets Palace must also include the staged images of the family presented on every other page of the biographical brochure, as well as the souvenir postcards sold on-site. These photographs further tie the performance of the site to the material and economic culture of the sideshows, which relied heavily on the production and sale of drawings and photographs of bodies on display. (Lewis, 2009, p. 65)

Everything in their life was meticulously planned and every detail was thought through before being showcased as part of the show that was their lives. The furniture in their house was to scale and the tourists who paid to participate in this human zoo were made to feel like giants (ChatNews Today, 2018). The Nicols marketed themselves well and were able to live a public life of extravagance. After both Philip Sr. and Rose Nicol died, their son took the tourist attraction over until it closed in 1990.

The history that I have shared during my literature review is not a full account of the history of Little People but has provided a foundation for my autoethnography. It provides a baseline for why Little People are treated the way we are today. Moving away from history, I began to research the perceptions that society has on disability and the impact that those perceptions personally have on Little People. Through this research, I discovered an article titled “Dating Websites and Disability Identity” (Milbrodt, 2019). This article examines how people with disabilities represent themselves online. I use this autoethnography to discuss the feelings towards the stare or gaze, or the vulnerability required when disclosing disability prior to meeting someone or being out in public as a physically disabled person. “The definition of ‘self’ and ‘identity’ have shifted from an ‘essential self’ which does not change, to a model in which individuals have many selves that are socially constructed” (Milbrodt, 2019, p. 72).

I have struggled to accept the word disabled and accept myself as disabled. Milbrodt (2019) states, “I examine perceptions of disability by disabled people, focusing on how they conceive of their disability identity, versus how they assume those outside of disability communities perceive of them” (p. 69). My experiences have led me to understanding the advantages to identifying as a disabled person. I discuss the journey in which that occurred and the language that I have had to explore and accept on my journey to self-love and Dwarf Pride. When discussing self-identity and Dwarf Pride, language will be discussed in depth. The language we use to describe ourselves can be powerful and empowering; alternatively, it can be humiliating and have consequences detrimental to our very being.

> We have rejected language of deviance for the language of power, self-love, and pride. We have described ourselves as “the unexpected minority,” rejecting “handicap” as social construction, and embracing “disabled” as an essential reality that has become integral to

> our personal identity – not an appended description. In short, the language we use in our everyday lives as well as in our written text has become an important element of our culture and cultural identity. (Peters, 2000, p. 590)

Ultimately, language can do much intentional harm. It has the ability to set rules on how one should be treated and valued and how one should progress in society. “When it comes to disability[,] there is a tendency to isolate the identity and oppression, and not fully problematize or understand the complexities of an intersectional lived experience” (Peña et al., 2016, p. 90). As such, one must be seen to be accepted into society. Being comfortable with one’s own disability can be perplexing to those with no history of personal disability. When discussing self-identity and Dwarf Pride, language will be discussed in depth, “the language we use in our everyday lives as well as in our written text has become an important element of our culture and cultural identity” (Peters, 2000, p. 590).

Peters (2000) discusses whether a disability culture exists. There are three views of disability culture discussed and from that develops a macro-sociological framework to review the views. Disability culture is discussed in my autoethnography, relating more to dwarf culture and what it means to live with Dwarf Pride. The views and framework developed by the author will be evaluated in relation to my experience. “Furthermore, for most disabled people (including myself), disability ‘flavours’ everything we do, whether it is the focus of our lives or not. Whether we come to see ourselves as ‘coloured’ or ‘black’ ‘crippled’ or ‘disabled’, these words describe an essential reality” (Peters, 2000, p. 584).

Peña et al. (2016) highlight students with disabilities discussing representation in post-secondary institutions. Specifically, the oppression that students with disabilities often experience from their professors while attending college. The discussion in this article centres around when a disabled person finally becomes comfortable with who they are, however, creates a complicated relationship when seeing other disabled people with similar disabilities in public. I will share my experience growing up and seeing others with dwarfism out in public and how I identified (or did not) during those interactions. In situations when I did not identify as being disabled or did not wish to draw attention to it, I did not deem it to be part of my self-definition. "Yet, to some disabled people –both in the US and worldwide—disability is not necessarily central to their self-concept and self-definition" (Peters, 2000, p. 583).

Aligning with Forber-Pratt et al.'s (2020) discussion, much of the literature discusses the negative aspects of the idea of the 'supercrip' narrative or what is known as inspiration porn. "The supercrip perspective is often lauded by nondisabled individuals, and frames individuals with disabilities as having 'overcome' their disability and as viewed as 'superhuman' because of achieving the unexpected" (Forber-Pratt et al., 2020, p. 8). This will be incorporated into my section of finding self. I have often been celebrated for things that for people without disabilities would be a simple expectation. The shock and awe that comes from simple mundane tasks never ceases to amaze me. I discuss the low expectations placed upon me from society at various times in my life and align it to how it impacted my ability to have pride in myself during those moments.

Forber-Pratt et al. (2020) "describe[] the initial factor exploration of disability identity and preliminary psychometric characteristics based on an adult/self-report tool" (p. 1). By developing a factor scale for the exploration of disability identity, the authors have developed a valid measure of disability identity itself. In addition to the four factors that I listed above, I use the four factors as my foundation and as a guide for my autoethnography. "Developing disability identity development then, becomes an ongoing process of internal and community engagement that is worth of further exploration and support" (Forber-Pratt et al., 2020, p. 8). The factors will guide me in my discussion and provide a type of 'how-to' for others seeking to find their pride or disability identity.

Dunn & Burcaw (2013) conduct a narrative study of disability identity. This study is important as it is a true accounting of the experience of coming to find one's disability identity. The study and subsequent article are intended to allow rehabilitation research and give those practitioners who work with disabled people more insight into the experience of living with a disability. It provides a resource for those mentioned above by including first-person accounts of disability identity and the path to finding disability identity, to "recognize disability identity as an authentic and important aspect of the social psychology of disability" (Dunn & Burcaw, 2013, p. 155). Using the first-person accounts from this article, I will align it to my experience of recognizing my identity. There are parallels between my experience and that of those detailed in the article to which I will share and discuss in more depth.

Finding a strong sense of disability identity in relation to self-love and pride cannot be understated for one living with dwarfism: "For people with disabilities, disability identity entails growing up with a positive sense of self, and a feeling of connection to and affinity or solidarity with other members of the disability community" (Dunn & Burcaw, 2013, p. 148). Furthermore, "identity can develop as a way to cope with social discrimination, outsider status and the recognition of being different in everyday life" (Dunn & Burcaw, 2013, p. 150). Once one has developed their pride or self-love and obtained a certain level of confidence, a barrier to outside negativity is established. Once this has occurred, the individual is provided with great tools to combat against the societal negativity that comes with being disabled.

When finding a disabled identity or when becoming comfortable in one’s own skin, there are layers towards self-acceptance and self-love. It is not a one size fits all approach; the journey is different for everyone. The journey to self-love and the continuation of self-love does not mean you love everything about your disability all the time, and it does not mean that it is always perfect, and you do not have to deal with any negativity. What it means is that at your core, your love for yourself will give you the ability to deal with the demons and layers that can come with being disabled. Many of these layers include how one views oneself when looking inwards and outwards, and how one deals with the image of seeing themselves in someone else.

Love and acceptance of ourselves should be at the forefront of how we care for ourselves. Once that has been achieved, one has unlocked the tools needed to deal with the daily exhaustion and inspiration porn that can come with being disabled in the public. At the end of finding and being comfortable with my identity comes an enlightenment that can only be described as Dwarf Pride, a type of culture that exists when one is truly happy with oneself and seeks to inspire others from the dwarf culture to thrive themselves.

Community

Understanding history, whether it be family or community, has a direct correlation with developing pride in oneself. The history of Little People provides for a good understanding of why Little People are often still treated poorly by the public. Being a Little Person comes with a unique burden different to any other disabled group. Like other disabled groups, our history is rooted in shame and tragedy. Where we differ is that our history also includes mockery and being bought and sold as a commodity. As our history is vast and encompasses many aspects, this responsibility carries years of history filled with as much heartbreak as there is storytelling. From the court dwarfs to present time, the public perception of dwarfism has changed many times. However, it is still rooted today in amusement and curiosity, unique to any other disabled group. Although the descriptions mentioned in the literature reviewed previously are not the full account of the entire history of Little People, it does provide for an understanding for today's experience. Actor Billy Barty had a tremendous impact on our community's history in addition to what has already been mentioned. After World War II, Little People were able to find more work outside of the entertainment industry than prior to the war and this was in part due to the efforts of Barty. In December of 1956, Barty was touring with the Spike Jones Orchestra which had an engagement at the Hotel Riverside. Ultimately, this event led to a conversation between Barty, Mert Wertheimer, the owner of the hotel, and others in attendance. During this conversation Billy was asked about the number of midgets in America and of any known meetings within the group. Out of that conversation grew an idea of having a convention for the 'Midgets of America.' Shortly thereafter, Barty was a guest on the Art Linkletter Show in February 1957 and announced that there would be a convention in Reno, Nevada. Ninety-three Little People wrote in, inquiring about the convention. They wanted a place to get together to talk about their problems and meet with other people like them. Werthheimer agreed to help the project by giving free rooms and half-price meals at the Hotel Riverside for all conventioneers. A mailing list was developed, and the convention was organized at the Hotel Riverside in Reno, Nevada. With 20 people registered for the first convention for Little People, the first meeting of "Midgets of America" was held in April 1957. The name was changed three years later to Little People of America (Harris, 2011).

Today, Little People of America is the world's oldest and largest dwarfism support organization and an international, membership-based organization for people with dwarfism and their families (Little People of America Online, n.d.). Although the acceptance of purchasing

Little People for amusement and the Freak Show era has ended, the impact of that time is still felt today. The history of Little People and how the media continues to portray Little People has and continues to impact our daily environment and ultimately, our confidence and pride in ourselves.

This thesis is written based on several themes. These themes include theory, history, media, self-identity and finding self, and Dwarf Pride. These themes were chosen based on the relevance that I felt each topic had to my personal story and to finding my self-love or pride in myself. I chose personal stories that fall within these theories and themes. Each story was chosen based on its significance to the theme of the autoethnography in which I felt all tied into me eventually finding my Dwarf Pride, despite any setbacks that I felt or went through. When thinking about each story, I was able to identify a defining moment where I was clearly in the process of developing my future Dwarf Pride while at times, living through unpleasant situations.

Freak Status by Samantha Rayburn-Trubyk

What level do you have to get to become a freak? Is this a goal that
is desirable?

Freak is a fancy word for zoo human animal.
In the zoo – the animals are stared at, laughed at, mocked, cuddled,
told they're adorable or cute, told they are incredible for eating a
banana, has their boundaries violated, their interrupted by the
constant tapping of their barricades, recorded, and photographed
without consent.

So yes, I have met the level of freak status.

Chapter III: Methodology

This study is written as an autoethnography and combines theory, current literature, and my story of finding my identity, I will explain why we not only have to embrace a disability identity model to create meaningful change but why it should be held to a higher standard. Finally, I will add personal poems that I have created from trigger words in the literature. I would find that I would read something and immediately have the intense need to write something down in the form of a poem. Often in flow state, I would write without realizing what was being written. The poems that are woven into the autoethnography are unedited and were created while in flow. Theoretically, my thesis is based on the disability theory, feminist theory and crip theory.

According to Ellis (2004), ethnography is a “framework for thinking about the world” (p. 26). In the book *The Ethnographic I,* the author discusses that “*ethno* means people or culture; *graphy* means writing or describing. *Ethnography* then means writing about or describing people and culture using firsthand observation and participation in a setting or situation” (Ellis, 2004, p. 26). As a form of social science, the researcher uses their experience combined with theory and data to tell the story from a personal perspective while tying it into current methods of thought and data, attempting to fill in current gaps in the overall research. Ethnographic studies allow readers to fully grasp social science concepts through the art of storytelling and emersion.

Autoethnographic forms of work are important and bind people and culture together to share stories, lived experiences and provide data that fill in knowledge gaps. The lived experience is not the focal point but enhances the research and provides data to what was once not there. “Stories are the way humans make sense of their worlds. Stories are essential to human understanding and are not unique to autoethnography. Stories are the focus of Homeric literature, oral traditions, narrative analysis, and fairy tales" (Ellis, 2004, p. 32).

After working on the literature review for this thesis, it became glaringly obvious that more of the literature needs to be written from disabled persons' perspectives and more from those born with dwarfism and a dwarf-centric perspective, especially when one is discussing Dwarf Pride and other issues specific to those born with dwarfism. Disability research completed by disabled researchers is not only important but necessary for moving the needle towards inclusion: "A primary reason for attitudinal antipathy is that many nondisabled people lack meaningful personal relationship with people with disabilities or have not had sensitization training" (Dunn & Burcaw, 2013, p. 150).

Disability identity is fluid and has aspects of all models of disability theories when finding and living one's identity. The disability identity model is as important as the social and medical models of disability. It allows for disabled people to be viewed as having a significant impact on the world, beyond just existing. The disability identity model must be embraced, taught, and evaluated on a consistent basis. Disability identity will be different for all depending on how one defines their own identity, however the model in which we explore our disabled identity should be foundational.

When reviewing the research from non-disabled researchers, there appears to be an undertone that disability is wrong, ugly, or simply imperfect. The tone is significantly different in such articles. This makes it not only necessary but urgent to produce research from disabled persons' experiences. "Practitioners who counsel people with disabilities can define and describe the potential importance of disability identity to their clients" (Dunn & Burcaw, 2013, p. 154). Furthermore, "narratives can inform both persons with and without disabilities about how individuals live with and learn from life with a disability or navigate the social stresses of being a member of an often-ignored minority group" (Dunn & Burcaw, 2013, p. 155). Having more disabled people writing from a first-person perceptive will prove to be an immeasurable benefit to society, allowing for learning, knowledge, and informed conversations where all can benefit.

As discussed by (Dunn & Burcaw, 2013), "Imperfection is the essence of being organic and alive. Organic life is vulnerable, it inevitably ends in disintegration. This is part of its beauty" (p. 153).

Chapter IV: Outside In

According to Forber-Pratt et al. (2020), disability identity is “considered a unique phenomenon that shapes the way individuals look at themselves, their bodies, and how they interact with the world” (p. 3). Disability identity will be different for everyone depending on how one defines their own identity. The definition may differ but the model in which we explore our disabled identity should be foundational. My life has been filled with paradoxes and second chances. This includes wanting to be inspirational but not wanting to be inspiration porn, to feeling beautiful and knowing that society often views me as anything but or even asexual. My disability identity and how I have constructed my identity is based on self-love and the work that I have done to get to a place where love and pride are not only possible but constant.

