“LOOK AT ME”:
DISABILITY, REPRESENTATION, AND THE FEMALE BODY

by

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A Thesis Submitted in Partial Fulfillment of
the Requirements for the Degree of

Master of Interdisciplinary Studies

in the Graduate Academic Unit of

Interdisciplinary Studies

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This thesis is accepted by the
Dean of Graduate Studies

THE UNIVERSITY OF NEW BRUNSWICK

October, 2013

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ABSTRACT

This thesis explores the representations of women with physical disabilities in the media, as analyzed by women with physical disabilities themselves, and then subverts and challenges those representations through the women’s construction of new photographic imagery. The goal is to allow women with physical disabilities to participate in the research process, work collaboratively with the researcher, and challenge how women with physical disabilities are represented. The research is grounded in feminist theory, critical disability studies, and arts-based inquiry; and uses methods of focus group interviews and photographs. Participants found the media representations to be complex, containing what they felt were both positive and negative components. The strongest reactions came from sexualized representations of women with disabilities. Discussions also centered on the lack of representations, the importance of including people with disabilities in the design of media representations, and the connection of disability with pain and pity. When it came to the construction of new photographic images, the participants used the photographs as a way of visually expressing their responses to the representations they saw during the focus group.

Keywords: disability studies, arts-based inquiry, feminism, visual media, popular culture
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CHAPTER ONE: INTRODUCTION

The Research Problem

Disability is one of the most ignored forms of social, political and cultural oppression (Christensen, 1996). It becomes clear, once you start looking, that disability is typically avoided or ignored in most critical studies research and in mainstream media. You rarely see a chapter in a critical study textbook or reader on disability. If disability is included in readers, there are usually only one or two articles. Other, more “acceptable” categories of identity, like race and gender, will have entire chapters dedicated to them. Discussions of disability do occur in mainstream educational and/or medical studies, but these subject areas tend to look at disability from a medical standpoint, which provides a limited, and in many ways oppressive, viewpoint. In the media, representations of disability are difficult to find. When they do appear, they are often mired in stereotypes; disabilities are often presented in the media as a burden to overcome, a voyeuristic curiosity, or a medical “problem.”

Although there has been some research on the representations of disabilities used by charities and telethons, and a few critical studies on disability in the media, there has been little written about the representations of women with physical disabilities in the media. Perhaps this is because there are so few representations of women with physical disabilities in mainstream media. Based on my own research, I found that most representations of physical disability that occurred in the media where usually men. It was hard to find representations of women with physical disabilities.

According to Reinharz and Davidman (1992), researchers can create a potential for social change by highlighting the positioning of a group in a society. By providing
women with physical disabilities a space in which to express themselves, I am “demystifying” their invisible needs (p. 191), and giving them an opportunity to express their opinions. I also attempt to increase their influence on the conditions under which I believe them to be oppressed, and challenge the current representations of women with physical disabilities.

The objective of this research is not just the end product, but the process itself. The women who participated in this research may not have ended up with new or changed identities, but I trust they were able to move beyond the identities society forces on them and begin to think more critically about what they see in the media (Reinharz & Davidman, 1992).

In order for real change to occur, Eiseland (as cited in Garland Thomson, 2002) claimed that society has to imagine disability and people with disabilities in a different way. The need exists to shift how the representations of people with disabilities are perceived in society, and in the imagination of non-disabled individuals. The first step is for people with disabilities to have more control over the visual representations of people with disabilities by creating images themselves and building an alternative for others to expand upon in future research.

According to Garland Thomson (2002), whose theories are integral to much of this research, disability is made up of four characteristics. First, disability interprets and disciplines differences of the body. Second, it creates a relationship between the body and its environment. Third, it produces both the non-disabled and the disabled. Fourth, it makes one aware of the inherent instability of the human body. By keeping the disabled body invisible, non-disabled people can continue to believe that their bodies will never
change and that to be without disabilities is “normal” and “natural.” The disabled body
 crunches the fantasy that the body is constant and enduring (p. 5), and highlights how
 quickly one’s world, and body, can change. The problem is the assumption that disability
 changes it for the worse.

 Any identity that can cut across multiple identities such as race, gender, class, and
 sexual identity is one that more people should be concerned about, and one more theorists
 should be discussing (Kudlick, 2003). Racism, disability, sexism, classism, and
 homophobia are not isolated from one another; they overlap in complex and convoluted
 ways (Pothier, 1992). Yet rarely is disability brought up in discussions on these issues or
 in related areas of critical analysis. When disability is included, often in medical and
 child development discourses, it is usually examined from a “lacking” point of view, and
 the disability is seen as a flaw or deficit. My concern centers around the scarcity of much
 needed critical analysis of disability, especially in work that claims to address disability.

 One possible reason for the absence of disability in articles that address critical
 theory could be that disability is seen as not representative of the human condition
 (Rohrer, 2004). That is, it is seen as the exception rather than the rule. But what could
 possibly be more representative of humanity than its variations? Another possible reason
 for disability’s absence could be that disability has been stigmatized as “other” in
 Western and European societies through a long history of exploitation and
 marginalization. This exploitation was almost always for the entertainment of
 nondisabled people and took the form of a carnival or “freak show” (Barnes & Mercer,
 2003). This “othering” of disabled bodies served to instill fear of what was different and
 created a separation between the disabled and nondisabled body.
The Questions

The three key questions addressed in this thesis are:

1. How are women with physical disabilities represented in visual media, including advertisements, fine art imagery, television, and movies?

2. How do women with physical disabilities respond to these images? How do the images contribute to the construction of their identities, or sense of self?

3. How would women with physical disabilities re-present themselves?

The Theory

The theoretical framework for this thesis is based in critical disability studies with a strong emphasis on feminism and arts-based inquiry. I incorporate critical dialogues and discussions about identity and the body from writings on gender, sexual identity, and race. Since disability can affect anyone at any time, for this reason, it is important to draw on multiple resources in the research process in order to account for the complexities of multi-layered identities.

The Methods

I began the research by conducting a focus group with six women who self-identified as physically disabled. The focus group met once and during that time we analyzed representations of women with physical disabilities found in the media. The participants also explored how their own identities were constructed in relation to the representations shown.

Following the focus group, I worked with each participant to create a series of
photographs (two per participant) that subverted and challenged the representations of women with physically disabilities. Photography, a method of arts-based inquiry, provided the participants with an alternative way of having their voices heard.

Once the photographs were completed and sent to the participants for review, I created an online questionnaire to gather further information from the focus group participants. The questionnaire was sent to all of the focus group participants as well as several disability organizations. The goal was to give the focus group participants another chance to be heard, and to include individuals who had wanted to take part but could not attend the focus group. The online questionnaire included representations shown during the focus group as well as some additional representations.

**Situating Myself in the Research**

At this point, it is necessary to position myself within this research since I am a member of the disabled community. I was born with – what the medical community calls – Miller’s Syndrome. It is a rare autosomal recessive “disorder” that affects approximately 75 people across the globe. According to the Foundation for Nager & Miller’s Syndrome website, the medical definition of Miller’s syndrome is as follows:

Miller Syndrome, (postaxial acrofacial dysostosis) is an extremely rare genetic condition that involves multiple physical anomalies.

The facial characteristics include downward slanting palpebral fissures (eyelids), the absence of a portion of the lower eyelid and or eyelashes, cleft palate, recessed lower jaw, small cup shaped ears, and a broad nasal ridge. Mild to severe hearing loss is usually noted and therefore repeated BAER hearing tests may be indicated to diagnose this hearing loss.

The hallmark of Miller Syndrome is the absence or malformation of the fifth digits, often involving both the hands and the feet. Limb anomalies include shortened and bowed forearms, incompletely developed ulnar and radius bones,
missing or webbed fingers and toes, as well as abnormal growth of the tibia and fibula bones (lower legs).