Finding self-identity based on factors within yourself is the key to having self-love and ultimately, constructing identity. The four factors scale as identified by Forber-Pratt et al. (2020) range from, *how one feels about their own disability,* to the *anger/frustration one might feel,* to a*dvocating and their connection to the disabled community,* and finally to o*ther contributions given to the disabled community from mentoring to fundraising.*

In my experience, the four factors scale is an evolution of discovering and being comfortable with your identity. If one were to ask me how I feel about my own disability, the answer would be drastically different today than it would have been 20 years ago. The journey to becoming comfortable in my own skin is just that, a journey. Simi Linton in Dunn & Burcaw Disability Identity: Exploring Narrative Accounts of disability describes her experience as a disabled person stating,

> I have become a disabled woman over time. I certainly would have rejected such a title in the beginning […] My advancement was due to other disabled people, and significantly,

> to the times were living in […] For me and other disabled people, the process of claiming disabilities as an identity and the disability community as our own is complex. (Dunn & Burcaw, 2013, p. 152)

Like Simi's experience, I too have become a disabled person over time and did reject the title at the outset of my identity journey. To me, before knowing better, disability meant peculiar, different, and more of an oddity than something meant to be desired. Over time and learning, my thoughts and ideas have progressed to no longer viewing disability as a bad word, but one to be embraced; "making sense of it had become the most meaningful thing I could do" (Dunn & Burcaw, 2013, p. 152).

As a young person, I struggled with my identity as most young people do. Add in the layer of being a disabled person, I felt confused often. Understanding that all teenagers want to blend in and not have their identity tied with being viewed as different or unique, I wanted to be viewed like everyone else. I did not want to be stared at everywhere I went, I wanted to blend in. Since the age of four and every year thereafter, I attended the annual Little People of America conference. During these weeks, I would have a feeling of immense pride in who I was and being born a Little Person. There, I was able to blend in with the crowd as most looked like me. For one week out of every year, I was part of a majority group. When I was younger, I knew that I felt in community and with people like me while attending these conferences. Although I did not have the language for it at the time, I knew that this week was special.

Outside of that week I did like myself and was provided the support to embrace self-love for myself. What I did not like was being viewed as different or treated as someone with a difference when out in community. I would see people like me in stature and not want to be associated with them. Even simple tasks like walking on the street would be embarrassing if I were to encounter another Little Person. Ultimately, I would pretend not to notice the other person or move to the other side of the street as I did not want anyone making any sort of comment about us. As Simi Linton stated,

> I was reluctant to approach any of the disabled people I saw on campus. I would often see a woman walking with a cane and could see that she had difficulty getting up the stairs […] But I talked myself out of speaking to her. There was an unwritten code I had grown up with that said you don't acknowledge a person's disability. (Dunn & Burcaw, 2013, p. 151)

I often wanted to spare the comedy routine that would often ensue. I wanted to draw the least amount of attention to myself as possible. Being stared at was my least favourite thing about being a Little Person – I hated it. Although I was able to develop strategies to deal with the stares, as Judith Heumann states, "Years of managing my feelings in the face of bold stares and invasive personal questions had honed my ability to keep a calm front" (Heumann & Joiner, 2021, p. 48). Though I could keep a calm front, I hated leaving my house knowing that I would be gawked at, laughed at, or looked at as an oddity. Staring "is a more forceful form of looking than glancing, glimpsing, scanning, and other forms of casual looking. Staring is profligate interest, stunned wonder, obsessive ocularity" (Garland-Thompson, 2015, p. 13).

Comfort

There were times when I was with friends and situations would arise where I would not only have to deal with the experiences but also feel that I needed to provide an explanation of how I was feeling about it. I felt like I was the one apologizing while explaining the situation. Those born without disabilities are often shocked and appalled during their first outing with me and how the outside world will react. When asked, I often tell people that I love seeing the shock on someone's face from meeting me for the first time and not expecting me to be a Little Person. Truthfully, this is a lie to remove the awkwardness felt when this occurs. I find the entire situation awkward and uncomfortable. "Usually, a person meeting a dwarf for the first time is apt to register some astonishment, whether visible or internally" (Adelson, 2005b, p. 88).

There is much pre-planning that occurs when leaving the house as a person with a disability. Understanding that the environment is not built for people like me, I am aware that it is my responsibility to ensure a smooth-as-possible experience when outside of my home.

> Due to dwarfism's rarity, the continuing humiliation of the impairment within the media has a profound effect on the dignity of all people with dwarfism. Therefore, people with dwarfism may avoid certain spaces in order to reduce the amount of unwanted attention they received, which lessens the amount of phyco-emotional disablism they personally experience. (Pritchard, 2022a, p. 108)

Every time I leave my home, I must create a plan that includes pre-thinking or strategizing which includes asking myself to think through scenarios. I consider questions like the following: Where will I park? What kind of tables will the restaurant have? How many stairs will there be? What will the crowd be like? Will they be drinking? Will the location be packed with people? Where is the closest exit? Is there good lighting in dark spaces? There is a lot that goes into leaving the house. It often becomes too exhausting to figure out, leading to a decision to put off the errands needed or the coffee with a friend postponed to another day. As Pritchard (2020b) states, "I get frustrated that I cannot even leave my house without having to put up with an ignorant person's view of dwarfism. I am a university lecturer, not a children's entertainer" (para. 6). Even with all the pre-planning that goes into a daily task, you cannot predict all scenarios.

In March 2019, I was interviewed by Doug Speirs of the Winnipeg Free Press. During that interview, I shared a story about a situation that had occurred while dining with my husband and son in Winnipeg. Our table was directly across the aisle from a family of three, two people appeared to be teenagers and the third appeared to be a parental figure. It was clear that the teenagers found the look of my son and I to be amusing in addition to using the word 'midget' several times. They were obnoxious. There was no amount of preplanning that could prepare me for the level of disrespect that was directed our way that day. On this day I had had enough. I often struggle with how I am going to teach my son to advocate for himself. This means teaching him to pick his battles and handle them in a way where safety is maintained while still being able to advocate. During this dinner,

> instead of confronting them over a term that is deeply insulting to Little People, they turned it into a teaching moment. "So, we quietly told the server we would pay for their meal, and then we left," she says. "We didn't confront them. I didn't want it to be their story. I want to be able to take the high road because I think that's more impactful. That will make the biggest difference […] I don't want to be seen as that person – "oh, everything bothers her." I want to fight for the things that are important and laugh off the things that aren't. (Speirs, 2019, para. 8)

I deem it important to own the story. For me, the road to finding my Dwarf Pride and self-love has been the ability to choose my own narrative and to take the power back.

<u>**What is comfort by Samantha Rayburn-Trubyk**</u>

Comfort is a funny word – it's a word that means so many
different things to different people.

To some, a sweater, or a scarf or warm home and a fire. To others
it's knowing what comes next and anticipating reactions.

> To me, comfort is being withing my four walls and knowing that nothing can harm me in my home. To me, it’s privacy. To me, it’s the safety of being with friends or family who do not see you differently – who almost forget you are who you are. To me, it’s mostly, the confines of my city where being out in public is not nearly as much of a spectacle as it is elsewhere where the advocacy is not as strong.
>
> To me, comfort is knowing that no matter what is thrown my way, I will manage it, or it will work out – it might not be an easy path, but life has a funny way of working out.

In 2020, I wrote a reflection paper for an Environment and Disability course at the University of Manitoba. I wrote about how the environment impacts disabled people and I shared a story about a former employer and my on-boarding experience. During this time, I was sent to Toronto for training for four weeks. I stated,

> I knew that the Company was aware of my disability as I had interviewed with the group however, I did not realize that I would become a series of oversights. The office in Toronto was progressive with a few traditional offices, open spaces for meetings, high bar stool type tables, etc. On my second day in Toronto my peers and I were invited to have lunch with some of the executives from the US. I grabbed my lunch and started to walk towards the area where I was told the group was meeting to eat together. Upon arriving, the entire group was sitting together at a long table that was reserved for this lunch. The table was a high-top table and there was absolutely no way I was going to climb to the top of the highchair similar to a child conquering the tower of a playground complete with sweat, panting and awkwardness. I abruptly turned around and found a low table close by and proceeded to eat my bagged lunch by myself, mortified. (Rayburn-Trubyk, 2020, p. 1)

The company realized what had happened and immediately apologized. I share this story to illustrate that simple things like table height and how the decision to sit at high-top tables can create unintentional exclusion and impact disabled people regularly. Simple decisions like where to sit can create a barrier and exclude disabled people interacting in office settings and with coworkers. Disabled people are made to feel as if the problem is theirs rather than the environment being problematic. For me, when attempting to find another seating arrangement, I was left with a feeling of embarrassment, exclusion, and otherness.

At a previous employer, I worked with two managers in a retail environment. I once listened to the managers tell me a story about their recruitment practices and how they choose which employees are a ‘fit’ to hire. These two seasoned managers stated that they would often meet their candidates at the front of the store and escort them to the interview room in the back. They would walk as fast as possible to the interview room and if the candidate was unable to keep up with them, they would not hire that person. This is a clear example of ableism, “denoting an attitude that devalues or differentiates disability through the valuation of able-bodiedness equated to normalcy” (Campbell, 2012, p. 5). I do not believe these leaders understood that their strategy was discriminatory and excluded disabled people from the workplace. As Tringo (1970) states, “A person with a disability may be well prepared to perform a job and to cope with normal life situations yet be unable to find employment because of prospective employers’ attitudes towards disabled” (p. 295).

One summer while visiting my friend at her cabin, we went to a party at her parents’ friend’s cottage. There were people of all ages at this party. One of which was a young boy who started to follow me around. This was not unusual given my size and the fact that young kids cannot comprehend the difference between my size and age. This boy was fascinated and wanted to become my friend. The conversation with the boy led to him not believing that I was a dwarf. In the eyes of this child and the bedtime stories that he had been told, he believed that all dwarfs were mystical and magical creatures. After telling him that I was a dwarf, most likely based on his question, *why are you so small?* and him still not believing it, the next comment that came out of his mouth was one that I had not been prepared for. The young child unable to pronounce all his words, stated, "If you're a dwarf then you must be 'magico' and if you're 'magico' turn that lamp into a table." Given this young boy's age, I understood that 'magico' meant 'magical,' however I was unsure how to respond and explain to him what dwarfism is. At that point I played along and told him I did not bring my powers to the party. Although innocent, it was clear that this child had a warped view of dwarfs and had received his misinformation most likely via mythology and folklore. According to Pritchard (2022a), "in mythology, dwarfs are depicted alongside elves, leprechauns, imps, dragons, and unicorns. This makes them seem mythical and unreal as opposed to actual disabled people" (p. 105). There are many stories of folklore regarding Little People and most with magical powers. In *Teutonic Mythology,* the elves were able to make themselves invisible (Adelson, 2005b, p. 103). In another example are the *Dwarfs of the Eddic Sagas*, where these dwarfs were able to "bring light to the world, creating days, nights and seasons" (Adelson, 2005b, p. 102). There are countless stories of dwarfs with mystical or evil powers in folklore. It is not surprising that this young boy would believe I had magical powers too.

This type of experience, although odd in the sense of the ask, is not uncommon. The media plays an important role in determining how society views one with dwarfism. Whereas the freakshows of the past dictated how one viewed disabled people, the media has continued where the freakshow has left off. Media representation can fall into two categories; those who want to collaborate with us and those who do not. With us are television shows, movies, and other media that collaborate and choose carefully to ensure successful representation. This includes where someone born with dwarfism is not depicted in a negative space or depicted as a stereotype, but rather as someone whose disability is a bonus to the role, not the feature of the role being portrayed. Those against us are producers, casting agents and other decision makers in Hollywood who fail to see a Little Person beyond their height. Right or wrong, how Little People show up in the media, whether by choice or not, affects all of us. As Pritchard (2022b) states,

> [E]nticing the audience to laugh at the dwarfs is problematic as the attention is based on their condition. The problem is some people just don't get the difference between fiction and reality. That means people with dwarfism like me are viewed in the same way and therefore seen as acceptable to mock. A person with dwarfism is easily recognisable and if someone has no other point of reference to them other than the pantomime, their perception is likely to be shaped by the dwarf on stage. A person they are encouraged to gasp and laugh at. (para. 16)

On December 10, 2022, Little People of Manitoba, an organization that I am currently the president of, was sent a seemingly innocent message from a profile not associated with our community. The message read, "Hello, I was wondering if I could hire a few on Christmas?" (D. Le, Personal Communication, December 17, 2022). There was no explanation, no further communication, just a simple request. These types of requests are not unusual and is a consistent theme amongst our community, like an example provided by Pritchard (2022b), "The mother who told me that her daughter found people like me 'hilarious' and asked if I would like to perform at her birthday party" (para. 3). Utilizing Little People as party favours is not new. The comments or insinuations are equally hurtful no matter how many times you have heard them. It is clear in both examples above that the requesters were clearly influenced by media where the negative stereotype of Little People reigns supreme and “imply that dwarfism is just something to be ridiculed” (para. 4). Such encounters elicit negative feelings towards the person whom the request is aimed at. In addition to perpetuating stereotypes, eliciting stares and curiosities,

> The sight of an unexpected body – that is to say, a body that does not conform to our expectations for an ordinary body – is compelling because it disorders expectations, of the visual status quo, attracts interest but can also lead to disgust. (Garland-Thomson, 2009, p. 37)

Social Media Fun by Samantha Rayburn-Trubyk

Social Media Instagram Message
To: Little People of Manitoba
Subject Line: Can we hire a few?
Date: December 10, 2022
Hire a few what?
Humans to laugh at.
Humans to mock.
Humans to point and stare at?
Humans to make you feel superior.
Humas to make me feel inferior?
Humans so you and your audience can share a collective sigh of
relief that you were born “normal” in your eyes?
Humans to perpetuate your stereotype of what I should be?
Humans so that you can go and tell all your friends about the wild
party you were at where you saw midgets in elf costumes?
Did you hire a few other humans from other marginalized groups
to mock? No?

Well, then, why do you want to hire a few of us?

Playing Small

Thinking of someone as less than simply because of their size or as something less desired is common in our current society. “People make these remarks to feel superior, for people with dwarfism like me, we are made to feel inferior" (para. 5). It is common to hear parents speak about their child's height as some sort of barometer of worth. When describing what percentile, they have been told their child is in and the estimated height that they will end up as in adulthood. Parents sit around and talk to each other about how excited they are that their child will be whatever height they deem as worthy when boasting. In addition, it is common for parents to have growth charts available for all to see in their homes where they proudly display each millimeter of growth for all to see. If you search *Growth Chart for Kids* on Amazon, the number of charts that are available for purchase is substantial. It is not uncommon to hear a woman list off the attributes that she is looking for in a hetero partner and often include tall, dark, and handsome. Mostly, every list has some sort of height requirement, and it is typically a requirement that the partner be taller than them. My son is a Little Person and this type of typecasting when someone is choosing a partner worries me for him. The fact that someone is choosing their spouse strictly on a pre-determined characteristic is unfair. However, there is hope. In January 2023, the New York Times printed an opinion piece titled "There has never been a better time to be short" where the author debates "the time is right to be short" (Altman, 2023, para. 7). The opinion piece suggests that "favoring the tall was 'one of the most blatant and forgiven prejudices in our society'" (Altman, 2023, para. 3). Furthermore, they shed light on the business of elective limb lengthening surgery and growth hormones; "Others go to extremes in pursuit of a few extra inches – more and more people are spending as much as $150,000 to get excruciating limb-lengthening surgeries, and parents give their healthy children growth hormone treatments with unknown side effects" (Altman, 2023, para. 3). It is refreshing to have a piece published in a well-known publication that supports the idea of being short without needing to fix it. Altman (2023) presents several good arguments as to why one should accept being short and furthermore be happy with it. Finally, Altman (2023) not only addresses why celebrating short stature should become popular, but also why it helps sustain if not improve the planet:

> [T]he short are also inherent conservationists, which is more crucial than ever in this world of eight billion. Thomas Samaras, who has been studying height for 40 years and is known in small circles as the Godfather of Shrink Think, a widely unknown philosophy that considers small superior, calculated that if we kept our proportions the same but were just 10 percent shorter in America alone, we would save 87 million tons of food per year (not to mention trillions of gallons of water, quadrillions of BTUs of energy and millions of tons of trash). (Altman, 2023, para. 6)

If the New York Times can publish an opinion piece beneficial to those with short stature, then I believe we are moving the needle towards greater inclusion to those born with dwarfism.

Society is constantly reminded of the negativity associated with being small, whether it be in the casting of stereotypical roles, in comedy shows, in songs or in everyday vernacular. In 2021, an MLA in the opposition party in Manitoba put out a Tweet intended to be an insult to the Premier. The tweet read, “Brian is a small man” (Fontaine, 2021). The Premier in reference was the former Premier of Manitoba, Brian Pallister. Premier Pallister is 6’7. He is not a small person, but this was intended to be an insult to him. Statements like this perpetuate a certain kind of discrimination that insinuates that if you are small or short, you have less value, less to contribute and are less desirable. Other popular societal statements like, ‘do not sell yourself short,’ ‘stop playing small,’ ‘get on the short bus,’ ‘stand tall,’ ‘you can grow from this experience,’ ‘I would like to thank the little people who got me here,’ and any reference to children as Little People are all derived from the idea that being small is negative. It is no wonder why finding Dwarf Pride can be difficult when everywhere you turn, you are reminded that height plays a significant role in how you are postured in society.

I recall having a friend who I went to school with as a young child. Our families were close, and it was a common occurrence on Saturday nights for our parents to get together to play Dominos while we would play in her basement. While on the playground at school, as young children do, we had a disagreement about something insignificant. The insult that she chose to use was about my disability “Sammy’s a midget, Sammy’s a midget.” I recall that I was hurt by my friend and more significantly this was the first time that I recall where I had experienced someone using my size as an insult. The situation was resolved by our parents, but the family relationship changed forever.

As my parents worked full-time, my summers were often filled with day-camps to keep me busy. One summer, I was enrolled in a nature camp at the Fort–Whyte Centre in Winnipeg. I was participating with the group of kids in my assigned camp when one of the young boys made a sexual comment towards me and then proceeded to use the word ‘midget.’ I am not sure what was more upsetting to me, either that a young boy used sexually graphic language towards me or if it was the term ‘midget.’ I shared this information with my mother at pick-up. We did not make it out of the parking lot before my mother turned around to address this with the camp counselors. My mother, the ultimate advocate, has a knack for getting things done and moving the needle on progress. The boy’s parents were contacted immediately, and he was suspended. When he returned, I was provided with a stuffed animal and a handwritten apology. There was no further issue with this boy for the remainder of the session.

Bullying is not always violence and name calling. It can take the form of manipulation and mind games. When someone can assess your weakness and use it to their advantage, this can be a form of bullying. I had a boss whom I considered a friend. We would share personal stories and opinions that always seemed to align. The more comfortable I got with this person, the more I thought that I was working for a close friend rather than a boss. That was my mistake. There were several situations where my people pleasing tendencies seemed out of control looking back at it and I would share something personal or private. It would always come back to hurt me; “a common tactic of bullies is to undermine or destroy the professional reputation of the target” (Vickers, 2009, p. 261). I can recall several situations where I would be walking down the hallway to her office and, as the walls were thin, could overhear her complaining or gossiping about me to my peers. The first time that occurred and I heard this, I was heartbroken by the betrayal. I always found it interesting when my peers would ask me questions that seemed odd at the time and unrelated to anything only to look back now and realize that they were being told information about me that was personal. Assessing the situation now, although I am hurt and angry at myself for allowing me to be manipulated, I realize that this person did this to all that come into their orbit. What was confusing was I was given countless, incredible career-shaping opportunities and voicing my opinion about how I was being treated (or others on the team) made me feel ungrateful. I was also gaslit by this boss, which ultimately is another form of manipulation. Understanding the situation now, I have developed different strategies should this occur again. At the time she had this unique ability to make everyone feel like they were the most important person on the team. That added to my need to be the MVP, Most-Valuable-Player/Employee. This person understood my weakness and used it as a form of manipulation. As discussed by Vickers (2009),

> Bullying can include hostile behaviours designed to negatively impact the target’s sense of self as a competent person […] [I]t has also been described as including persistent,

> intimidating, malicious or insulting behaviour, the abuse of power and unfair penal sanctions, making the target feel upset, threatened, humiliated, or vulnerable. (p. 262)

Being disabled often comes with a perception that you are less than, that you are easy to take advantage of or will put up with anything as you must be grateful just to have a job. I believe that this was an example of those perceptions.

It is easy to get into a victim mentality when you have been told a certain narrative for most of your life from those outsides of your bubble. What does such treatment do to someone's mental health?

> We may also ask what being treated as a "freak" or oddity does to a person's conception of self-identity […] Persons travelling through life with the stigma of being significantly shorter than their peers, however, might use another category to define themselves. (Gordon, 2020, p. 237)

You want to show the world that you have value, but often this is shown in a way that is detrimental to your health. I have always felt this where I could be equal (or perform better) than anyone else was at work. I always strived to be the MVP of wherever I was working but it would always come at a cost, either to my family, my health or both. I knew that with my disability, people would always underestimate me. I also knew the perception that most able-bodied employers have of those with disabilities in the workplace; "disabled people are often treated as though their way of doing things is disruptive to the 'normal' speed, flow, or circulation of people, commodities, and capital because the 'waste' more time and space than they should reducing profit margins" (Hansen & Philo, 2007, p. 499). Therefore, being aware that employers could think that having me on the team could cost more than the average employee and that I could be perceived as needier than the 'normal' employee, I would outwork everyone to try and combat that perception. If I did not know something or wanted to know more than someone on a certain topic, I would spend hours, sometimes days, researching and understanding the topic in question. I always loved being the underdog at work, where less was expected, and they were shocked by how wrong they were. I would never admit that I was unable to do something or had too much on my plate. When asked to do something the answer was always yes, with a smile. Never once did I put my hand up and say that I did not have the capacity to take on more work. Hansen and Philo (2007) note this trend in their research:

> Various women remarked on feeling that they had to do *much more* than their non-disabled colleagues in order to be accepted as equals in the workplace, which could mean putting in more hours, completing more reports or thinking of more angles, just so that they avoid being regarded as "slow" workers […] "You feel that you have to prove yourself to be superhuman." (p. 499)

Work is derived and built upon ensuring that companies make a lot of money quickly and with the least amount of headache. Workers must be productive, available whenever needed and with the least amount of conflict. As suggested by Moulaï et al. (2022), "work environments give rise to the expectations around how workers should behave and be" (p. 4501). Furthermore, work is built upon the idea of the ideal worker,

> whose attributes are measured against by colleagues, managers, and workers themselves […] both a psychological aspect of worker identities and a motivational tool for management, the ideal worker image shapes workplace dynamics as employees strive to develop themselves to realize this image in practice. (Moulaï et al., 2022, p. 4501)

What is fascinating is how this capitalist and ableist view of disability and work aligns with Da Vinci's *Vitruvian Man,* known as the ideal human. In an essay that I wrote titled *Representation*

Matters for Disabled Girls, I discuss how disabled people are viewed as less-than-human or something not to be desired (Rayburn-Trubyk, 2022, p. 3) and “Da Vinci’s *Vitruvian Man* as the idealist figure of an exclusionary hegemonic cultural model (white, European, male, handsome, able-bodied). Those outside the archetypal humanist ideal are considered less than human or inhuman” (Goethals et al., 2020). The comparison between the ideal worker and the ideal man cannot go unnoticed. Both deem the disabled person less than ideal. Both comparisons create added pressure on disabled people to try to conform or hide their disability as to want to appear ‘normal’ or more ideal. “The power to construct organizational norms around ability unfolds through individuals’ intra-personal efforts to who they are relative to who they feel they are supposed to be” (Moulaï et al., 2022, p. 4504).

In work settings, the negative stereotypes plague disabled people. “Despite such assumptions being politically incorrect, and having little evidence to support them, they continue to influence the treatment of people with disability at work” (Vickers, 2009, p. 258). The stereotypes are vast and range from the belief that there will be higher absenteeism, to higher costs, to less productivity to more time spent with the worker. All are false.

> Flawed stereotypes prevail: people with disabilities are not productive; they do not “fit in” with other workers, especially if they require accommodations; they require more supervision, they take more leave, and they are not likely to especially useful to the organisation that is striving to do more with less. (Vickers, 2009, p. 258)

As I mentioned, my career was important to me. I could not admit that I could not do something, and I always strived to be the MVP of whatever task or job I was doing. In 2014, I spent a lot of time travelling for work. I was a corporate trainer often flying to other cities and working with leaders in various stores. I recall one Sunday when I was about to fly to Ontario and then Alberta in the same week. I called my father to check-in. I knew that he had been battling pneumonia, but at the time believed he was on the upswing. He shared that he was not feeling well, and I had offered to go and visit him before I left for my work trip. He declined. Everything in my gut was screaming at me to not go on this trip. I decided to go and flew to Thunder Bay. I called my dad when I landed, and he had mentioned that he was going to go and get a prescription for additional antibiotics for his pneumonia as he was not healing. Again, my gut told me to get home. I kept working. I was scheduled to fly from Thunder Bay to Edmonton that night. When I went to check-in for my flight, we were informed that there was an issue with the plane, and I had to be rerouted to Toronto and then Edmonton the next day. My gut told me to head to Winnipeg instead and skip the Edmonton leg of the trip. As I was travelling with others and did not want to appear as if I was not focused on my career, I flew to Toronto for the night only to be rerouted to Edmonton the next day. My father was admitted to the hospital that night and upon checking his stats, the doctor found that he had cancer. To make matters worse, the cancer had spread throughout his body. Still, at the time, he was scheduled to be released later that week while waiting for an appointment with Cancer Care Manitoba. Once again, I knew I had to get home. It was the night before I was scheduled to fly home that I got a call from my husband. Two days after my father had been admitted to the hospital, he collapsed and was unable to be resuscitated. My father had died. The guilt that I carried from missing his death, for not listening to my gut or paying attention to the signs, and worse, that I had consciously chosen to put my career ahead of my family, is something that I will live with forever. I had built up the idea of wanting to outperform everyone. I had wanted to be as productive as possible and as perfect an employee as I could be and ultimately this influenced my decisions to choose work over family. As mentioned by Moulaï et al., (Moulaï et al., 2022, p. 4502) the ideal worker is one based on productivity and ultimately determines one's value at work. "While aspiring to be an ideal self can be source of internal meaningfulness, it can lead to harmful excess and frustration" (Bailey et al., 2019)

Once I started working professionally, beyond my teenage part-time jobs, I would spend evenings and weekends working, not because I had to, but because I wanted to. I understood that having dwarfism meant that I would also be considered as someone who is less than others in the workplace. Workplace discourses around ability norms establish the idea of an ideal worker and create pressure on workers to align their performance with these ideals (Ortliebe & Sieben, 2019). I can recall a time when I had taken on more than I could handle at work and could not admit that it was too much. I would start my days at home on my computer at 4:30 AM to attempt to get ahead. I would be in the office by 7:30 AM and end working in the office at 4:30 PM. I would have dinner with my family and then head into the home office around 7:00 PM and work for a couple more hours. I would be in bed by 9 PM only to turn around and do it again the next day. On the weekend, I would wake up early, work a few hours before I would start my weekend errands. Ultimately a year of doing this consistently led to a significant burnout. Part of the idea of wanting to be the MVP or an ideal worker means having to compromise myself and my values. Fleming (2015) discusses that modern organizations create "the ideal employee who never sleeps: habituated the notation of working for the sake of it, unable to stop" (p. 21). I had hit my proverbial wall, I had no more to give, and worse, I was giving too much of myself and sacrificing time with my family. I was hoping for a lifeline, and I knew that depression was surfacing. With not taking care of myself, it had overpowered my body and mind. Around this same time, there were significant changes with leadership at my workplace. With working consistently, and fear of the unknown coupled with workplace tensions, it created a perfect storm for burnout. I had burned out as Nagoski and Nagoski (2020) describe in their book, *Burnout*:

> The problem is not that women don't try. On the contrary, we're trying all the time to do and be all the things everyone demands from us. And we will try anything – any green smoothie, any deep-breathing exercise, any coloring book or bath bomb, any retreat or vacation we can shoehorn into our schedules – to be what our work and our family and our world demand. (p. ix)

I felt that my life was on the wrong track, and I had this intense feeling that I was not supposed to be where I currently was. My life needed a bolt of energy to get on track, and quickly. I knew that if I wanted to live up to my full potential and have true pride in myself, finding myself was key. It was at that time that I started to collaborate with my therapist and start to put some real boundaries in place for my work life. Women tend to take on more when their life is already at full capacity, combined with the natural tendency to people-please. Women are expected to be everything, to everyone, all at once; "put differently women are required to overcome; to be flexible, to be resilient and to adjust" (Mason, 2014, p. 442). At the time, I felt all of that and had no control over any of it. Now, still struggling with saying 'no' at times, it has become easier to spot when I need to take reevaluate and pivot. I can now spot when I have said 'yes' to something and should not have and have allowed myself the forgiveness of pivoting to a 'no' when I had originally said 'yes.' Although it is still a struggle to admit when I have taken too much on, it is something that I can identify more easily now and put boundaries in place when need be. I can be proactive when feelings of nothing inside start to surface. Ultimately, this has led to a significant increase in self-love and Dwarf Pride as I now understand the benefit to true self-care.

Heigh-ho, High-Ho the Remastered 2022 Dwarf Edition for the tired Dwarf by Samantha Rayburn-Trubyk
(Sung to the melody of the Disney song from Snow White and Seven Dwarfs, "Heigh-Ho")
High-Ho, High-Ho, it's off to work I go.
Shut up and do and don't complain, heigh-ho, heigh-ho, heigh-ho,

Heigh-ho, heigh-ho, it's continuing to work I go.
Do all the work and pretend to smile heigh-ho, heigh-ho heigh-ho, heigh-ho.