Medical intervention is usually required at birth to aid in breathing due to the narrow airway, recessed lower jaws. Clefting of the hard and or soft palate difficulty breathing and swallowing usually means that feeding will be an issue. (http://www.fnms.net/about-miller-syndrome)

I would now like to describe my disability in non-medical terms. Miller’s Syndrome affects mainly the face and limbs. For me, the bottom of my eyes droop, exposing a small portion of reddish flesh. When I smile, this droop and the exposed red flesh, disappears. The only real issue I have with my eyes is occasional dryness, which I combat with drops. I have had several surgeries to “fix” this problem and as a result, I have a crescent scar under my left eye. I had a cleft palette when I was born, which meant I had no roof on my mouth. I was fed through a feeding tube for the first six months of my life. The feeding tube actually made my mother’s life easier as feeding time was automated by a machine and growth was determined by calculations involving calories and weight. The cleft palette was fixed when I was a toddler. I also have a recessed chin; it is rounded and pushed back into my face. The last surgery I had as a teenager was an attempt to fix my recessed chin; to bring it forward and give my face a more defined jawline. My secret dream for that surgery was to have a jawline that resembled my parents. It was a purely superficial surgery as my recessed chin did not affect my health or wellbeing. However, the surgery did not work as well as I had hoped. My chin was brought forward but I did not get the definition or true “chin” of my dreams. I also wound up with a swollen jaw for almost 10 months, which made me surprisingly
self-conscious. In addition, I was left with a small bump (i.e. protruding bone) on one side of my jaw that can be felt but not seen.

However, the most noticeable thing about me is my arms. The bones from my elbow to my wrist are short, measuring approximately half the length of the average forearm, and they are not the same length. The inner bone (closest to the body) is slightly longer than the outer bone, causing my hands to tilt away from my body. My arms somewhat resemble an “S” shape, but in a less graceful, more jagged way. I also have four fingers on each hand and my hands are small, about the size of a child’s.

My arms affect my day-to-day life but only in minor ways. I can’t carry a lot of items, my wrist strength is nonexistent, some doorknobs require both hands to turn, and I can’t twist my hands or reach the back of my head or neck. But I have learned to adapt. If I am not able to pick up a box with my hands, I place my entire forearms under the box and lift with my upper arms. If I have to take change from a cashier, I twist my entire arm and shoulder so my palm faces up. I wear long necklaces that simply fit over my head, so I don’t have to deal with clasps. If I have to deal with a clasp, I rotate it to the front and utilize my mouth to secure it. And so on, and so on. I would like to add that, when reading through a draft of this thesis, my mother commented that when I was a baby, the local doctors wanted to perform surgery on my arms to “correct” them and make them look “normal.” However, being the critical thinker that she is, my mother sought a second opinion. She went to Toronto and met with the top orthopedic surgeon in Canada, who informed her that I could do 90 per cent of what most children my age could do. The surgeon also told my mother that if I were to have surgery on my arms, it could take over two years of difficult physiotherapy for me to re-learn how to use my
arms and hands, and that some functionality would probably be lost forever. His final words of wisdom were that function was far more important than appearance. In the end, my mother elected not to get the surgery.

Kudlick (2003) argued that one of the most challenging aspects of disability is to convince people who identify as non-disabled that, even when disabilities include pain and hardship, they are not always tragic. Instead, non-disabled people need to learn that disabilities can add value to one’s life. For example, my friends sometimes ask me, “Why don’t you have more surgeries? They could probably improve your disability.” But what they are seeing is lack, or something in need of fixing, not something that is part of me. Even if modern medicine could “fix” my twisted arms or “heal” my weak ankle, I would not be interested. To me, my bad ankle tells me when it is time to stop walking, because I have walked enough for one day. When my four-fingered hands cramp from writing, I know it is time to get out my laptop, or better yet, start talking. But more importantly, my disability is part of who I am. I would not risk losing my identity just to look like everyone else. For me, Koch (2001) put it best when he said: “The life resulting from my modest differences more than compensates for the limits inherent in my physiology. To argue otherwise would be to deny the life I’ve lived” (p. 373).

So how can we shift the view of disability as deficit? How can we make it more visible and emphasize its value without exploiting it? One way is to broaden and enhance disability studies, and include discussions about how disability intersects with race, gender, class, and sexual identity, for example. Disability studies, an interdisciplinary field that dates back to the mid-1980’s, encourages people to see disability not as an isolated medical pathology but as a social category on par with race, gender, class, and
sexual identity (Kudlick, 2003). By promoting disability studies, and conducting more creative research with participants who have disabilities, I challenge the dominant discourses and images that construct disability as a deficit, and show why disability deserves broader and more critical attention.

The Layout

The chapters in this thesis have been arranged in the following order: literature review, methodology, discussion, conclusions, and photography images. In chapter two, I look at theory and research by other researchers and authors on a wide variety of topics related to disability studies, feminism, fine arts, and visual media. In chapter three, I talk about the methodology this research is based on, as well as the complexities of conducting research. I finish the chapter with a discussion of the specific methods used in the research. In chapter four, I analyze and discuss the information that resulted from the focus group interviews and the online questionnaire. In chapter five, I briefly discuss the construction of the new photographic images before presenting the photographs themselves. I include a description with each photograph explaining the message or story behind the image. In the final chapter, I summarize ideas from previous chapters and provide suggestions for future research. I also offer a list of things for media to consider when constructing representations of women with disabilities.
CHAPTER TWO: LITERATURE REVIEW

This chapter sets up the theoretical framework of this research and situates the work in the growing field of feminist disability studies. I begin with a brief history of people with disabilities, including the definitions and models of disability. Following this, I discuss the culture of normativity, feminist disability theories, and feminist theories of the body. The chapter then looks at the complexities of using disability in advertising and in the fashion world, and concludes by talking about disability stereotypes, the stare, the disability arts movement and disability performance art, marginalized voices, and the idea of interconnected identities.

A Brief History of Disability

The category of disability, as we know it today, is a fairly recent phenomenon. Previously, disability was classified under labels such as “abnormal,” “imperfect,” or even “monstrous.” Aristotle was one of the first to contemplate the idea of the perfect human body by categorizing what made up an “imperfect body.” The arguments Aristotle used focused mainly on women’s bodies. He claimed all women were lacking and that anyone who was “deformed,” “mutilated,” “monstrous,” or “deviant” was imperfect (Kudlick, 2003, p. 766). The effect this language and line of thinking had on many societies is still evident today. Also, this method of defining one identity by positioning it against another, and thereby creating an “anti” or “other,” is still prevalent in present day research. Most recent discussions about disability, race, sexuality, gender, and class define one’s identity by stating what it is not (Longmore, 2005). For example, able-
bodiness is identified by a body that is not disabled; in such binary thinking, the first identity usually becomes the norm, while the “anti” or “other” becomes that which is different, and deemed inferior.

This view of imperfect, or abnormal, bodies continued throughout the Middle Ages and, as time passed, these “abnormal” bodies began to be exploited for entertainment purposes. For example, many royal courts in Europe had Little People as court jesters or kept a team of “fools” for amusement (Barnes & Mercer, 2003). By the nineteenth century, these types of displays had turned into “freak shows”, which, according to Barnes and Mercer, offered a “formally organized exhibition of people with alleged physical, mental or behavioural differences at circuses, fairs, carnivals, or other amusement venues” (p. 91). Freak shows were extremely popular in Europe and North America throughout the nineteenth and early twentieth centuries.

By the mid-twentieth century, according to Bogdan (1990), freak shows fell out of favour and disabled bodies were no longer seen as an acceptable form of entertainment. It was at this time many non-disabled people began to look at disabled bodies as a social burden or “useless” because they no longer provided the value of entertainment. The theory of eugenics then took this line of thinking to the next level; in its most basic form, eugenics claimed that if you were attractive, you were a good person and, conversely, if you were “flawed” (i.e. imperfect), you were a bad person. These eugenic theories were often backed by pseudo-scientific and medical studies that were deeply flawed, biased, and based on racist ideologies (Davis, 1995). Eugenics was quickly assimilated by Nazi Germany and used as the reasoning behind the Holocaust, which led to the extermination
of thousands of people with disabilities. But the genocide of people with disabilities during the Holocaust is a history seldom discussed (Kudlick, 2003).