Heigh-ho, heigh-ho, I'm still at work, you know?
Grind it out and take on more, heigh-ho, heigh-ho heigh-ho, heigh-ho

Heigh-ho, heigh-ho, I am really tired I know?
Don't look high maintenance and pretend to like it, heigh-ho, heigh-ho heigh-ho, heigh-ho

Heigh-ho, heigh-ho, I'm burning out, you know?
My mental health is screaming for help but keep on going to prove you're the best, heigh-ho, heigh-ho heigh-ho, heigh-ho.

Heigh-ho, heigh-ho my depression is bad I know.
I must sleep and quiet my mind, or I will not survive, heigh-ho, heigh-ho heigh- ho, heigh-ho.

Heigh-ho, heigh-ho, I must save my energy now.

Peter Dinklage, the Eighth Dwarf?

In January 2022, during an interview on *Marc Maron's WTF podcast,* Peter Dinklage spoke about Disney's decision to cast a Latina actor as the character of Snow White in the upcoming remake of *Snow White and Seven Dwarfs.* Dinklage states,

> Literally no offense to anyone, but I was a little taken back when they were immensely proud to cast a Latina actress as Snow White – but you're still telling the story of *Snow White and the Seven Dwarfs.* Take a step back and look at what you're doing there. It makes no sense to me. You're progressive in one way, but then you're still making that

> fucking backward story about seven dwarfs living in a cave together? What the fuck are you doing, man? Have I done nothing to advance the cause from my soapbox? I guess I'm not loud enough. (Parker, 2022)

When that story came out, I was asked to provide my perspective on a local morning radio show, *The Start* (CJOB 680). As President of Little People of Manitoba (LPM), I am often asked to share my viewpoints on such stories. This one was different. After informing the Board of LPM, a debate ensued about the meaning of the *Seven Dwarfs* and who would win the debate on the topic: '*well, that is not how I see it*' average size people or those with lived experience. A divide was clear in our LPM community. It is important to note that the divide was between some members of our average height board members who 'did not see anything wrong with the story' vs. board members of short stature. Everyone in the community agreed with the principle that these types of roles are stereotypical roles. Where the difference lies is in the difference of perspective. Some in the community are looking at this in the present state and others like Dinklage are looking to improve on the future state. A portion of the commentary is looking at things right now. Remaking *Snow White and the Seven Dwarfs* means seven acting jobs for Little People. If you do not make that production or if you change that production to animate those roles, you are costing seven Little People seven acting jobs. What Dinklage is saying, in my opinion, is the future state. He is not asking for any reduction in acting jobs for Little People; he wants better acting jobs for Little People. Why are most acting jobs available for Little People stereotypical roles, the ones where mocking is encouraged? Dinklage is saying, 'Have we not moved past this? Can we have a Little Person cast as a leading character perhaps? Why is it that when a Disney production comes out, if a Little Person is being used, we know that it is to be one of the *Seven Dwarfs*?' We know that the Little Person will not be cast as *Prince Charming* or one of the princesses or someone in a title role. Ultimately, Little People are not looking to reduce the number of jobs; we are seeking better jobs. Like other marginalized groups that have had similar struggles in Hollywood regarding playing stereotypical roles, they have graduated from that typecast and are now playing better roles. So why have we not? Snow White herself is a Latina actor in the upcoming Disney production, therefore the question is, 'Why is it these other groups can evolve and emerge in title character roles and Little People cannot?' Ultimately, both sides are arguing for the same thing, but we are just looking at it from a distinct perspective, not what is happening to these seven jobs right now. Why is it in 2022 that these are the only jobs that Disney is offering people like me – stereotypical roles?

My feelings were simple and below is an excerpt of what I shared during the interview. Given the debate within the group, I conducted this interview representing myself,

> I agree with his (Dinklage's) statement 100% but I do believe that they require clarification and possibly context. Statements were clearly made out of anger and there was a lot of passion and pain that was evident in the way that he spoke. I can recognize that on the surface many people might look at a film like *Snow White and the Seven Dwarfs* and question what could possibly be wrong with that.
>
> Seems like a wholesome movie, the Dwarves seem like a happy family, one might even say, but the point is that for someone like myself and others like me, these types of iconic characters become a source of pain. For many decades Little People were type cast into exploitive roles – Oompa Loompas, munchkins, etc. – which created ammunition for harassment and for bullies to use against people like myself. So, while *Snow White and the Seven Dwarfs* may bring back warm memories for many folks, and many average size people who enjoyed a Disney masterpiece, for me, it's a source of pain. It's something

> that was used to ostracize me for my size. What Peter Dinklage was saying is that Little People were not alone in being exploited and given these roles that mocked them or subjected them in some way. But as society has evolved and Hollywood has adopted a more equitable perspective on these types of sensitive issues, we are seeing people of colour cast as the protagonist, or the hero. In the *Snow White and the Seven Dwarfs* remake that he was commenting on they've casted a Latina actress as Snow White. The LP community is one that, unfortunately, has been overlooked in this regard.
>
> Now, with that being said, Peter Dinklage is an exceptional actor, and he has starred in some groundbreaking roles as a standout actor, like *Elf, Game of Thrones*, *Station Agent*, etc. And he has worked very hard and beat some very long odds to move the needle in the right direction, where Little People are not there to simply mock or ostracize. I can understand why the person who has broken that mold would be as upset as he was to see another remake on a movie that does not cast the brightest light on Little People. (Global News Radio, 2022)

As the media can perpetuate stereotypical roles, it creates an unfair playing ground for a Little Person in the 'real-world.' As Mark Povinelli states,

> I think the challenge with people with dwarfism and certainty within Little People of America, and the representation delivered by the media of what dwarfism is, be the leprechaun at the bar just makes it that much harder when they go in for a job as a professional, you're really working from a disadvantage. (Disability in Hollywood, 2022)

Additionally, it is not surprising that the media dictates beauty standards. Whether it be in magazines, on the internet, on television or in movies, the media has a strict definition of what beauty is and what it is not. Unfortunately, disabled beauty is not on the list of what is deemed beautiful, and representation rarely matters for disabled people. In 2022, I wrote an essay titled "Representation Matters for Disabled Girls." I argue that "disabled children are not meant to view disabled adults represented in the media as role models, they're meant to see people with disabilities as a means to survive" (Rayburn - Trubyk, 2022, p. 5). Furthermore, disability is often portrayed as pity, in need of a fix or as inspiration. Due to the media impact on beauty standards, disability is often not viewed as beautiful or something to be admired in the real world, but rather pitied or created to be victimized. Thus, dwarfism is something to be stared at, worthy of a shock-value type of treatment; "we stare at what interests us" (Garland-Thomson, 2015, p. 18).

Who do you think you are?

Who are you to tell me what I can and can't do?
Who are you to tell me what you can and can't call me?
Who are you to gawk, point and stare at me?
Who are you to tell me that I need to be fixed?
Who are you to tell me 'god bless you?'
Who are you to tell me that I'm not worthy of being a mother?
Who are you to tell me that I should be happy to just have a job?
Who are you to tell me that I should be thankful?
Who are you to determine what my life will or will not amount to?
Who are you?
You are ignorant.
You are rude.
You are narrow-minded.
You are cruel.
You are uninformed.
You are privileged.
You are next.

During my undergraduate degree program, I had become friendly with a fellow classmate. We became close and she and I would often spend time together after class or on weekends. One day while we were sitting with our classmates the topic of friendship came up.

Speaking about her life, she informed the group that she tends to surround herself with friends who she deemed uglier than her. In her defense, I knew she lacked confidence in herself and often sought the compliments of others. Thankfully, my classmates noticed my facial expressions as I was processing this, and one classmate asked how I fit into this. I will never forget that she responded with a laugh and a shrug. For me, it was not the fact that she deemed herself superior to me, it was that she was using my disability as her barometer of what ugly was. Adelson (2005b) explains, "Study after study confirms the existence of discrimination on the basis of attractiveness. People judge the adjustment of good-looking people as better than that of unattractive ones" (p. 90). Not only is this ableism, but this is also too common where people with disabilities are made to feel inferior to able-bodied people. Where disability is not seen as beautiful but rather monstrous or grotesque. As Adelson (2005b) explains, most medical doctors in the late nineteenth and early twentieth century were "transfixed by dwarfs' 'abnormal' appearance and doctors focused on the unduly" (p. 122). Furthermore, Adelson (2005b) discusses that there were few articles about dwarfism at the time of her publication and those that were available describe dwarfism using words like "their grotesque appearance" (p. 123). I do not fault my classmate for believing that I was inferior to her in terms of looks, because when the medical field, which tends to be marketed as the all-knowing, deems you as grotesque with a need for an immediate fix or cure, that thought process would be scooped up by the media and naturally trickle down to general society. "[M]onstrosity is referred to as something 'irregular, enormous, excessive,' out of natural proportion, a definition that implies a moral contrast with the neoclassical values of balance, decorum, and symmetry" (Gordon, 2020, p. 233). In a study titled *The Hierarchy of Preferences towards Disabled Groups*, the researchers found that dwarfs were the least preferred regarding physical disabilities: "Dwarf (14) and hunchback (16) are low rated physical disabilities that suggest the influence of an aesthetic factor" (Tringo, 1970, p. 304). To me the lack of research and the story about my classmate highlights the need to see more representation in the media and more education for those consuming it.

In March 2022, I was tasked with writing a paper for a Women and Disability course at the University of Manitoba. I argued that disabled girls are not exposed to positive representation in the media. Exposure consists of perpetuating stereotypes and/or inspiration porn. As explained earlier, inspirational porn "a portrayal of people with disabilities as one-dimensional saints who only exist to warm the hearts and open the minds of able-bodied people" (Weinberg, 2017, para. 10). In the assignment, I state, "[A] lack of positive representation in the media of people with disabilities gives an impression of unworthiness" (Rayburn-Trubyk, 2022, p. 3). As disabled people are often viewed as less than desirable, this thought process aligns with why representation either seeks to exist, is limited, and often perpetuates stereotypes. If the general society is consuming these same forms of media and seeing the same lack of representation or perpetuating the negative stereotypes, the message given is clear: Disability is undesirable and laughable. Therefore, it is no wonder my friend felt that my height dictated my beauty as she was heavily influenced by messaging perpetuated by beauty representation in the media.

In elementary and middle school, I went to an all-girls private school. In seventh grade, I was enrolled in a debating class. One of the assignments was to perform an improv based on a word that the class picked. I cannot recall the word that I was presented with or the topic, but I do recall that I made the class roar with laughter, and ultimately received an A+ for that assignment. At that time, I could not believe how easy it was to get a high mark. I remember thinking that I was not sure what I did that was so funny. I knew it was intended to make people laugh, but I did not put any effort into the assignment. The reward outweighed the effort and although I did not have a word for it, I knew that I could utilize a formula that most other classmates could not. That formula was (lack of effort) + (dwarf performing it/writing it/speaking it/doing it) = A+. In my mind, it was that simple. Although I did not have word for it at the time, this was my first experience with inspiration porn.

> It tends to convey a single feeling, paper-thin sentimentality, which crowds out all other possible interpretations. Instead of describing the complicated ups and downs of living with disabilities, showing us the varied personalities of disabled people, or calling attention to the real problems disabled people face every day, Inspiration Porn pushes us towards a single 'Awww' response, and one mood, a mix of condescension and pity […] Relentlessly repeated stories of admirable, charming, high-achieving disabled people tend to create misplaced pressures on other disabled people to behave in certain ways and achieve certain markers of success. (Pulrang, 2022, para. 17)

I am not one to think that all of what is defined as inspiration porn is bad. If used properly, it can be used strategically to influence societal change. There is a difference between an uninformed, eager-to-show-off parent who takes a video of their disabled child doing a typical thing for their age group who posts it with the intent to make it go viral because 'gosh, look how inspiring my disabled child is,' versus someone professionally speaking and achieving things that most others will not do despite ability. In my experience, people tend to listen to you more if they believe you are doing something ordinary extraordinarily well. Change happens when society is taken off-guard and least expecting it.

Freud states, "anatomy is destiny" (Sayers, 1979, para. 1). Inspiration porn is a paradox in and of itself. For one, I live my life hoping to inspire the next generation of Little People to make the changes necessary for the world in which they want to live in:

> If we could change ourselves, the tendencies in the world would also change. As a man changes his own nature, so does the attitude of the world change towards him. […] We need not wait to see what others do. (Weiner & Swaminathan, 1965, p. 472)

I wish to do things or present in a way others will see power, influence, and the ability to make change or disrupt some foundational feathers. Sometimes that comes across as doing everyday things where the expectation is not for someone like me to complete or compete. People make comments such as ‘you’re incredible,’ ‘I could not do that if I were you’ or other unhelpful commentary. My wish is for society to view the things that I do as extraordinary as such rather than believing that everything I do is extraordinary. The message is lost when everything is viewed as some sort of mountain that has been climbed every time I drive the car or make a public speech. All of it is nothing more than ableism in hiding.

In 2021, I met with Winnipeg photographer Teri Hofford. I was interviewed and photographed for her project titled *A Series of Flaws.* Teri’s mission is to create a space for body positivity to reign supreme. Her aim is to positively impact the world for all marginalized groups. As Teri explains,

> I created the series because #1 most photography education focuses on how to remove parts of people, make them smaller, hide them, make them adhere closer to beauty standards, etc. #2 photographers (at least the ones that I mentor) are afraid to ask questions and be vulnerable (like most humans, to be honest). They are afraid of saying the wrong thing or doing the wrong thing, but that prevents them from asking how they can do better and therefore, they unintentionally cause harm to their clients, particularly those in marginalized bodies. (Hofford, 2020)

Therefore, I enrolled my dwarf body in the project. Terri's message seemed foreign to me, important and urgent all at the same time. I spend a lot of my personal time striving to be a positive role model for children born with dwarfism. My mission is to have any child born with this disability grow up to feel empowered, in control and amazed by their own body. More than anything else, I want to leave a legacy where I have impacted the world positively and changed the way that society and the environment treat the dwarf experience. Disability in the media, specifically Little People, is something that does not often have an empowered, pity-free, or non-medical spin on it, and it is spurred by the environment in which we live. Little People are often represented in a way that evokes pity, laughter or an emotion that triggers the idea that we need to be fixed. When represented in the media in such a way, these messages give members of society the approval to conduct themselves in a way that allows ableism to ease through everything that they do. By Teri taking this perspective and changing the narrative, she is undoubtedly positively impacting the environment for persons living with disabilities. For Little People, the landscape needs a change given the history between Little People and the media and how that combination impacts the treatment of Little People in our environment. The commentary that is often put toward Little People is generally a result of how representation in our own individual environments is because of the media landscape.

The Dreaded Midget

UGH by Samantha Rayburn – Trubyk
Don't say it, don't say it, don't say it, don't say it, don't say it.
Jaw clenched, knuckles white, neck tense, eyebrows furrowed,
don't say it, don't say it, don't say it, don't say it.

Sweat beading, headache starting, stomach churning, muscles
tightened, don't' say it, don't say it, don't say it, don't say it.
Don't say it, don't say it, don't say it, DO NOT SAY IT, midget,
ugh. Said it.

The crowd roars with laughter and I become the tiny lion cub
trying to act tougher than my size.

I have spent much of my advocacy work attempting to eradicate the term ‘midget’ from popular vernacular. ‘Midget’ is a term that is considered highly offensive by most in our community. The term midget

> originates from the word “midge,” defined as a tiny fly that spreads diseases. This term dates to the nineteenth century, and its origin has been attributed to P.T. Barnum, who used to put Little People on display as a carnival sideshow. (Rayburn-Trubyk, 2021a, p. 309)

As I have mentioned above, the media plays an enormous role in how we think and act, and nothing is truer than the use of politically incorrect wording. I have had much experience with political correctness and spent much of my adult life advocating for change. Mostly successful, eradicating the term ‘midget’ has been a hard battle to fight. Successfully, we have eradicated the term from sports organizations in Manitoba and nationally at Hockey Canada. In December 2019, I attended a school board meeting in Dickenson, North Dakota. The school sports teams in Dickenson are known as the ‘Midgets.’ The term is proudly displayed throughout the town of Dickenson including a team bus with the word and mascot proudly displayed on the side of it. It is also in their sporting goods store with a wall of clothing including a bright orange shirt with the word ‘Midgets’ written for all to see. The intent of the meeting with the school board was to request a change in terminology and change the sports team to something less offensive and discriminatory. Shortly after this meeting, I was interviewed by Cindy Boren of the Washington Post and stated, “The bottom line is that this word is offensive to Little People, and the [Little People of America] has been very clear on this point” (Boren, 2019, para. 3).

> There are infinite possibilities of what to name a team that do not encroach on being disrespectful to a group of people, and there are only a handful of schools left in the country who are clinging to this mascot. Time is long overdue for a change, and there is absolutely zero good defense for keeping this archaic, overdue term alive in public schools. (Boren, 2019, para. 3)

The article continues: “As we round the corner on 2019, every school must commit some portion of their curriculum to teaching diversity, inclusion, and tolerance in their classrooms” (Boren, 2019, para. 12).

> And the point we were making is we were curious how schools maintain their credibility when on one hand they educate their students about treating everyone equally and then on the other hand they support the use of a divisive, discriminatory word [etched] right on the gymnasium floor. Consider, for a moment, if you were a Little Person attending high school and you were being bullied with the term “Midget.” Would you feel like your concerns could possibly be taken seriously by the administration or by the folks that you should be able to trust if they support using the very same word in their athletics program? School is supposed to be a safe place for kids. (Boren, 2019, para. 13)

Use of this term is still all too common despite the time and energy put into attempting to eradicate it. One night, in 2021, my husband and I attended a comedy show at a local club. The comedian was half-way through their set when the word came out and the club roared with laughter. The joke was about midgets. Pritchard (2017b) states,

> [I]n relation to dwarfs, representations of them often encourage people to laugh at them. This is not to suggest that other impairments have not been used for humorous purposes,

> or are not laughed at, but they are not promoted as humorous in the same way dwarfs that in the entertainment industry are. (p. 4)

At the time that the joke occurred, most of the audience was aware that I had walked in and the stares after the joke were immediate. To add an additional layer of uncomfortableness, the club sat us beside two people that we knew. I knew that when the show was over, I had two options; either I could leave as fast as possible before the lights went on or I could wait until the crowd had left and leave quietly. Nonetheless, I was mortified. The comedian finished their set, and the lights went on. We waited for the crowd to dissipate. My experience is not uncommon for people with dwarfism, and often those born with dwarfism will avoid certain venues to not be put situations that render them uncomfortable or vulnerable. In *Dwarfism, Spatiality and Disabling Experiences,* a story is shared where someone with dwarfism avoids seeing films that have known characters with dwarfism cast in the movie: “[A]voiding a film with a character with dwarfism in it can be seen as a strategy which minimizes how much unwanted attention both Amanda and Naomi receive” (Pritchard, 2022a, p. 109). After leaving the comedy club, I was finally able to exhale, and I was angry. Angry that it was 2021 and we were still dealing with this. I was angry that the work that our group has done does not ever seem to be enough. Sadly, I was also angry with myself for not doing enough advocacy work. “It’s a peculiar sensation, this double consciousness, this sense of always looking at oneself through the eyes of others, of measuring one’s soul by the tape of a world that looks on in amused contempt and pity” (Adelson, 2005b p. 317).

The next day, I made a post on social media to vent my frustration and the feedback was incredibly positive. Most were supportive and shared my disdain. My allies were supportive, my community understood, and others wanted to debate the ‘joke’ and this idea that society now takes itself too seriously. To me there is no debate; "there is a difference between being laughed '*at'* and laughed '*with'*. The former is degrading as it constructs the person being laughed at as inferior" (Pritchard, 2022a, p. 104).

Typically, at this stage in my life, I do not tend to become unnerved by interactions the same way as I was at one time. I tend to think I have heard it all and when something does happen, I have got my shield on, and I have tunnel vision when things occur to protect myself. This one was different and rocked me to my core. I could not get over it. Perhaps it was because I was on the brink of turning 40 when this incident occurred, and I had spent the last decade of my life advocating for Little People. Perhaps it was because my son had just turned 16 and I wanted him to mature into a world that was tolerant to us. Regardless of the reason, nonetheless, aligning with second factor as outlined in the factors scale by Forber-Pratt, et al. the anger and/or frustration one might feel. Regardless, I was angry.

Unfortunately, this type of situation is not new and can often play out like a broken record. As a younger child, my mother treated me to a concert with a local Acapella group playing at the Gas Station Theatre in Winnipeg. During one of their songs, the term midget was used and intended as a joke. My mother, the ultimate advocate, was up and out of her seat walking towards the manager of the group before the song had ended. "Whilst dwarfism's acceptance as a disability is often contested, its perception as a form of amusement is not. Dwarfism is a disability, but a disability that is acceptable to laugh at and is actively encouraged within the media" (Pritchard, 2017b, p. 10). The group ultimately apologized. I believe that it was at that moment when I started to understand the world as it relates to me and my dwarfism, and ultimately lead me towards advocacy work.

As a child, my friend and I enjoyed trick-or-treating at Halloween. As all kids do, we aged out. However, still enjoying Halloween as teenagers, we decided to create a spooky experience at her house for the next generation of trick-or-treaters. I grabbed a full head mask to wear and stood outside of her house beside an attached column. I attempted to stand still as I wanted to appear to be statuesque to scare people as they came close. I was having a great time scaring the local audience until one teenager yelled at the top of their lungs, ‘It’s a midget.’ My stomach started to churn, and my heart sank and once again. I was humiliated. “We glean some dehumanization of fellow humans through the process of labelling them ‘special’ affects not only human ‘objects’ themselves, but the viewers as well” (Gordon, 2020, p. 232). Not much has changed from how dwarfs are treated in modern times from treatment in the courts of the past.

> Dwarfs […] could sometimes be regarded as special, as natural curiosities meant to amuse the royal family. At other times they could be viewed as freighting, or at the very least inconsequential, as unfortunate accidents or demonstrations of God’s displeasure with mankind, or His desire to sow us a physical embodiment of our moral indecency. (Gordon, 2020, p. 233)

In addition to those that want to make jokes about your size or use of the term ‘midget,’ there are phobias associated with a fear of Little People. I had not been aware of such a condition until 2012. I recall hearing about this while watching an interview with comedian Rosie O’Donnell. At the time, I was a fan of Rosie O’Donnell’s and can remember the disappointment I felt when hearing this. I understood that given her popularity at the time, that this would impact my community negatively. During an interview with Chelsea Handler, O’Donnell stated,

> I'm a little ashamed about it [but] I have a mild fear or anxiety around Little People. The problem with me is I can't put the two things together. This is an adult person, a Little Person ... it's so hard for me. (Entertainment Tonight, 2012, para. 4)

After researching, I discovered that there was a term for this type of phobia, it was called achondroplasiaphobia, Nanosophobia or Lollypopguildophobia, meaning the "fear of Little People or midgets" (Olesen, 2020, para. 1). Furthermore,

> [T]he fear of Little People can be debilitating as a person might refuse to go to circuses, casinos, fairs, or malls where Little People are thought to be present, at least in the phobics mind. In one of the more extreme cases, a pregnant woman encountered a frightening dwarf during her pregnancy which led her to believe that her unborn child would be a dwarf too. This led her to have repeat nightmares about it and an eventual miscarriage. (Olesen, 2020, para. 2)

Not long after the Rosie O'Donnell and Chelsea Handler interview, my husband and I were in Las Vegas for vacation. We were there during a fight weekend and the city was swollen with people. The night of the fight, we were walking back to our hotel around the time that the streets were filling with people. As we were dodging in and out of the crowds, I suddenly heard a loud, blood-curdling scream. I looked around to see what the person was frightened of, only to realize it was me. This woman had seen me and screamed with fear alerting the entire street of my presence. Everyone stopped and turned around to stare at me, and she yelled, 'It's a midget.' I was horrified and my husband and I picked up the pace towards our hotel. It was that same night as we had escaped the horror of the situation with this woman that we were close to our hotel when a group of young men driving on the Las Vegas strip saw me on the sidewalk and yelled, 'Hey, midget.' It was that night that we vowed never to return to Las Vegas during a fight weekend. People fear things they do not understand or perceive as out of the ordinary. Whether calling it a phobia or not, having a fear of a person's specific characteristic is what Hansen and Philo (2007) describe as follows:

> [I]t is not only a matter of appearance, for what also comes into play are the differences of how impaired bodies *do things*, whether moving, gesturing, speaking, undertaking a task at work such as telephoning or typing, and so on. If people's comportment seems out-of-the-ordinary, being too slow or taking too long, involving "curious" jerks, postures, or facial expressions, perhaps accompanied by "odd" sounds or smells, then the risk is that they become treated with suspicion or even hostility […] Maybe disabled people are forced to account for these different bodily performances, too often they are shunned[.]and they constantly feel pressure to perform as 'normally' as they possibly can… (p. 496)

The Importance of Community

In 2013, I was watching my son develop his own relationship within the Little People of America community. I knew the value that this organization held for me, but to now observe this as a mother of a child with a disability was incredible. With LPA, I felt an immense sense of gratitude and an intense need to give back to my community. For any of the negative stories that I have due to my disability, the positives have always outweighed them. I am genuinely happy with who I was and am. I know that this organization had a big part to play in that realization. I was not sure how I was going to give back at that time but knew that "as I grew older and wiser I [I] began to recognize the value and appreciate the value of that organizations advocacy work" (Rayburn-Trubyk, 2021a, p. 308). I knew that I needed to give significant energy to a community that I loved and valued. Ultimately,

> I was led to pursue advocacy in my spare time through my connection to this organization [Little People of America], as well as my son coming to an age where he would be attending school and beginning to deal with insensitive and offensive behaviours from others. (Rayburn-Trubyk, 2021a, p. 308)

It is safe to say that during this time, I was in what Forber-Pratt et al. (2020) describe as "contribution to the disability community" (p. 7) in the finding self-identity scale. In 2015, I became President of Little People of Manitoba (LPM), a non-profit, registered charity, dedicated to creating awareness about the prominent issues affecting people with dwarfism, and providing social support for Little People in Manitoba (Little People of Manitoba, 2023). At that time, LPM was not as known as it is now outside of our immediate community. My parents had become members of LPM when I was two years old and stayed with the organization throughout most of my early teenage years. I had lost touch with the organization until my son was born in 2005 and was sporadically in and out until I officially joined the board in 2014. In 2017, through advocating, Manitoba became the first province in Canada to annually declare October 25 as Dwarfism Awareness Day. This was the foundation of future important advocacy to come.

As explained in *Still Living the Edges*, "In July 2018, the LPM set out to take on its most controversial advocacy work to dates: the eradication of the word 'midget' from all minor sports in the province" (Rayburn-Trubyk, 2021a, p. 309). The backlash that came from attempting and then accomplishing this goal was unpredictable. The personalized hate that I received was hard to swallow, but each piece of hate fueled me to keep going. In 2019, all sports in Manitoba agreed to remove the word 'midget' from their age classifications. Furthermore, since then, Hockey Canada has removed the term from their vernacular as well. Ultimately, removing this term from major sports was a massive win for advocacy and our community.

The importance of this change cannot be understated. For LP kids growing up today, they will not have to feel conflicted knowing that a word that is so readily used in the sports world is one that causes them so much pain. I often think how it must be confusing for the public to hear that this word is offensive but was one that was associated with sports classifications. Without the context of the word, I can imagine that it felt like we were just another group with a problem that seemed so insignificant that it did not warrant any attention or change. It is only now that we can start to truly make changes as the public starts to understand the importance that change like this has in our community.

Pride, Trust, Being Underestimated and Trauma

As mentioned previously, disability pride is taking pride in your whole self, finding community, celebrating the existence of disability, and using it to further progress towards acceptance. Pride "refers to being proud of one's identity and, in the process, acknowledging possession of a socially devalued quality" (Dunn & Burcaw, 2013, p. 150). Finding pride in oneself is not an easy task and, I would argue, harder to find as a Little Person in an average-size world. Constantly portrayed in the media based on stereotypes, consistently stared at, or gawked at in public settings and often the butt of the joke, "dwarfs are portrayed as figures of fun, happy to always be laughed at, but rarely with" (Pritchard, 2017b p. 10). Finally, being someone that others think they can take advantage of can get exhausting to always be combatting against.

As a young professional, I was sent on a work trip that included meeting with other people in the company who worked in a similar role. After a long day, the team decided to go to the bar for a drink before bed. Meeting with another group at the bar, a patron and I struck up a conversation. Half-way through our conversation, he asked me to 'do the thing.' I was confused and asked him to repeat himself. He said, 'Can you do the dance?' Still confused I asked for clarity, he asked me to do the *Lollipop Guild* song from the popular 1939 American movie *The Wizard of Oz.* This fictional story is about a young girl named Dorothy played by Judy Garland.

> After a tornado hurls through Kansas, Dorothy Gale and her dog, Toto, are swept away from their home to the colorful and vibrant Land of Oz. In order to find their way back home, they must embark on a journey to the Emerald City, where the Wizard of Oz resides. On the way, they are accompanied by a Scarecrow who wants a brain, a Tin Man who wants a heart, and a Cowardly Lion who wants courage. They are hopeful that the Wizard will be able to fulfill their wishes, but not far behind them is the Wicked Witch of the West, who is out for revenge on Dorothy after she accidentally killed her sister, the Wicked Witch of the East. (*The Wizard of Oz (1939) - IMDb*, 1939)

This fantasy film allows the viewer to step into the dream world with Dorothy and follow her on an unforgettable journey that includes meeting interesting and memorable characters including *The Munchkins*. "The Munchkins were a group of Little People who inhabited Oz, the place Dorothy landed when she bumped her head in the tornado" (Harding, 2020). In the movie, *The Munchkins* collectively sing a song called *The Lollipop Guild* while doing a synchronized dance – their voices are distinctive, and the dance is effortless.