Garland Thomson (2001) argued that the history of people with disabilities in the Western world is, at least partially, a history of being on display. But it is also a history of being hidden, exploited, and silenced (Bogdan, 1987). At the same time that people with disabilities were displayed, their appearances were controlled. Even after freak shows ended, the disabled body was still fiercely controlled through the prohibition of marriages between “defectives” (in the U.S. and Germany), forced sterilization programs, and supported euthanasia (Garland Thomson, 2001).

**Defining Disability: What’s in a Name?**

According to Riley (2005), there are over 54 million Americans with disabilities. Since so many people are considered disabled, one would think that the definition of disability would be straightforward. But that is not the case. The term “disability” is difficult to define and there is no clear consensus on what exactly constitutes a disability. Kudlick (2003) argued that this is because human bodies and society are, by nature, unstable and, therefore, anything connected to the body will also be unstable.

The question of what defines disability is a politically and economically loaded one that has plagued the disability community since the earliest civil rights activism of the 1960’s. The inability to find a clear-cut definition that suits everyone has hampered efforts to build support for the disabled cause (Riley, 2005). If a group cannot define themselves, one might start to think they are not a group at all. One of the main problems is that people inside and outside the category of disability disagree on who
deserves to be classified as disabled (Riley, 2005). There is also the issue that whether a particular condition is disabling can change according to time, place, and societal expectations. Technology, education, architecture, attitudes toward physical appearance, and the pace of life all influence what counts as a disability (Wendell, 2006). In other words, disability is fluid.

What is considered a disability today may not have always been considered a disability, and what was once disabling may not, due to technology or other causes, be disabling today. This creates confusion when it comes to trying to define what it means to be disabled. For example, should someone who needs glasses to see be considered disabled? And if they get corrective lenses, are they no longer disabled? The problem with the idea that technology and medical advances can “fix” bodily differences is that it blurs the distinctions between need and desire. It also threatens to broaden the definition of disability to include even the smallest cosmetic imperfection (Kudlick, 2003).

For the purpose of this thesis, I am not going to put forward one absolute definition of disability because I am not certain it is possible to create a definition that would satisfy everyone. I also have issues with the negative language used in most definitions of disability. For example, according to the Americans with Disabilities Act:

The term ‘disability’ means with respect to an individual (a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) a record of such an impairment; (c) being regarded as having such an impairment. (as cited in Riley, 2005, p. 7)

The United Nations offers the following definition (emphasis theirs):

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function. Disability: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or
prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual. (as cited in Wendell, 2006, p. 244)

And, finally, the World Health Organization provides a generalized definition of disability:

...disability exists when one's impairment is a limiting condition that adversely affects one's performance. (as cited in DePauw, 1996, p. 21)

All of these definitions use language that implies a lack, limitation, or abnormality that is caused by disability. I am not sure if it is possible to define disability without using this kind of language but I do not feel comfortable putting forward a definition that represents disability in this way. Instead, I will leave the above definitions as they stand and allow readers to formulate their own opinions on what constitutes a disability. I will also focus on a group of people within the category of disability – women with physical disabilities.

For Rohrer (2004), women who are born with disabilities have different conceptions of their bodies, especially if their disability is not progressive. I hesitate to differentiate between people who are born disabled and people who become disabled because I do not want to further split the disabled community. Therefore, in my research I did not limit disability in this way. My participants may be born physically disabled or have become that way during their lives. My only restriction was that the women must have had their disability for five years or longer. I made this decision to avoid encountering someone who is still in the stage of accommodating, or adapting, to her new-found disability. This is not to say that the views and voices of newly disabled women are not important – indeed, I think it would be extremely interesting to complete a study that focuses solely on women who are “freshly” disabled – but this research is not
that study. I am focusing on women who have had their disability long enough that it has become an ingrained part of their identity.

Models of Disability

The medical model.

There are two “models” of identity that categorized and defined disability in the twentieth century: the medical model and the social model.

For most of the twentieth century, disability was, and continues to be, framed by the medical profession. As a group, people with disabilities were defined in terms of sickness, pathology and disease (Christensen, 1996). The medical model was formed on the belief that disability was a disorder or disease that needed to be minimized, corrected, or cured through medical intervention (Schriempf, 2001). This model positions disability as a lack, or abnormality, that one needs to overcome. The medical model assumes that differences from the “norm” produce defective members of society and any difficulties experienced by people with disabilities are due to problems within the individual, not as a result of barriers within society (Israelite & Swartz, 2004). This places the “problem” of disability on the shoulders of the person with the disability instead of on society and culture; thus, it becomes the responsibility of the person with a disability to find a “cure” and become a valued member of his or her community.

The labeling and categorizing of disabilities, which defines what is most distinctive about each disability, also serves to segregate members of the disability community. Even when multiple people are said to have the same disability, the medical community tends to separate disability based on varying criteria and often ranks an
individual according to the severity of the disability. Severity is most often determined based on the level of limitation, pain, and physical or mental difference that a disability causes.

Because many disabilities are viewed as distinctly different from each other, a community becomes more difficult to establish (Siebers, 2001). After all, how do you bring together people with such differing disabilities and needs? For example, from a medical perspective, as I discussed in Chapter One, I was born with Miller’s Syndrome, a rare autosomal recessive “disorder” and I am one of approximately 40 people in the world who have been identified as having this “disorder.” My father refuses to acknowledge the label because he says, “You’re you and that’s all I need to know”. He also feels that it does not add anything to my life to connect with the medical community, but he does not realize that by claiming this disability, I become part of a group of people.

As much as a medical label can limit people with disabilities and separate us from one another, it can also provide a community and a support system. Having a label for one’s disability can also help bring closure to family and friends, and start the process of adapting or simply learning to live (and I believe, enjoy) one’s disability.

The history of disability suggests that the medical model is based in Enlightenment values and scientific emphasis, and worked to eradicate pre-modern discourses of the abnormal body as supernatural or monstrous (Millet, 2008). The rise of science in the Enlightenment came to mean, especially in the case of one’s health, that medicine informed people of the reality of their bodies (Holmes, 2000). Further,
Foucault (as cited in Holmes, 2000) argued that medical discourses shape and control the way people approach and experience the body.

An interesting aspect of the medical model is that it does not just affect people with disabilities. Homosexuals, ethnic or racialized groups, and intersexed individuals have also medicalized, pathologized, and labeled as diseased and “abnormal” (Holmes, 2000). I point this out in an effort to highlight yet another intersection between disability and other social categories of identity.

The current belief among many critical theorists and scholars is that the medical model is outdated and hurts more than it helps. Many are quick to dismiss the medical model because it has created a stigma of disability as a “flaw.” Worse than that, it positions disability as a flaw that needs to be “fixed” so one can be more “normal.” But there may be some merit to the medical model. Although it certainly has its flaws, the medical model has components that are beneficial – it can help people with disabilities get funding for accommodations and provides a community of support, albeit a medical one. Also, having a disability in North American culture, especially a physical one, means you are part of a (medical) community, in some way, for at least a portion of your life (Hale, 1979 as cited in Shapiro, 2004).

No matter how it is considered, people with disabilities have a connection to the medical community. It is a part of their lives and, as Hall (2005) said, preventing illness, suffering and injury is a humane objective. However, when that objective turns into the elimination of unacceptable bodies simply because they are different, it takes on a far more eugenic tone.
The social model.