The lyrics to the song are simple:

> We represent the Lollipop Guild
> The Lollipop Guild, the Lollipop Guild
> And in the name of the Lollipop Guild
> We wish to welcome you to Munchkin Land. (Arlen, 1939)

This simple ask was not a compliment and would play into a stereotype. Finding pride despite how the world often views you requires a fair bit of introspection, selective tunnel vision and thick skin. I said no to this request and proceeded to go to bed.

Finding trust in others can be difficult; often you question intentions. There are times where those you who thought could be trusted disappoint you. Given the vulnerability associated with being disabled and small, trust is not something that is easily handed out but can be quickly broken. An example of this is someone you thought was an ally turns out to be ableist. When I was pregnant with my son, a former friend and co-worker asked me if I knew if I was going to not have a Little Person or a ‘normal’ baby (her words). I shared that we were informed that he would be born average size. At that time, she offered her opinion and shared her relief with me that I was not going to give birth to someone like me and not bring another disabled person into this world. I was hurt that someone who I considered a friend could have such feelings about me. Worse, she could not understand how hurtful her ableist attitude was.

A break in trust from those in a role of authority can be detrimental to one’s life, not to mention the impact on their ability to have pride in themselves or self-love is damaging. At the age of 4, a neighbor sexually assaulted me. “People with disabilities are at a higher risk for SV [sexual violence] owing to increased reliance on caregivers, communication/language barriers, being perceived as less credible victims, being socialized to have unquestioning compliance, and perceived vulnerability” (Ledingham et al., 2022, p. 895). In the 1990’s, it was not uncommon to play on the street with other kids without parental supervision. If you were with the kids in the neighbourhood, you were safe. I was playing on the street with the other children in my area. This was not unusual as there was a group of us who were in and out of each other’s yards and houses. Back then, playdates were not scheduled; you simply played with whomever was on the street at the time and returned either at dinner time or when it became dark. One summer afternoon, I recall being in this neighbour's backyard with their child and we were playing with body paint and crayons. Our faces, arms and legs were filthy from the colouring. I do not recall much other than a series of flashing images but a series of events that ended in a bathtub and was put in a situation that a young child should not experience. As I was smaller than others, I recall this young child's father being able to use his force to trap me and I was unable to leave. That story, that snippet has taken me over 33 years to share and only now, can only share what amounts to one paragraph publicly. It is painful but a stark reminder of the power that those in authority have and another reminder of how disabled people more likely to be abused. People with disabilities are at greater risk of sexual violence which may be partially attributed to greater vulnerability, negative social attitudes and perceptions and abuses of trust." (Government of Canada, Statistics Canada, 2017, para. 18), "The rate of sexual assault among those with a disability are approximately two times higher than those with no disabilities" (Canadian Women's Foundation, 2022, para. 3).

According to a study published in the *American Journal of Preventative Medicine*, 43.5% of women with disabilities who reported non partner sexual violence never sought help (Malihi et al., 2021). Furthermore, disabled women "reported experiencing sexual violence in their lifetime approximately double the proportion of that experienced by nondisabled women (»30% vs 16.9%)" (Ledingham et al., 2022, p. 895). 83% of women with disabilities will be sexually abused in their lifetime (Stimpson & Best, 1991). I have only recently shared my story of assault with those that are closest to me as I did not think I would be believed. It was 2019 when I shared this story with my mother who was not previously aware that this had occurred.

> [I]f an abuser is in a position of authority in their workplace, school, sports team, family, or community, it can be difficult to report. Survivors may be afraid they will not be believed, and that abuser's status means their word will be believed more. (Canadian Women's Foundation, 2022, para. 6)

Furthermore, in my experience, when you are born with a disability, you are keenly aware that some (not all) people feel that your life is not worth living and moreover, that your life is there for others' power; "individuals who commit sexual assault perceive the person they are victimizing as unequal. That creates a rationale for their control, humiliation, intimidation, and abuse" (Canadian Women's Foundation, 2022, para. 2). You are viewed as less than and not important and thus that you deserve what happened to you. Disabled people are abused daily, and not enough justice is being done. A recent example of this was a post created by social media influencer Erin from *Claiming Disability*. Erin was born with Cerebral Palsy and uses her disability identity to advocate for people with disabilities. Last year, Erin posted on her Instagram page, "My dad who hated me for being disabled & fat. Who called me a worthless cripple girl & sexually assaulted me and my siblings…I hate you…not all parents love their disabled children…" (Claiming, 2022).

Finally, being born with a disability often allows others to feel that they can take advantage of you, underestimate you or treat you as inferior. One summer, I took my car to a local car wash. The car wash was one where you would drop your car off and an employee would take it through the building for a thorough interior and exterior cleaning. As the car I drive must be modified, my car had extensions on the pedals. These are raised pedals that attach to the regular pedals in the car allowing my feet to touch the extended pedals. As I drove to the front of the line, I informed the employee that my car had been modified and needed extensions.

Furthermore, I informed them how they could drive the car. I proceeded to the drop off area and hopped out of the car and gave the keys to the next employee. I walked inside the building and sat on the couch waiting for my car. An employee claiming to be a manager abruptly came inside the building and shouted out my license plate, attempting to find the owner of the car it belonged to. I stood up and informed him that it was my car he was shouting about. Loudly, and for all to here, he proceeded to berate me in front of all customers in the building. It apparently was my fault that I was informed to proceed into the line. It was my fault for my car being modified and furthermore, it was my fault for bothering them. That situation was humiliating. I was made to feel like the problem and made to feel that I should not be participating in an activity that is afforded to others. Not wanting this to happen to others, I advocated for change. Reluctant at first, this car wash has now created a training program for all employees to participate in at the start of employment regarding how to provide good customer service to customers with disabilities.

Often employers do not know how to handle uncomfortable or harassing situations for employees with disabilities and often things that should not be tolerated are expected to be moved past as quickly as possible. “[O]verall, alienation and harassment of employees with disabilities, regardless how widespread and offensive, are readily tolerated by the various supervisory levels in the workplace” (Robert, 2003, p. 153). At one of my former employers, I was an HR manager for a retailer. Part of the HR role included managing the sales floor one shift per week. There would be a daily floor meeting with the employees where we would set the tasks and expectations for the day. During one of those floor meetings, I was working with a co-worker who was also managing that day and we were hosting the floor meeting together. We were bantering back and forth and created a type of comedy routine for the staff. There was a point where my co-worker became annoyed and stated, jokingly, ‘would you shut up,’ in front of everyone. As he was saying that he did so while patting the top of my head, like a dog that was being scolded or a child that was made to feel inferior. After being patronized in front of those I was supposed to be leading, I was mortified. Belittling someone by patting them on the head regardless of if it is done in private or not is one of the most insulting gestures that you can do to someone, let alone a Little Person. In an interview conducted by Hansen and Philo (2007), a participant named Trudy states,

> What can also happen is that pitying and patronising go hand-in-glove – Trudy […] complains about being constantly patted on the head: “I’m not a dog, don’t pat me!” – fuelled by a chronic lack of expectation on the part of non-disabled people regarding he capacities of impaired bodies. It is largely assumed that the latter can achieve little by themselves. (p. 497)

Had I had been an able-bodied man; this situation would not have occurred. I recall leaving that meeting and hustling to my office. I was sobbing so hard that I could barely see before the door closed and I was in disbelief that that had occurred in front of people that I managed and in a professional setting. As I was informing my leader of the incident, it became obvious that I had to justify my feelings. She was empathetic but it was clear did not understand the problem. There was no recourse for the employee. I was expected to move on. “Employees with disabilities often are expected to prove their right to such treatment. Paradoxically, this often means that they should simply accept, without complaint, whatever treatment comes their way” (Robert, 2003, p. 152). Of their own volition, the employee apologized the next day.

It was during the same period that I was closing the store for the evening. Part of our duties included locking the public doors and double checking to ensure that they were locked. I recall that I was unable to reach the locks and there was no accommodation created for me. I had to take matters into my own hands. Unable to admit that I could not do something, not having a ladder or a stool tall enough to reach the locks and knowing that I was fully accountable should something go wrong, I positioned a shopping cart that had a driving cart attachment for children. I climbed on top of the cart, wheels in motion and all, and strained and twisted my body so that I could reach the lock. Believing I had locked the door, I walked towards the door to ensure that the motion detectors on the door were off and thus, that the doors were locked. As I approached the doors, they did not open. I believed the store was secure. As I left the building for the night, I drove to the front of the building to ensure the doors were locked from the outside. I again attempted to walk towards the doors to check if they were unlocked. Again, they did not open, and I left for the night. Not understanding that my height was below the motion detector barometer, the doors were not locked. I came in the next day to find that I had left the store unsecure. It had not occurred to my manager that I would need accommodation for basic managerial tasks, nor did I speak up and advise that I needed assistance. There was debate about this situation as there was a possibility that I would be disciplined for said situation. Being someone that takes my career seriously, this would have been one of worst things that could happen to me and my career. In the end, I was not disciplined as this was out of my control, but this scenario and how it was handled left me feeling unsettled and I started the process of seeking other employment.

Around this same time, I recall that my people pleasing skills were on high alert. At the time, I reported to a boss who often underestimated me and felt that I was someone who could be taken advantage of. This boss would berate and belittle my peers. I was incredibly uncomfortable with how they treated my peers and I felt that it was bullying behaviour. I was so uncomfortable and nervous that the spotlight could turn on me at any point that I did whatever the manager asked of me and well beyond the scope of my job. Worst of all, I did not stand up for my peers and the treatment they were receiving. One in five people witness bullying in the workplace and 90 percent witness bullying in the workplace (Einarsen et al., 2002, p. 150). I can recall several situations where I was asked to leave my actual work task to simply carry her bag into the office or leave to run an errand that was not work related. I felt pressured to answer inappropriate questions about my life. I feared displeasing this person so much that I went overboard with the people pleasing. I was nervous that if I did not do what was asked, my career would be impacted, or worse, be taken away from me. I realize now that that would not have occurred, but at the time, it felt real. I felt alone. I ultimately ended up quitting because my mental health was suffering. I could no longer be a bystander to how my peers were treated and not do or say anything. As bullying can affect mental health, I was dealing with depression. "Exposure to workplace bullying leads to unfavorable health and work outcomes such as mental strain, burnout, job dissatisfaction and reduced job performance" (Samsudin et al., 2020, p.1066), During that time, I would have to energize myself up before going into work every day as my depression was out of control. For me, depression shows up as a feeling of nothing inside. I have no feelings inside of me but simply am going through the motions of life. I describe it as feeling dead inside. There is no spark, no joy, no anger, no frustration, simply nothing. As Gilligan (2016) describes, "I didn't lie in bed and think my life is so totally worthless. It wasn't that. It wasn't like profound unhappiness. It was just nothing" (p. 56). I felt nothing. As someone with high functioning depression, I offer Grande's (2023) definition:

> a term used to describe someone who, despite having the symptoms of a depressive disorder, can function well in various aspects of life, like work, school, home, and

> relationships. They may have milder symptoms of a depressive disorder, and they might mask their depression altogether. (Grande, 2023, para. 2)

I would hype myself up to take on the day. I was exhausted and not because I was overworked but exhausted by the emotion of trying to please. “[I]n short, emotions are tunnels. If you go all the way through them, you get to the light at the end. Exhaustion happens when we get stuck in an emotion” (Nagoski & Nagoski, 2020, p. xxii). Ultimately, I would lie in bed longer than I should or during the day and must visualize myself getting rid of the negativity before I could start to get ready. I would visualize something that I coined as a ‘brain scrape.’ Essentially, I would think about my brain. I would visualize a paint scraper or a car window scraper going around my brain and scraping off all the dark grey hard mud that was around it. The dark grey hard mud represented the sadness I was feeling. I would have to do this before I would go into work. That minimal visualization was just enough to get me through the day. I somehow felt that I could not do any better, that I would be stuck at this job forever. “[C]ontinual exposure to this type of attack can result in low self-esteem, depression, and anxiety” (Vickers, 2009, p. 264). I was depressed in such a way that I could not see myself getting out of this job. It was my husband who helped me understand that what was happening at work was not ‘normal’ and he helped me navigate through.

Sadly, what I have mentioned above is not the only time that my people pleasing or fear of losing my job if I declined a non-work-related request would be at the forefront of a decision. I recall a former boss requesting that I complete a task for them where my ethics would be in question. Looking back now, my younger self should have questioned why this person would not complete the task themselves. More importantly, why was I the one that was asked to complete said task? Why had I felt the need to be so loyal to this employer that it cost me my self-respect?

When asked, I protected my boss. I was loyal. Before seeing my therapist, I always felt this need to morph into whomever I was trying to impress, whether it be a boss or a mentor. For me to feel valued, I became a chameleon to whomever I was spending my time around. If you like grey skies, I liked grey skies. If you liked anchovies, anchovies became my favourite. If your favourite sport was lacrosse, my favourite sport became lacrosse despite never seeing a game. If you did not like someone, I would not like them either. I would become the person I was seeking approval from only to be liked. Nagoski and Nagoski (2020) describe this as Human Giver Syndrome: "Human Givers have a moral obligation to give their humanity to the human beings. Guess which one women are" (p. xiii).

Object of Fascination by Samantha Rayburn-Trubyk

What is an object – is it a thing?
Is it something that someone can touch, can hold, can fondle?
Can you take pictures of the object? Is it in a zoo or in a fishbowl?
Is an object there to please? Is an object expected to be touched, to
be held, to be fondled?
Is an object clear? Is an object tough?
Is an object funny? Is it there to make you laugh?
Is the point of the object for your ridicule or your video?
Is an object cold? Is it hard?
Is it hot and soft?
What is an object?
Does an object have feelings?
Yes – the object has feelings.

To be Fixed or Cured?