Up until the 1990s, disability was thought of in terms of medicine, rehabilitation, special education needs, and social work. Following the 1990s, British disability studies began to grow and another model was borne out of these critical discussions and theories. This model was called the social model (Goodley, 2011). The social model sees disability as a social construction. In other words, a disability is not caused by a deficit in one’s body but is a result of society’s failure to provide appropriate services and accessibility (Israelite & Swartz, 2004).

For example, consider a woman in a wheelchair. The medical model would say that her body is the problem, and would label her “disability” as a flaw resulting from her bodily abnormalities. The social model, on the other hand, states that this woman’s disability is not the fault of her body, but systemic and institutional practices. If this woman approached a building in a wheelchair and found no ramps, the system would be the one that had created the limitation by denying her access. Inaccessibility becomes the barrier, not her body. If the building had ramps, the woman in the wheelchair would be able to enter freely and would seemingly not be impaired or disabled. The benefit to defining disability as a social construction, rather than a bodily flaw, is that it challenges old definitions of disability and brings it out of the realm of rehabilitation, special education, and other medically-related fields (Kudlick, 2003). The other advantage is that the social model gives people with disabilities a commonality: social oppression. Although struggles with disabilities are extremely diverse, one could claim that social oppression affects all people with disabilities (Wendell, 2006).
But while the social model challenges the negative constructs that the medical model created, and takes disability outside the body, it also denies the real physical lived experiences of people with disabilities (Siebers, 2001). Even if there were ramps on every building in the world, the woman in the wheelchair would still be in a wheelchair. Her body would still be different from many others. That is a lived reality she deals with every day and no number of ramps will eradicate that. As Siebers (2001) noted, it is “tempting...to see disability exclusively as the product of a bad match between social design and some human bodies,” but it is important to remember that “disability may also trouble the theory of social construction” (p. 740).

A new model?

Wendell (2006) called for a new model of disability; one that takes into account aspects of both the medical and social models. The new model should also incorporate the psychological and epistemic issues of living with a disability (p. 260), as well as critical discourses from feminism, disability studies, cultural race theory, gender studies, class analysis, and gay/lesbian theories.

Some scholars (Israelite & Swartz, 2004) believe that this new model can be found by simply updating the social model, since there are positive aspects to that model. Instead of focusing on society creating impairment or disability, scholars argue for a model that “acknowledges the relevance of bodily experience to the lives of disabled people” (p. 475). Turner (2006), however, goes further and takes an interconnected position that disability is created by a person’s social and cultural identities, his or her position in society, social and medical discourses, institutional practices, and individual
environments, all of which act together to shape the experiences and identity of people with disabilities (Turner, 2006).

The interconnected model I mention above is the one I will use in this research. I choose not to limit myself to the social or medical models because neither of them adequately defines, in my opinion, how people with disabilities form their identities. As a woman with a physical disability, I am not the product of my body, medicine, or society alone. My identity is complex and multi-layered; I am at once disabled, female, non-religious, Caucasian, middle class, heterosexual, in my thirties, healthy, and slim. All of these identities overlap, intersect, and influence each other – and it is important to acknowledge these influences, privileges, and intersections.

‘What Happened to You?’: Understanding the Culture of Normativity

“We live in a world of norms” (Davis, 1997, p. 3). Throughout our lives, we attempt to be as “normal” as possible, or we deliberately (perhaps even rebelliously) avoid that state. According to Davis (1997), to better understand the concept of disability, we must look at how normalcy is constructed and how it creates the “otherness” of disability.

Many scholars assume that the idea of the norm has always existed, but normality is more a feature of one’s culture than an inherent human condition (Davis, 1997). The words used to describe the concept of “normal” and “abnormal” only entered the English language around 1840, with the concept of the norm appearing nine years later. What did exist prior to this was the idea of the “ideal,” a term that dates back to the seventeenth century. The ideal body was closely linked to the Greek gods as a body that was not
attainable by humans, but should still be admired for its perfection. Davis claimed that this ideal was never expected to exist in the human world because perfection was not possible except in the world of gods and myths.

The modern concept of normality is said to have begun with statistics and that French statistician Adolphe Quetelet contributed most to the generalized notion of the norm (Davis, 1997). Quetelet noticed that the “law of errors,” used by astronomers to locate a star by plotting the sightings and averaging the errors, could be applied to the distribution of human features, such as height and weight, as well as human morals. This statistical formula took the shape of a bell curve, with the average always located in the middle of the curve.

Quetelet then took the notion a step further and, using the bell curve, constructed the “l’homme moyen,” or the average man (Davis, 1997). From here, the average man quickly became the standard for a middle way of life, which developed into the notion of a norm. Of course, as with any curve, in addition to the middle, there is always a bottom and a top. Thus, the concept of the abnormal, or inferior, and the ideal, or superior, was borne.

**Marginalized voices: Do you hear what I hear?**

Western culture is at once obsessed with, and conflicted by, the disabled body (Garland Thomson, 2001). The disabled body is to be feared, avoided, revered, concealed, and reconstructed. Yet, it is perhaps one of the most universal and fundamental human experiences. The entirety of disability identity is created by the story behind why one’s body is different from others (Garland Thomson, 2000). Often, people with disabilities begin to learn who they are through the responses they receive from
other people. For example, when a disabled body appears in public, it inevitably prompts the question, “What happened to you?” (p. 334).

As a woman with a disability, I can speak to the frequency with which my disabled body provokes the question “What happened to you?” Most of the time, the question is asked by children who are curious about my disability. I respond, “I was born this way,” they nod knowingly, as if they “get it.” They need no further explanation. Adults tend to want more; they often probe for a medical term, and sometimes their questions are tinged with a voyeuristic curiosity about how I cope in my day-to-day life.

A point that I would like to take a moment to discuss – a point that I have not seen discussed elsewhere – is that sometimes the question of “What happened to you?” is not directed at me, but at my friends and family. They are confronted with a demand to know what happened to my body. When this situation arises, my disability is thrown in front of them and my differences are suddenly brought to their attention. On almost every occasion, they react with a mixture of surprise, shock, and, occasionally, anger. One could argue that this is what happens when disability appears in public spaces, whether in visual media or on the street. People tend to react with surprise, shock, and sometimes, anger.

This reaction may stem from people not wanting to see me, or others, as disabled because being disabled is believed to be a flaw. To be disabled is not just different; it is “inferior.” Additionally, because disability is made invisible in society, when it does appear it demands a stare from most everyone around. But, as with my family and friends, after repeated encounters, disability has a tendency to fade away. It does not turn
invisible, or become hidden; it simply becomes commonplace. What was once
considered “abnormal” becomes the new normal; it is no longer different.

According to Jardine (2005), listening to the “truths” of people who are
marginalized can bring freedom to our thoughts and actions. Jardine references Michel
Foucault and states that the “truths” expressed by marginalized groups can critique power
relations through the re-emergence of previously hidden knowledge. Being attentive to
the knowledge of minority groups, which has a long history of being ignored and/or
repressed, can start to challenge entrenched assumptions and beliefs about normalcy and
the human body (Jardine, 2005). What Jardine is trying to argue is that people with
disabilities come from a different vantage point because they exist in different bodies.
People with disabilities help reveal how cultural ideals of the body are not “natural” or
“normal,” but rather, an artificial social creation that oppresses everyone (Siebers, 2001).

Further, Wendell (1989) claimed that people with physical disabilities have
experiences that are not available to people who identify as nondisabled and, therefore,
people with disabilities are in a better position to transcend cultural mythologies about
the body because they cannot do the same things as a nondisabled body. Wendell (2006)
argued that if people with disabilities were “truly heard,” there would be “an explosion of
knowledge about the human body and psyche” (p. 120). However, we must be careful
not to fall prey to the idea that women with disabilities are inherently more attuned to
these things simply because they are disabled. If we do, there is a danger of
sentimentalizing the knowledge possessed by people with disabilities, thereby continuing
to position them as “other” (p. 121).
In my study, instead of positioning the women with disabilities as all-knowing, I have chosen to work with the participants to write new stories about the representations of disability. I want to challenge the dominant assumptions and beliefs with the participants, not through them. By working together, the participants and I become agents for personal and collective transformation (Lawrence, 2008).

**Feminist Disability Theory**

One of the theories I will incorporate into my research is feminism. According to Fine and Asch (1988, as cited in Wendell, 2006), 25.1 million or 16 per cent of all women in America are disabled. In Canada, the numbers differ with over 3.6 million Canadians, or 10.4 per cent, defined as disabled, and over half of them women (Israelite & Swartz, 2004). These statistics show that a significant number of women live with a disability.

Garland Thomson (2002) argued that feminist theory can offer profound insights, methods and perspectives to the field of disability studies, as well as foster a more intricate understanding of the cultural history of the body. Combining feminist and disability theories can also help build on previous feminist work, which looks critically at the assumption that women and members of minority groups are inherently inferior. Feminism identifies these oppressive systems as exclusionary and isolating (Garland Thomson, 2002). Using these critiques in disability studies brings to light the ways in which the bodies of women with disabilities are oppressed and negatively stereotyped.

Incorporating feminism can also serve to highlight why many people refuse to claim the identity of “disabled.” For Garland Thomson (2002), this avoidance of the
disabled identity stems from a lack of means to understand and discuss disability that is not oppressive. Most people are aware of what I call “body pride,” such as “Black is beautiful,” and, “I’m here, I’m queer, get used to it!” But what would body pride look like for people with disabilities? Can people with disabilities find new and positive ways to reconstruct their bodily identities by utilizing the ways other minority groups developed their own body pride? Is there a way to build body pride for such a diverse group of individuals?

Some scholars might argue this is already happening with the inclusion of women with disabilities in advertising and modeling. But, as I discuss later, this may not be an entirely progressive or beneficial inclusion. In addition, inclusion does not automatically equal body pride. It is important for researchers to look critically at how people with disabilities are included, why they are included, and whether they had a hand in that inclusion.

One important question, tackled by Garland Thomson (2005), is, what is feminist disability studies? According to Garland Thomson, feminist disability studies is more than simply research about women with disabilities. Similar to traditional feminist studies, feminist disability studies “is academic cultural work with a sharp political edge and a vigorous critical punch” (p. 1557). Feminist disability studies attempts to disrupt stereotypes about women with disabilities and challenges the myths that surround what it is like to live as a woman with a disability. These studies turn up the volume on silenced voices, highlight the connection between the body and the self, and reimagine disability. Reducing the discrimination against women with disabilities is one of the goals of feminist disability studies. It encourages the view that disability is a variation, not a lack
or inferior state of being. Through this new viewpoint, women can claim the identity of
disability without stigma and shame (Garland Thompson, 2005).

Feminist disability studies focuses on three aspects of current feminist theory:
female embodiment, identity politics, and intersectionality. Feminist scholars have
discussed how gender intersects and interacts with race, sexuality, and class, but few have
viewed it from a disability perspective. The focus, within feminist disability studies, is
on how identity operates and strengthens discourses on the body and identity (Garland
Thompson, 2005).

Lisi (1993, as cited in Ferri & Gregg, 1998) claimed that because women with
disabilities do not fit into the feminine stereotype, they are able to be more of who they
are as women. In other words, when a woman is not defined in relation to the beauty
ideal, she can develop other parts of herself. I question this claim by Lisi because women
with disabilities are defined by their bodies, just not in the same way as nondisabled
women. And I would wager that many women with disabilities would enjoy being seen,
at least once in a while, as a sexual object since far too often they are stripped of their
sexuality.

My research utilizes the theories put forward by feminist scholars regarding
women’s bodies and reflexivity in research. I also incorporate critical feminist theories
about the representations of the female body in the media. Unfortunately, I found that
many feminist studies did not include discussions of disability in their research. I attempt
to fill that gap, in my work, by combining critical disability theory with feminism.
Feminist Theories of the Body

Since the 1970’s, feminism has become more aware of the importance of analyzing visual media from a feminist perspective. With the creation of movies and television, the “rules” for femininity, according to Bordo (1993), have been transmitted more frequently through standardized visual images. No longer do women only receive verbal or written descriptions on how to behave or dress. Today, the “rules” are also communicated through images that tell us what clothes to buy, what body shape is desirable, what movements are permissible, and what behaviours are acceptable. For Bordo, this disciplining of the female body, and its view as normal and natural, has to be acknowledged and analyzed for what it is: “a durable and flexible strategy of social control” (p. 166). Because the body is a medium of culture, everything we do with it expresses our cultural ideals and “rules”.

Garland Thomson (2002) explained how the ideal female body, when it first appeared in classical theory, was simply meant to be idolized – not imitated. As time went on, however, that ideal became the image that all women were encouraged and, some would argue, forced, to attain. Although the body ideal has changed from time to time, it has existed at least as long as human culture. However, Wendell (1997) argued that body ideals go beyond mere appearance and include ideals of strength, energy, and proper control of the female body. By presenting society with a physical ideal, the media tries to control women’s bodies by forcing us to meet that ideal, and by constructing the myth that such a body is possible with enough hard work and discipline. Any woman who fails to control her body is seen as a failure.
Representation

Disability: consumer or commodity?

One of the areas in media that often uses people with disabilities is advertising. According to Garland Thomson (2001), advertisers have learned that disability sells. Companies who use people with disabilities in advertising are attempting to show they are a charitable company. Advertisers also realize that the disabled market is largely untapped.

It seems contradictory that advertising would utilize the disabled body since it has a long history of emphasizing beauty and bodily perfection. Haller and Sue (2006) argued that this emphasis on perfection has led to the exclusion of people with disabilities in advertising images. The authors also argued that this exclusion in early advertising stemmed from nondisabled people’s fears of becoming disabled. Thus, Haller and Sue theorize that companies were hesitant to use people with disabilities in advertising because they were unsure how the viewing public would react.

Advertising often tells society who or what is acceptable in terms of appearance (Haller & Sue, 2006). By appearing in an advertisement the model is positioned as someone the viewer wants to emulate. The point of advertising is to sell a product; therefore, advertisements must instill in the viewer the idea that if they buy the product they can become the model, whether by appearance or lifestyle. But are advertisements merely reflecting popular culture or are they dictating what is considered beautiful? There is no easy answer. Could advertisements be at once reflective and descriptive?

Holding an image in front of someone and claiming it is beautiful does not work unless the person already believes what they are seeing is beautiful. In this way,
advertising is reflective; it exploits our pre-existing views on beauty and perfection, and reflects them back to us. But images can also describe to us what should be considered beautiful. One could also argue that if an image is seen frequently enough, it will eventually come to be seen as beautiful over time. Much like hearing a song on the radio, an image can become popular and desired through repetition, which breeds familiarity and comfort. It is in this way that advertisements can also be descriptive.

In their article entitled “Are Disability Images in Advertising Becoming Bold and Daring? An Analysis of Prominent Themes in US and UK Campaigns,” Haller and Ralph (2006) analyzed a selection of advertisements in an attempt to understand whether advertisements that use people with disabilities have changed through the years. Their findings revealed some improvements but also found that many advertisements continued to stereotype people with disabilities.

While I found Haller and Ralph’s article informative, the article would have benefited from a feminist critique of the advertisements they analyzed. Within the article, there was no discussion of the differences between advertisements containing men with disabilities and those that included women with disabilities, even though the examples they used clearly showed a difference. Based on the examples described in the article, none of the advertisements showed women with visible physical disabilities. Of the women with disabilities, the advertisements only revealed that the women were disabled at the end, as a shocking twist or surprise. One advertisement was of a blind woman, who was only revealed to be blind at the end when she took out her walking stick. Contrary to this, another advertisement included a man with a disability; he was shown in a wheelchair with a visible disability. It seems, based on the examples provided
in the article, that men are allowed to transcend body ideals and have visibly disabled bodies but women are not.