The medical model of disability defines the disabled person as the problem in need of a fix, that they are ones who need to be fixed. It makes no mention or consideration that it could potentially be the environment that is the issue, the environment that needs to change, or the attitudes of others that need an adjustment. Society, including the medical industry, mostly subscribes to the medical model of disability. This model "focuses on the disadvantaging impact of physical or mental impairments rather that of the environment in which they operate. The impairments themselves are thought to be disabling" (Samaha, 2007, p. 1256). In addition to often being considered a joke, constantly knowing that the world believes you should be fixed or 'cured' is hard and harder when trying to defend why you will not go for the fix or the 'cure.' This is even worse when defending why your child will not be subjected to this. As most doctors are medically trained with the medical model of disability as their moral compass, it is not surprising that they pursue speaking with parents or patients on the 'benefits' of the treatment or cure options. As doctors tend to look at Little People or all disabilities for that matter as something to be studied, fixed, or cured, it is no wonder disabled people have more negative experiences when associating with the medical industry. Adelson (2005b) states,

> [A] review of medical articles written during the late nineteenth and early twentieth centuries reveals that very often, transfixed by dwarfs' "abnormal" appearance, doctors focused upon it unduly. Unable to "cure" these patients and needing to do *something*, physicians recorded body measurements. As the title of one 1896 work reveals, dwarfs were of interest chiefly because they were among the "anomalies and curiosities of medicine." (p. 122)

There have been many advancements for 'treatment' of dwarfism. From limb-lengthening to most recently big Pharma companies promising growth with their injection treatments, the business of dwarfism has become a big money-maker for the medical industry. Parents are being pressured by the medical industry to put their child on a treatment. One cannot hold judgment towards parents for choosing this avenue for their kids. When disability is presented as it is in the media, one that evokes shame, discomfort, and pity, then it is not shocking why someone would choose an option where their child may escape that. In February 2021, I wrote a reflection paper on the topic of history and disability, specifically the stories that are told are not from disabled storytellers or lived experiences. I discuss that the rate of unborn pregnancies being aborted after dwarfism has been detected in utero has decreased (Rayburn-Trubyk, 2021b). Now, to the public, this could be considered a positive statistic. However, as stated in my reflection paper,

> this is not due to the general society becoming more enlightened and accepting the diagnosis of dwarfism, but rather the ability to do a quick Google search in which parents can find a multitude of information regarding different "treatment" options to "fix or cure" dwarfism. Therefore, more parents are choosing to carry their child to term rather than proceeding with an abortion due to belief they can be cured. (Rayburn-Trubyk, 2021b, p. 3)

There are a multitude of studies on treatments for dwarfism. One of the most recent drugs that has been approved by the FDA is created from a big Pharma company named BioMarin. The treatment that they have developed, called VOXZOGO (Vosoritide), is being marketed to not only increase a child's height, but also help with other conditions that are often common with Achondroplasia, the most common form of dwarfism. Such promises include helping with spinal stenosis and sleep apnea. Currently there have been no improvements to either spinal stenosis or sleep apnea for any child on this treatment despite being marketed as such. This treatment runs at a cost of $300,000.00 (Hoover–Fang, personal communication, November 6, 2022). However, it is covered by most insurers in the U.S. At present time, VOXZOGO is not available in Canada.

In addition to the treatments promised by big Pharma, Elective Limb Lengthening (ELL) is an option that promises increased height. ELL requires a great deal of time and pain to occur before the completion of the bone growth. According to Paley Orthopedic and Spine Institute, ELL

> works by gradually growing new bone and soft tissues (skin, muscle, nerves, blood vessels, etc.) Bone and soft tissue regenerate when they are pulled apart at a very slow rate, a process known as distraction. The rate of distraction is typically one millimeter per day. […] Lengthening is divided into two phases: distraction and consolidation. Lengthening happens during the distraction phase. After the desired length is obtained, the newly regenerated bone is still very weak. The hardening and calcification of this new bone is called the consolidation phase. (Paley Orthopedic & Spine Institute, 2022, para. 1-2)

This surgery is painful and must be completed at a young age. In a *New York Times* article from 1986 titled “Enduring Agony: A Boy’s Made Taller,” Dr. Stephen Kopits, an orthopedic surgeon specializing in Dwarfism, states,

> [D]octors in the United States generally reject the procedure, because risks of side effects are great. ‘The induced bone growth often is weak and vulnerable to breaks and infection’, he said. In several patients, he said, ‘muscle is damaged, and the result is an inability to control the foot and a waddling gait. I am appalled by how many parents I see who ignore all this,’ he said, ‘because all they see is height.’ (Winerip, 1986, p. 3)

The article features Anthony Taraboochia Jr. and his mother. She states, “[E]very doctor I went to said, ‘Accept him as he is.’ It was easy for them to say. I love him, I accept him, but will the world accept him” (Winerip, 1986, p. 2). Both ELL and Vosoritide treatments must be decided on when the child is young. Parents are providing informed consent on behalf of their child with no understanding of the psychological damage that the child could develop as an adult. Parents are making decisions based on what they see in the media and their own perceptions and fears, as stated by Anthony's mother Mary; "since birth my goal has been to find something for him. I thought that if they could transplant hearts and send people to the moon, they could help Anthony grow" (Winerip, 1986, p. 2). The article discusses the immense pain that Anthony endured, and I deem it important to share the end of the article during this discussion:

> Anthony said he was a little worried about the next series of operations, to lengthen the thigh. "Why?" he said. "The pain." "We'll wait a year for the next one," his mother said. "You said, maybe two," Anthony answered softly. (Winerip, 1986, p. 4)

It is important to highlight the statement currently found on the Little People of America website. Specifically, the complications that could occur and the statement,

> While it may have benefit in preventing certain orthopedic and neurological complications in some skeletal dysplasias, the procedure is primarily being performed for adaptive, cosmetic, and psychosocial reasons. Research is being done on the safety and long-term functional outcome of this procedure. Currently no prospective, randomized studies have yet to be completed. (Campbell, n.d., para. 3-4)

This procedure is purely for height. LPA has been vocal about the potential negative aspects that such surgery can do to a child. In a membership newsletter titled *LPA Today*, published in 1988, the Board of Directors put out a statement against the ELL procedure. The Board states,

> [T]he BOD felt it was vital for LPA to speak out, mainly for the dwarfed children who may suffer the consequences of well-meaning decisions made by the family […] [T]he contact is especially critical for the LP and family to realize that "it is ok to be short and to go get the best from your life." We feel that in the end most LPs and families would, in the end, not opt for ELL. (LPA Today, 1988, para. 4)

The pain that one must endure only to receive a few inches seems to outweigh any benefit someone may justify when deciding if their child should consider this surgery.

Subjecting my child to Elective Limb Lengthening surgery or participating in a treatment option was never something that his father or I considered. Perhaps because of my upbringing and my parents' influence on developing confidence and advocacy in oneself, I always felt that my child was better off without such influences and, ultimately, was perfect without intervention. I felt and still feel that raising my son with confidence and the belief that he could be anything he wanted, as I was raised, was the best way to combat any insecurity that he may feel one day due to his size. I do not fault any parent for considering or choosing these options for their child given the intense stress and influence they are under when making these decisions for their young children. I do wish, however, that more time was spent researching Dwarf Pride and speaking with adult LPs who have made the decision to not undertake these options for themselves or their children. Ultimately, more time needs to be spent in the community understanding the reasons to not put their child through this, rather than only being influenced by the medical industry or those profiting from endorsing such treatments and surgeries. I do believe that if parents understood that hardships are going to occur regardless of if their child has a disability or not and spend more energy being influential in developing their child's pride in themselves, then more parents would choose not to partake in such ventures.

It was hard for me to not take the fact that parents were choosing treatments for their children personally. My sentiments matched that of Pulrang's (2020); "it's hard not to feel that some efforts to 'reduce the incidence' of disability are telling us, essentially, 'we wish you weren't here'" (Pulrang, 2020, para. 21). At that time when the new drug treatment VOXZOGO (Vosoritide) was being assessed and was gaining more traction, I took it to believe that parents were choosing these treatments to not have their children be like me. I took it personally and to me it meant that parents would rather choose the unknown and potentially risk putting their child in harm's way rather than have their child grow up to look like someone like me. It was obvious that I was not alone. There was much miscommunication in our community and a lot of fingers pointing out that the lack of communication was doing more harm than anything. Parents looking for answers to their queries about the drug were being attacked on our private online forums due to others who, like me, were feeling personally attacked. Little People adults who felt much pride in themselves could not understand why parents would entertain this option for their children and were taking to social media to share their feelings behind the comfort of their screens. Both groups were blaming the organization, Little People of America, for not defending their side enough. Much in-fighting was occurring online.

In 2022, at the annual Little People of America conference in Spokane, Washington, there were two meetings scheduled on the agenda to assist with combatting the tension and helping both groups find answers in an environment in which they felt safe to ask. One was specifically for average-height parents who wanted to have the opportunity to discuss and ask questions about these treatments without fear of judgment. The second was a meeting intended for only Little People. I hosted the Little Person specific meeting. The agenda was clear; it was a safe space to share our feelings about how we felt when parents made the choice to put their child through this drug trial. I was not alone in my thinking that it was personal but knew that for this community to come out of this unscathed, we needed both groups to come together and discuss our feelings in an open and honest way. Unscheduled, we decided to bring both groups together to heal the community. The future of Little People of America depended on both groups hearing each other because what was at risk was far more serious than we could imagine. What was at risk was our beloved organization losing members who felt unwelcome and, ultimately, with the dwindling numbers, we would risk this organization no longer being available to future generations.

We decided to bring both groups together for an unscripted conversation where the only rule was respect. Anyone could say anything in this meeting, but it needed to be rooted in respect and with the intention of helping the community heal. My co-host, an average-height parent who had hosted the meeting adjacent to my original meeting, and I went in with much trepidation. We knew that this could be risky and could have the potential to do more damage than good if not steered right. Given that it was a conference and conference attendees request for events in advance, we were unsure if anyone would show up and if anyone would want to show up regardless of pre-planned events or not. We had approximately 100 people in attendance, more than expected. It was a good mix of average-height parents, Little People, and doctors. The doctors attended as spectators as they are often the ones referring their patients for the treatments and are often asked questions about the lived experience of those with dwarfism.

The beginning of the meeting was difficult. There was not much audience participation and we felt like we were forcing conversation rather than a natural flow. It was not until an average-height parent decided to speak from the heart about their decision to choose the treatment for their young daughter that the meeting started to change. The meeting lasted 90 minutes, 30 minutes over schedule. At the end of the meeting, we had run through a lot of emotions. There were tears, anger, laughter, but most importantly, we came out with an understanding of each other. I came out with a fresh perspective that this was not a personal attack against me or my community. This was simply parents trying to make the best decision that they could for their child given the information that they had. Will parents stop choosing these treatments? No. But I have changed my outlook and am not taking it as a personal attack against me. Do I agree with it? No, my stance has not changed on that, I believe that when parents are choosing this for their children there is an underlying hidden message, whether conscious or not that is being given to these children. The message being that that they are not good enough or that they are broken and need to be fixed. Although I disagree with the 'treatments', I do understand that parents are trying to make the best decisions for their children and their families. I will use what I learned to open future dialogue with these parents of Little People and ensure that they always feel welcome when speaking with me. Whether they make the choice or not, I will be more welcoming to these families, as I know that these kids need me and my experience regardless of what is injected into their bodies or which bone is manipulated to stretch and grow.

When I was pregnant with my son, my OB/GYN and I were preparing for my planned C-Section. Being one of the only Little People in this Province to have gone through a pregnancy at that time, I was something to be studied, unbeknownst to me. As a 23-year-old, I had not developed my advocacy persona and found myself consenting to things that I should not have. During one visit, as we were getting closer to the due date, my OB/GYN casually mentioned her students would be observing my planned C-section. I was not asked; it was stated as a fact. I felt uncomfortable but did not know that I could decline the spectacle. Judith Heumann describes her experience with receiving a medical exam as one of the criteria to obtaining her teacher's license. Her experience, albeit different than mine, had a similar theme. As Heumann states, "I felt totally alone. She could do anything she wanted to me, say anything she wanted to me, and there was nothing I could do about it. There were no rules, no boundaries" (Heumann & Joiner, 2021, p. 49). I too felt alone and knew that I was uncomfortable with not only being observed while completely vulnerable, but also that I was not asked, but rather told as to what the sequence of events would be. My son arrived early and unscheduled, and I was rushed in for my C-section earlier than planned. There were no spectators at the birth of my son.

In a 2021 essay titled “Life as I know it,” I wrote, “The day after my son was born, before I was discharged from the hospital, a doctor came in to ask me probing questions about how I was coping with my son being born with Dwarfism” (Rayburn-Trubyk, 2021a, p. 307). Prior to my son’s birth, we had been informed that was going to be born average size. After his birth, it did not take long for me to recognize that he had many of the same distinctive features that I had, and he had been born with Achondroplasia. The doctor’s tone and demeanor when questioning me was that of someone grieving. I was confused with the questioning and the pity I felt directed towards me. At that moment, I knew things had to change in the medical industry. As often doctors who were delivering the news to new parents that they had, had a dwarf baby were doing so from the place that this was a negative diagnosis. Change in the messaging needed to happen immediately. Sadly, my story is not unique. I have heard many stories from new parents about how they received their baby’s diagnosis. Some were told that their child would be like that of someone who performs in the circus. Another parent informed me that the doctor recommended that they should watch one of the many reality shows to gain a better understanding of what life will be like. As Ablon (1990) notes, when parents are informed that their child has been diagnosed with dwarfism, most times there is an

> overwhelming shock that is the universal initial response. Because most parents have seen only a few dwarfs, they have no knowledge about their lives. They reiterate the immediate need for parents for information about how their child will fit the normal expectations of family and society. (p. 880)

Although the terminology has progressed since Ablon's (1990) article, "Ambiguity and Difference: Families with Dwarf Children," the message is consistent today; "profound distress is usually experienced by parents at the birth of a physically or mentally different child. The impact of such difference begins when diagnosis and labeling occur" (p. 880). Furthermore, "physical or mental characteristics considered to be 'deficiencies' or 'handicaps' may seriously affect the parents' perception of their own identity and self-worth so that they are overwhelmed by shock, anguish and sorrow" (p. 880). Doctors are still presenting the message of a dwarfism diagnosis from a negative, medical model of disability point-of-view. Things need to change drastically. As someone who is a Little Person and could understand that this diagnosis is not terrible, what occurred did not change my perspective on my son's life at all. However, I can imagine for parents with no history of dwarfism in their family, this could be traumatic. Little People of Manitoba has created brochures and other items that are given to pediatricians and delivery doctors who can provide information to new parents at the time of diagnosis. The information is intentionally written from a social model of disability perspective and is intended to provide comfort and support as opposed to how many doctors share the diagnosis with new parents coming from a place of pity and fear.

The personal stories that I have shared in this chapter are examples of some of the themes that I identified at the outset of my research. Within this chapter I discussed the impact that the media has on people born with dwarfism. I used such examples as what I shared when discussing Peter Dinklage, my experience with Terri Hofford, the Manitoba MLA who attempted to insult the Premier by using size as the barometer and the representation of disabled people in the media. I shared stories that include my experiences with struggling with my identity as a young person, my experiences with being ridiculed, laughed at, called names, and mocked. These align with my research question: How does one find pride within themselves when society views you with curiosity and disregard? This ultimately sets the foundation for me finding my self-identity and pride in myself.

Chapter V: Inside Out

The I in Identity by Samantha Rayburn-Trubyk
I – intelligent
D – daring
E – extraordinary
N – noble
T - teacher
I - iconic
T -tender
Y – yearning

It seems in more recent years that although I have become more comfortable with myself and my Dwarf Pride, I cannot pinpoint the exact time, but I set out on this journey of self-love when my son was born in 2005. As I was someone raising a Little Person, I understood the stakes should I not present a positive role model for him to journey into self-love. Nothing has been more interesting or heartbreaking for me to be a part of – him coming into his own. When he was six, I took him to an LPA conference in California. My entire family, my father, mother, and stepfather travelled with us to these conferences as they often wanted to experience it with us. I vividly remember this was the year my son realized he was small, and it shocked him. He walked into the hotel lobby, saw others that were his size, including adults and children, and made a beeline for the room. This was around the same time he went on a play date and met his friends' mother. He asked his friend where his 'real mom' was. When he explained the comment, it came down to him not believing that the mother he met was the 'real mother' of his friend because his friend's mom was not small like his mom. My son and I have spent a great deal of time discussing pride and working on strategies for self-love when he is met with disdain from the world.