The inclusion of people disabilities in advertising is an important part of this research because it is one of the few areas where the representations of women with disabilities can be found. However, this inclusion is not without its complexities, which I discuss in-depth in chapter four.

**Disabled fashion models: Is anything better than nothing?**

Another genre that has recently begun including women with disabilities is the fashion world. On the one hand, because visual culture is so widespread and commanding, fashion models with disabilities can challenge long-held beliefs and opinions of what a model should look like (Garland Thomson, 2002). But is this the kind of public consciousness we want?

For Garland Thomson (2002), the emergence of fashion models with disabilities is a form of unintentional activism, but it will not necessarily lead directly to positive social change; the appearance of disabled models is merely “a result of market forces” (p. 24). However, no matter how stylized and unrealistic the portrayal of the disabled model may be, it nevertheless brings disability out of the shadows and into the public sphere (p. 25). In other words, the ability of people with disabilities to be able to envision themselves as part of the ordinary and consumerist culture is both liberating and oppressive (p. 25).

Moreover, the representations of models with disabilities can often be contradictory. They can challenge dominant cultural beliefs about beauty, perfection, and normalcy, yet reiterate the rhetoric of sexual objectification of the female body. Many
images of models with disabilities also still adhere to the “ideal” and slim body size of a stereotypical model. One only has to look at the contestants on the 2008 reality television program, *Britain’s Missing Top Model*,¹ a show focused on female models with disabilities, to see that the contestants, while disabled, were also all slim and Caucasian. Thus, certain beauty ideals were still upheld within the show. Yet, at the same time, the show was progressive because it gave women with disabilities visibility in a world focused on perfection. Unfortunately, the show only ran once and was not picked up as a recurring series.

In the case of fashion models with disabilities, while I do not agree with the continuation of an unattainable beauty ideal, I do think some visibility is better than none at all. But, at the same time, I wonder if there is a way to challenge the beauty ideal of Western culture, while still producing images that are beautiful. Is it possible to change what is considered beautiful? Is visibility the answer or simply a starting point? This research touches on these questions.

**Our visual culture.**

Since this research includes a critique of the representations of women with disabilities in the media, it is important to look briefly at how we interact with the visual world on a daily basis. According to Mirzoeff (1999, as cited in Darts, 2004), our lives are now more visual than ever before. Visual culture is not just part of our lives; it *is* our lives. For Garland Thomson (2001), images express not only our desires but also who we are.

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¹ The official BBC Three website page for Britain’s Missing Top Model describes the television show as follows: “Eight beautiful disabled girls, desperate to be models, battle it out to win the prize of a fashion shoot in top style magazine Marie Claire, photographed by Rankin.” The series ran once and was 6 episodes long. The first episode aired on July 1, 2008. ([http://www.bbc.co.uk/programmes/b00cfhhh](http://www.bbc.co.uk/programmes/b00cfhhh)).
envision ourselves to be. Photography, and visual imagery, has made us see ourselves as images (p. 337). Stanczak (2007) argued that these images demand more than a simple “objective” reading; images elicit biases from individuals that can, and should, be probed and analyzed. In other words, as the world becomes more visual, it is important to learn to critique the images we see each day.

There has long been a “chicken and egg” debate about the media and reality. Some argue that the media reflects the culture around it, while others believe we construct our culture and meanings from what the media shows us (Sturken & Cartwright, 2009). I would argue that the images we see in our day-to-day lives help to construct our view of the world and reinforce what is deemed normal, ideal, and acceptable. Walters (1995) theorized that the concept of an image as just a reflection of reality, i.e. a mirror of the world around us, inevitably leads to disappointment because no single image of a woman can capture every type of woman, so someone will inevitably feel that the representation they see is unrealistic, because it is not them.

Most critiques about the representations of the female body in the media are based on the belief that somewhere in the world a “real woman” exists who can be revealed in a single image. But this can only occur if “negative” or “inaccurate” images are removed (Walters, 1995). The problem with this argument is that no one image will ever be able to represent all women. Instead, a reworking of the dominant cultural discourses regarding beauty and body ideals is required.

It is also risky to simply compare “bad” images of women to “good” images of women because the definitions of “good” and “bad” are relative to each woman. In this research, I am concerned with finding out how women with disabilities construct their
identities based on representations found in the media, and challenging those representations in relation to the stereotypes that exist about women with disabilities in Western culture. I try not to focus on “good” or “bad” representations of women with disabilities.

Regardless of whether representations are understood as a reflection or the cause of cultural stereotypes, it is important to acknowledge that viewing an image is not a one-way street. Images do not simply act upon us; to believe they do is to ignore the role of the viewer in creating meaning (Walters, 1995). When someone looks at an image, in that instant, they create meaning for the image; they provide a context in which the image means something to them. This context, or meaning, is grounded in the viewer’s positioning in society.

**Stereotypes of disability: What I see is not me.**

Stereotypes are complex and possess potential for change; but I also think they are, in most cases, hopelessly embedded with stigma and shame. Stereotypes are not neutral; they are deeply embedded in oppressive structures and dominant discourses, and they can become prescriptions for expected behaviour as well as a form of social control. According to Walters (1995), stereotypes work because, on some level, they speak to a perceived “real” quality of the group they are targeting. In other words, stereotypes connect to a view that a majority of people believe to be true in some way, feeding off a “commonsense veracity” (p. 42). Stereotypes take a view, either a personality trait or common group identity, which is held by many people to be true, and enlarge it or exaggerate it. The effectiveness, and I argue insidiousness, of stereotypes is based on the experience of them as reinforcing ideological beliefs from one’s culture (p. 42-43).
addition, stereotypes have an innate ability to change and evolve over time and within different cultures making them difficult to challenge or eradicate (p. 43-44).

Any argument for fewer stereotyped images avoids a critique of the structures that built that stereotype in the first place (Walters, 1995). To simply omit the stereotype, or dismiss it, does nothing to change its hold. It also denies individuals the chance to change or challenge the stereotype itself. It is important to look at how stereotypes are produced and how they come to have meaning for us, in addition to what the stereotyped images look like (p. 45-46).

Garland Thomson (2001) has narrowed stereotypes about people with disabilities into four broad categories: the wondrous, the sentimental, the exotic or spectacle, and the realistic. The wondrous stereotype, or “supercrip” as it is commonly referred to, often takes on a heroic tone whereby people with disabilities are shown as having “overcome” their disability. They have succeeded despite being disabled (Fritsch, 2004). The supercrip is also meant to inspire awe in the viewer because the person is shown doing things a non-disabled individual probably could not do (Barnes, 1992). An example of this is a news article where a man without legs climbs Mount Kilimanjaro\(^2\). People who identify as nondisabled are meant to be inspired by this image because most of them could never imagine climbing a mountain in a wheelchair, yet the person with a disability has “risen above” his disability to become almost super-human.

\(^2\) This article was written published on June 20, 2012, in an online newspaper called MailOnline. The article begins with the title: “Man who lost his legs as a child scales 19,000ft-high Kilimanjaro by crawling on his HANDS for seven days” [capitalization theirs]. The article begins, “It’s a feat most able-bodied people would struggle to achieve...” (http://www.dailymail.co.uk/news/article-2162085/Disabled-man-legs-climbs-Mount-Kilimanjaro-Spencer-West-scales-mountain-using-HANDS.html)
While the image of the supercrip might reduce “otherness” in the eyes of some, it also creates an ideal that most people with disabilities cannot meet, thus increasing the alienation felt by people with disabilities (Wendell, 2006). Another problem with the supercrip stereotype is that it positions disability as a flaw. By presenting people as “overcoming” a disability, the disability is viewed as a limitation, a barrier that one needs to get past. The value of the person with the disability becomes his/her ability to move past his/her disability; no value is placed on the disability itself.

The second stereotype, the sentimental, has been kept alive by its extensive use in charities and telethons (Garland Thomson, 2001). The sentimental view sees the person with a disability as a sympathetic victim or helpless sufferer that needs protection or assistance to survive. It evokes pity and, according to Garland Thomson, it developed as part of a “larger nineteenth-century bourgeois culture of fine feelings” (p. 341). Longmore (2005) argued that this connection of disability and the sentimental came about because of telethons.

Telethons were a uniquely American invention that combined variety shows with infomercials, and patriotic feelings with pity. Created by disability-related charities, telethons identified people with disabilities as “afflicted” and “less fortunate.” Through telethons, and the guise of charity, people with disabilities saw their problems, needs, and entire identities defined by medical and social pathologies. Most often, children were used to represent the disabled body and any disabled adults who appeared on screen were treated like children. The reason for this was that adorable defenseless children evoked a strong sense of pity in viewers, which prompted them to reach out and donate (Longmore, 2005).
One of the most lasting stigmas to come out of the telethon was the idea that people with disabilities could not be part of society unless their disability was "cured" or "corrected." Throughout the twentieth century, growing numbers of Americans with disabilities began to resist this view, which eventually lead to protests and criticism of telethons during the 1980s and 1990s (Longmore, 2005). Even today, images of helpless "victims" of disability are used by charities to raise money and awareness of the "problem" of disability. But there is progress. Some charities are actively moving away from this stereotype and representing people with disabilities in a more joyful and upbeat manner.

The third stereotype is the exotic. The exotic often portrays people with disabilities as alien, sensationalized, or entertaining in their differences. It reproduces an ethnographic mode of looking that is characterized by curiosity and comes out of Western imperialism (Garland Thomson, 2001). According to Garland Thomson (2001), the exotic stereotype "turns the spectator into tourists...who imagine themselves as...enlightened, or titillated by their encounter brought to them by the...alien body at a safe distance" (p. 344). Freak show photographs, as well as images taken by many early anthropologists in the name of "research," often expressed the exotic stereotype. Today, this stereotype is rarely seen because of its connection to colonialism and its imperialistic undertones. However, one could argue that many of the "reality" television shows on TLC\(^3\), including *The Woman with Half a Body*, *The Man Whose Arms Exploded*, *Little People Big World*, are a new form of the freak show.

\(^3\) According to the official TLC Youtube Channel: "TLC is television network dedicated to covering "real life" reality and finding fun and beauty in the unexpected!" Source: http://www.youtube.com/user/TLC
The fourth, and final, stereotype is what Garland Thomson (2001) calls the “realistic.” These images are most often journalistic in nature and their goal is to evoke feelings of tragedy and loss. The term “realistic” does not, claims Garland Thomson, entail that the images are more truthful. Reality is far too complex and elusive to be captured in one image. Instead, the realistic stereotype plays on one aspect of reality and attempts to construct an illusion of what people believe to be true. Most often, the images encourage the viewer to become concerned or involved and the end message is that one does not want to be disabled (p. 364). The realistic stereotype, like the sentimental, invokes pity and convinces the viewer that they do not want to be like the person in the image. This stereotype warns against becoming disabled, and positions disability as a tragic conclusion or consequence.

Examples of the realistic stereotype are most often found in photojournalism and can be seen in articles on war, third world countries, and areas in the midst of a crisis. Similarly to Garland Thomson (2001), I argue that the goal is to create a reaction in the viewer; to create pity and spark a desire to make a difference. Similar to the sentimental stereotype utilized by charities, the realistic image used by journalists has a distinct purpose: to make a bad situation better by raising awareness, which is an admirable goal. But it becomes problematic, and unsettling, when a deformed or disabled body is the method they choose to express how “bad” the situation was or has become.

In addition to the four stereotypes discussed above, most scholars agree at least two other stereotypes exist. The first additional stereotype is the villain, whose very evil nature is expressed through a body deformity or disability (Dodd, Sandell, Jolly, & Jones, 2008). Shapiro (2000) argued that connecting disability and “evilness” has negative
consequences because it teaches individuals that disabilities and deformities are something to be afraid of or ridiculed. According to Shapiro, these villainous representations also equate goodness with beauty, and often show people with disabilities attempting to ravage the beauty of nondisabled people (p. 3). Dodd, Sandell, Jolly, and Jones (2008) describe the “demonic cripple” as being an individual who is warped by his or her deformity. They believe the disabled villain stereotype implies that disability involves the loss of an essential part of one’s humanity (p. 25).

The second additional stereotype is the disabled person as a clown or object of ridicule (Sandys, 1996). According to Clark (2003), society has been deriving humour from the disabled body for centuries. Many royal courts employed jesters, “fools,” and people with disabilities to provide entertainment. In the media, according to Clark, comedy involving characters with disabilities has traditionally taken humour from the limitations of the impairment or disability. Rarely are people with disabilities in charge of this ridicule; it is almost always at their expense (p. 13). Clark argues that the absence of people with disabilities from the writing, acting, directing, or producing of disabled comedy means that the portrayals are often seen by people with disabilities as “negative.” The consequence of the clown or ridicule stereotype is that it “seriously undermines what little opportunities they have to be taken seriously by non-disabled society” (p. 13).

These stereotypes impact how Western and European cultures view people with disabilities, and rarely leave room for the idea that being disabled can add value to one's life, or that a life with a disability can be something other than tragic, flawed, or lacking.

Often, the representations of people with disabilities found in the media are based on the stereotypes discussed previously. Because of this, it is important to critically
analyze the stereotypes that exist and talk about the complexities of the representations that use these stereotypes. In this work, I encouraged the participants to do just that.

The Gaze

Since this research includes a collection of photographic representations of the participants, I now turn my attention to a discussion of the connections between the gaze, the stare, and photography.

Mulvey (2001) defines the gaze as “the pleasure of looking” and as a “key element in the construction of modern subjectivity, filtering ways of understanding and ordering the surrounding world” (p. 5). Unlike the stare, the gaze is thought to be far more passive and involves aspects of pleasure and sexuality. Renowned scholar, bell hooks (1992), claimed that the gaze was, at least for Black people, political and mired in a history of power relations. She argued that by gazing, defiantly, at the oppressor, one declares: “Not only will I stare. I want my look to change reality.” (p. 116). Even in situations related to dominance, the ability to use one’s gaze against those who attempt to dominate opens up the possibility for change and agency. For hooks, the gaze has been, and continues to be, a place of resistance for colonized Black people around the world. When dealing with oppression, “one learns to look a certain way in order to resist” (p. 116).

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4 hooks regularly interchanges the words stare, gaze, and look in her article. She seems to view all the words equally and does not differentiate between them. In this thesis, I have chosen to use only the word “gaze” when discussing the works of hook.
Further, argues hooks, when a Black individual gazes at a television show or movie, they engage with what they see and are fully aware that mass media is a system of knowledge and power that aims to reproduce white supremacy. For example, Black viewers of mainstream cinema and television laughed at the white representations of blackness through the decades, but they also looked at these representations critically. These interrogating "black looks" (p. 117) were mostly concerned with issues of race and racism, and how whites determined the representations of Blackness in television and cinema. The same arguments could be made for representations of disability in mainstream visual media. For decades, many individuals with disabilities watched representations of themselves in the media that had been constructed by people who identified as nondisabled. I argue that people with disabilities have always been aware of this lack of control over our own representations and, like the critical black looks described by hooks, they have also looked critically at what existed in mainstream media.