Pride

I have often discussed Dwarf Pride with my friend group. Like me, they have an immense feeling of self-worth and value. Finding Dwarf Pride has not been easy, but we all share commonalities. For one, all of us were raised in supportive homes where our dwarfism was celebrated. As stated in a press release issued in 1988 by the Little People of America Board of Directors, “dwarf children, when raised in a supportive environment, learned to cope effectively and that people’s quality of life depended on their self-esteem and accomplishments, not on their height” (LPA Today, 1988). Height, or a lack thereof, has nothing to do with how one truly feels about themselves. Dwarf Pride is not based on a height barometer, but rather aligned with the social model of disability and based on environment. I know that I am lucky to be born who I was. Although it is not always easy, I understand my privilege of being born into the family that I was, and the country that I live in. I have found connection and strength from the disability and dwarfism culture that I identify with. I know many of my experiences would not have occurred without my dwarfism diagnosis. For that, I am grateful. One’s disability identity or Dwarf Pride is often that of performing a role, the role we play for ourselves, and the role that others weave into the fabric of society, all of it contributes to how we develop and become comfortable with our own self – identity.

> Theoretically, the link between self-identity and behavioral intentions is predicated on the basis of identity theory which conceives of the self not as a distinct psychological entity, but as a social construct specifically. More specifically, Stryker proposed that we have distinct components of self for each of the role position that we occupy. The self is, therefore, conceived as a collection of identities that reflects the roles that a person occupies in the social structure. (Terry et al., 1999, p. 226)

Finding Dwarf Pride, disability pride or self-love has not been easy.

> I saw […] how big disability is, not the condition I or others have, but the elaborately constructed network of ideas and practices that keep disabled people in place […] I have gotten to this place not by denying my disability or, implausibly, "overcoming" it, but by sailing headlong into it. Making sense of it had become the most meaningful thing I could do. (Dunn & Burcaw, 2013, p. 152)

I am not someone to shy away from a challenge or the opportunity to better myself. In grade ten, I played on the high school basketball team. I did not tryout and join because I thought I was going to be the next Michael Jordan, but rather because it looked like fun. Recently, I joined a badminton league with my son. We wanted to challenge ourselves to find an activity that we could compete in and do together. I am competing against athletes in the sport who have been training for a long time. The only background I have in badminton is from high school. I embarrass myself often but am having a great time and developing a skill. Developing Dwarf Pride or disability pride is pushing myself to do things outside of my comfort zone.

It can be exhausting to venture outside of your four walls. I find that I have different strategies depending on whom I am out with. If I am out alone, I generally try to dart in and out of spaces to attempt to not be detected. I have become quite good at being stealthy. If I am out with my son, I find that I am often trying to act as if things do not bother me when they do. I am cognizant that I am trying to teach him to react to situations and to figure out what battles he needs to advocate for and which ones he needs to steer away from. If I am out with average size people who have never been around me in public before, then I must go into the situation knowing that the time spent together will be difficult as I attempt not to notice them taking in the shock of being in public with me, where people are staring and, at times, mocking. I then attempt to lighten the situation with making jokes or answering the question that all seem to have: ‘Doesn’t it bother you?’ I always reply ‘no’ and laugh it off when it always does.

I find advocacy to be important and exhausting. I am committed to making the world a better place for the next generation. I am committed to changing the perceptions of those in the world to become more tolerant, but doing so forces me to step out into the public sphere and expose myself. I am forced to be vulnerable and act as if nothing bothers me, as if I am immune to the challenges and comments. I am not. Any time something comes up that I need to address in the public sphere related to dwarfism, I know that the comment section will be active and most of the trolls will be unreasonable, hurtful and spew hate towards my community. I know that I am the one left feeling awful about myself. I know that I am the one who must shrug it off and do it all over the next day regardless of how I am feeling. I know it is important work and I am committed to doing the work, but it is hard.

Therapy has been beneficial to finding my Dwarf Pride in my life. Additionally, it has helped process the guilt I felt surrounding the death of my father, my best friend, and other past trauma that I have mentioned previously. What I have found to be difficult is not having a therapist who understands disability or has lived experience. There are times where I have mentioned something, and the advice provided, or the insight provided has been the exact opposite of what was needed at the time and showed a clear confusion of the lived disability experience. Through no fault of their own, my therapist does not understand certain aspects of my life, disability identity or person-first disabled experiences.

I recently listened to a conversation from actor Tom Hanks on the idea of *This too shall pass* (Hanks, 2021). He spoke about how when life is going well or when there are bad days, it is important to understand that you go through both quickly. The idea is not to dwell and to just keep going. I have found this thought process to be helpful in developing self-love and pride.

> I wish I had known that this too shall pass. You feel bad right now, you feel pissed off, you feel angry, this too shall pass. You feel great, you feel like you know all the answers, like everybody finally gets you, this too shall pass. Time is your ally and if nothing else, just wait, just wait it out. (Hanks, 2021)

When it comes to finding my Dwarf Pride, I have found that every time that I progress myself forward, I often must go backwards first. I have had to ‘wait it out’ more often than I would have liked to, and through this I have created guidelines for myself when I find myself wavering on the pride I have in myself.

In this chapter, I have shared my experiences when discussing Dwarf Pride with my friend who was born with dwarfism, the benefits that therapy has had on my life, and how patience is beneficial to living through the negative experiences in life. I have discussed how advocacy is important and can also be equally exhausting. This chapter provides an overview for finding self and Dwarf Pride within my community.

Chapter VI: Conclusion

At the outset of my research, I set out to find the answers to several questions. The first question was ‘How does one find pride within themselves when society views you with curiosity and disregard?’

One of the sub questions was ‘Why is it appropriate for society to ridicule someone strictly based on their looks?’ The answer to the first sub question may lie in seemingly innocent events. The excitement of a parent in marking another notch on a growth chart is imparting to the child a belief that height is not only an important measurement, but it is an achievement to be valued. Fairy tales read to children without age-appropriate explanations of the fantasy or fiction of the story help to establish belief systems as well that can result in discriminatory attitudes and behaviour. In essence, we are teaching children from a young age that height really matters. We are also teaching children through entertainment at a young age about dwarfs through movies like *The Wizard of Oz, Charlie and the Chocolate Factory,* and *Snow White and the Seven Dwarfs.* We also read stories to children where a dwarf is a troll or a mythical or magical character.

Ultimately, it is a response and attitude rooted in belief systems developed at a young age. The second sub question was ‘How can we change society to be truly inclusive of all?’ For the dwarfism community to be mainstreamed, respected, accepted, and included, society must reach an understanding that it is unacceptable to make jokes, mock, or discriminate in any way against individuals who are part of other marginalized groups such as those based on ethnicity or race.

In terms of the first question, ‘How does one find pride within themselves when society views you with curiosity and disregard?’ as I did the research and considered each of the theories and themes available in the literature, I realized many of my life experiences were examples of those theories and themes. One example is the experience I had in debating. I had put in little effort and my receiving a high mark, an example of Inspiration Porn (page 73). Expectations of me were low and so my efforts were highly rewarded. I gave several examples of discrimination, ‘midget’ jokes at a comedy club (page 78), and the Halloween experience (page 81). There were examples of the Disability Theory which also were reflective of the Medical Model. The discussions around Elective Limb Lengthening Surgery or the use of medication for growth (page 96). There were also examples of my experiences that were examples of crip theory (pages 75, 77 and 78).

These stories were examples of theories, but they were also my lived experience. The research did not provide one specific answer to the posed question, ‘How does one find pride within themselves when society views you with curiosity and disregard?’ The answer to that question was found in my personal journey.

For the dwarfism community to be mainstreamed, respected, and accepted, the same process must happen to make it completely as socially unacceptable to make jokes or mock Little People as it is for any other marginalized group. Only when mainstream society is influenced by the media will it care and realize that it is politically incorrect will the change actually come.

To change the experiences for the next generation and to avoid a continuation of history repeating itself based on what the research has shown, the following are the foundations that I believe have helped me develop and find my Dwarf Pride.

The Foundation for Finding my Dwarf Pride

My guidelines for developing and maintaining my Dwarf Pride:

Identity – who you are to you. “a vital point in any stigmatized group’s pilgrimage towards self – affirmation is its decision to shed ‘identification with the aggressor,’ that is, seeing oneself through the eyes of the dominant other and trying to emulate that authority” (Adelson, 2005b, p. 317). Put in the work to understand who you are when you are by yourself. Develop your identity and do not let anyone take that away from you. Who you are, disability and all, is perfect. Do not fall into the trap of ‘trying to be normal.’ Ableism will tell you that because you are different than the average that you are not as good, you do not compare to, you need to be taller/skinnier/etc. or do something this way or that way to fit in. Do not believe it. Do not be tricked into believing that you need to be ‘normal’ to be considered outstanding.

Boundaries – develop them. Figure out what you will put up with and what you will not. Communicate those boundaries and do not compromise yourself.

Pick your battles – not all fights need to happen. It can be more impactful when you take a step back and do not react. Although you may want to fight all battles, choose them wisely as they will have the most impact.

Persevere – whatever you do, do not give up. It will be hard. There is no way around it. There will be days that will be terrible. Keep going. “Embrace the suck” (V, 2022). There is no avoiding it, but learning how to deal with it or internalize it in a healthy way will be your superpower.

Do not be afraid to get dirty – if you want to change, do it. Get in there, figure it out and get a little dirty along the way. As Brené Brown states,

> I want to be in the arena. I want to be brave with my life. And when we make the choice to dare greatly, we sign up to get our asses kicked. We can choose courage, or we can choose comfort, but we cannot have both. Not at the same time.

(17 Badass Brené Brown Quotes That Will Inspire You to Lead, 2022, para. 9).

Forgiveness is one of the greatest gifts you can give yourself.

Choose your support system wisely and pivot as necessary – This cannot be understated. Your support system is everything. Who you choose to have around you to spend time with will have a direct impact on how you feel about yourself and the goals that you will or will not accomplish. Pivoting may be necessary if you find that those that you are surrounding yourself with are no longer boosting your energy or not supporting you as a person with a disability.

Determine what you want the next generation to feel in terms of their Dwarf Pride and work to model that now. Be the role model that you needed growing up.

Remember to laugh and have fun – Life can get serious fast. Remember to take a breath, laugh, and have a lot of fun.

Self-care is critical – This is not about getting pedicures or massages, this is about embracing silence, working through your thoughts, meditating, seeking the assistance of a therapist when needed. Self-care is not selfish as I once believed.

Discomfort will get you to pride – “Invite discomfort in as if it’s a friend. I look at discomfort and pride as cousins […] it’s the steppingstone” (*99: Learning by Doing With Robin Arzon.*, 2019).

Control your inner critic – Your inner critic can say the worst things to you about you or it can say the most encouraging things to you about you. Silence the negative and promote the encouragement. Tell yourself you can, you will, you are, etc....

Understand that there are naysayers, always, no matter what you do or how hard you try.

Try something new and do not be afraid that you are not an expert. Be vulnerable. I started badminton at 40. Not because I secretly loved badminton, but because it was something that I could do for exercise that was good for my joints. I play in a league with people that have been playing for years and I embarrass myself often. I took it up with my son so that we could do this together. As he ages and becomes the person he is meant to be, badminton is something that we can always come back to and enjoy doing together.

Find people like you. All too often I hear from average-size parents when asked why they have not joined LPA or another LP group or attended any events that they do not think their child needs the community. It is not about whether they think their child needs it or not (the child does, whether they want to believe it or not) but it is about your child having someone who is like them, who understands completely what they are going through. It is finding someone they can talk to about the stuff that bothers them. I do not know where I would be if I did not have my best friend who, like me, was born with dwarfism. She and I can relate on so many levels. Her friendship has been one of the greatest gifts of my life.

There is something invaluable about being part of a community of people who are similar in identity to you. The ability to mentor or support others and have someone mentor or support you who ‘gets it’ is priceless. In an article written for the Independent Living Institute, Sisco (1992) explains,

> I realized how important it was for a person with a disability to have the experience of meeting and talking with another person with a disability. I also realized the uniqueness of my own experiences and how valuable it was to me to share those experiences. This is what peer counseling is all about. The peer counselor is that individual who has attained disability related experiences, knowledge, and coping skills, to assist others with their disability related experiences. The goal of peer counseling is directed toward enabling the

> individual to meet personal needs to more fully function and take control of his life, in his home, community and employment. (Sisco, 1992, para. 3)

Little People of America had and continues to have a profound impact on me. It has helped me develop my Dwarf Pride, has given me some of the most important relationships in my life. It has given me that place where I feel equal and safe. Given what LPA has provided for me and how it has enriched my life, I want to help it provide for others in the same way that it has for me.

Enjoy the ride. I had the opportunity to ask both my father and my grandmother for their life advice prior to their deaths. Both said the same thing: ‘It goes fast.’ Enjoy every minute because before you know it, it is over. Days will be tough and hard, but you will get through them, and the sun will rise the next day. Enjoy it all and learn from it all.

Developing Dwarf Pride is ongoing. “Developing disability identity development then, becomes an ongoing process of internal and community engagement that is worth of further exploration and support” (Forber-Pratt et al., 2020, p. 8). Throughout this autoethnography, I have shared my vulnerabilities to show that although things are not always amazing, if loving yourself and having pride in who you are is at the forefront of everything you do, you can get through anything and persevere.

In 2019, when I was interviewed by Doug Speirs for the Winnipeg Free Press, I stated “my ultimate goal for us is to make the next generation of Little People- like Yale- have so much self-love and be comfortable in who they are that they can go out in the world and do great things” (Speirs, 2019, para. 2). That goal has not changed. My life has been full of twists, turns, and pivots. I have learned to forgive myself more than once, to not take life so seriously and to be vulnerable. I have developed pride in myself despite the world often being against me because of ableism. I have had the greatest supporters, allies and friends who have all made me better. I have made mistakes – big ones – and have come out the other side. I have felt like a fraud and wrestled with imposter syndrome at the same time as knowing that I have something to offer this world. I have loved and been loved. I understand my privilege and wish to use what I have been given to help others. Primarily, I have learned that second chances are the best chances. All of this has led me to love myself, to work on myself and to have a massive feeling of Dwarf Pride and gratitude in all that I am and who I have become.

THE CHALLENGE

So

You want to be tough

You want to be rebellious

You want to be a badass

Then show your heart to everyone…

EVERYONE.

-Michael Xavier

(Heart Like a Hammer: World Edition)

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