Gillespie (2006), in his article "Tourist Photography and the Reverse Gaze," discussed the interactions that occur between the photographer and the photographee. He argued that the photographer-photographee relationship is a complex interaction that affects each individual. The gaze of the tourist is believed to have the power to commodify local culture and create self-consciousness among local citizens captured by the camera (p. 344). However, the "reverse gaze" of the photographee can play a critical role in constructing the self of the photographer; it can position the photographer within the interaction and make them acutely aware of the situation. To further his point, Gillespie used examples from his time doing fieldwork in Ladakh, northern India. On one occasion, a Ladakhi woman in traditional attire turned the tables on a tourist
photographer who had been following her by taking a camera and pointing it back at the tourist. The tourist became acutely aware of the interaction and left with a flushed face and embarrassed expression. The author argued that the embarrassment of the tourist implied that his self-image had been altered and he had been, within this specific interaction, repositioned. By using a reverse stare (or even a questioning look) the photographee can momentarily reverse the relationship between the photographer and photographee (p. 347).

I argue that this concept can be taken a step further. By constructing an image and controlling what is seen and how it is seen, a photographee can also challenge the stare/gaze of a viewer. Like the Ladakhi woman, the photographee can change the relationship between a viewer and an image and create a reverse stare that repositions the viewer in relation to the photograph and the photographee. In this research, by forcing the viewer to stare at the disabled body, the photographees are, in a sense, constructing a voyeuristic gaze. Yet they are also controlling what is seen, so the power of the image rests with the photographee. The viewers are being permitted to see the image in a manner deemed appropriate by the photographees, which could create self-consciousness in the viewer.

**The stare: What are you looking at?**

Looking is a process of observing and recognizing the world around us. It is an activity that involves a sense of purpose and direction. Each day we look to make sense of the world (Sturken & Cartwright, 2009). This means that when we look at something, or someone, we make meaning out of that thing or person. Like speaking, writing, and signing, looking involves relationships of power (p. 10). As anyone with a visible
disability knows, being looked at is probably one of the most universal experiences of being disabled (Garland Thomson, 2001). However, it is important to note that when people look at a person with disabilities, it is less a look than a stare.

Staring, according to Garland Thomson (2001), is an intense version of looking that at once creates a spectator and a spectacle. In this intense exchange of looks, the starer becomes the subject with the power while the staree becomes the object acted upon. Staring at a person with a disability instantly positions them as "other" and different. The act of staring registers the disabled body as different (p. 340-341).

As human beings, I argue we have a tendency to look at things that are different. Perhaps, at one time, noticing what was out of the ordinary, what was different helped humans survive. It can be a gut reaction to do a double take when something stands out as being different, whether that is a person or an object. I claim that the problem is not noticing or looking at what is different; the problem is when that look becomes a one-way stare. The refusal to allow the staree to look or gaze back creates an uneven relationship of power.

When someone stares at me because I have a visible physical disability, I do not mind; I look different and I am aware of that. I accept it as part of my life. In these instances, I always look back and smile. My return gaze and smile is an attempt to normalize the situation and let the starer know there is no shame in being different. If the person returns my smile, the power, I argue, is evenly distributed because the starer is allowing me the chance to define myself. For me, the problem arises when the starer refuses to smile back or looks away quickly in shame. As Garland Thomson (2001) stated, the disabled body is a paradox because it is at once to be stared at, but at the same
time not to be looked at. It is stigmatized as inferior and shameful in most cultures, and those caught staring often feel shame or pity for the disabled person. I believe this is a large part of why many people refuse to let me gaze back. They are uncomfortable accepting my difference as mere difference, so they look away ashamed and deny me the power to define myself. They have cast their definition of “other” onto me with no potential for me to redefine that “otherness.” They have positioned me as the receiver of the stare and refused to let me possess any other role.

Some might argue that the starer is simply feeling ashamed or embarrassed for being caught staring at me – but why are they ashamed and/or embarrassed? The act of staring is not in itself shameful. Do they feel ashamed and/or embarrassed when caught staring at a beautiful flower or an ornate building? Is there shame in staring at a work of art in a museum? Or in an individual wearing an unusual outfit? Their shame does not come from being caught staring but, instead, it comes from being caught staring at a disabled body. It is the disabled body that causes the shame, thereby reinforcing the connection of the disabled body and shame.

I would like to clarify that I do not believe that this is always a fully conscious act. People are not out there purposefully denying me the ability to define my identity; just because it may be an unconscious act, does not mean it does not happen. I also argue that some people may not be exactly sure why they look away; they just look away because it has been drilled into them to do so.

My point is that the stare sets up an uneven relationship of power and it is an act that should be more deeply analyzed and discussed. If we remove the shame of staring,
perhaps by allowing people with disabilities to look back or giving them more control over their own representations, we can begin to change how people see disabled bodies.

**The Disability Arts Movement**

In the Disability Arts Movement, disability is seen as a valid and meaningful subject for artwork. According to Allan Sutherland (2005):

…the generally agreed definition of disability arts, the one that we in the disability arts movement have found most accurately reflects what we are doing, is that it is 'art made by disabled people which reflects the experience of disability'. (as cited at www.disabilityartsonline.org.uk/what-is-disability-arts)

For Barnes and Mercer (2003), the Disability Arts Movement is an important and significant point in the transition of how people see disability as it can help portray people with disabilities in a more positive light and is a source of political awakening for people with disabilities. Sutherland (1997, as cited in Barnes & Mercer, 2003) argued that disability politics separates a disability artist from an artist with a disability. According to Barnes and Mercer, the Disability Arts Movement has several dimensions: it argues for people with disabilities to have access to mainstream artistic consumption and production; it explores the experiences of living with an impairment; it offers a critical response to the experience of social exclusion and marginalization; and it involves the use of culture and media to expose discrimination and prejudice that people with disabilities face. One of the goals of the Disability Arts Movement is to generate a more positive group consciousness and identity.
Disability performance art.

Disability Performance Art, according to Garland Thomson (2000), is “a genre of self-representation, a form of autobiography that merges the visual with the narrative” (p. 334). Through its ability to see and tell, Disability Performance Art positions the disabled body as an object to be at once viewed and explained. The disabled body becomes not only the medium but also the content (p. 334). Disability Performance Art can be a platform for the creation of liberating representations of the disabled self, wherein the artist controls the terms of the encounter (p. 335).

In her article, “Deconstructing Images: Performing Disability,” Kuppers (2001) discussed the marginalization and invisibility of the disabled performer who is “relegated to the borderlands, far outside the central area of cultural activity, into the discourses of medicine, therapy, and victimhood” (p. 25). Kuppers argued that while people with disabilities are invisible, they are also, at the same time, hypervisible because of their different bodies, which draw immediate and fixed attention. The disabled performer, then, has to negotiate two worlds: invisibility, and hypervisibility with instant categorization.

Through their work in the public sphere, performers with disabilities break down stereotypes about passive and submissive bodies of difference. They can also challenge and confuse concepts of what constitutes a performance, what bodies are supposed to do, and the meaning of disability. The choice to perform as a person with a disability helps to open a dialogue in disability narratives (Kuppers, 2001).

In some ways, the photographic images constructed by the participants in this research could be considered performance art. The act of constructing the photographs
and presenting them for an audience is, for me, a type of performance. One could also argue that my presence throughout the creation of the photographs implies an audience, as I am witnessing the “act” of creating the images. Additionally, through the construction of photographic images, the participants are breaking down stereotypes about disability and forcing viewers to rethink what it is disabled bodies are supposed to do and be. The photographs also aim to open a dialogue between the participants and the viewer about the representation of women with physical disabilities.

Intersectionality

I would now like to turn my attention to the interconnected aspects of identity and discuss select works by scholars writing about sexual identity, race, and intersexuality. In the following pages, I show how other identities overlap with the category of disability and I highlight the ways disability studies could incorporate theories from other discourses.

Lesbian theories.

Rich (1980) wrote a ground-breaking article, titled “Compulsory Heterosexuality and Lesbian Existence,” which inspired many future scholars. Rich argued that a retreat into sameness (i.e., trying to assimilate) is one of the most passive and debilitating ways to react to oppression. I found Rich’s article to be relevant to disability because medical and cultural discourses encourage both the lesbian and disabled body (as well as the racialized, ethnic, classed, intersexed, and gay body) to “pass” as a heterosexual or “normal” body. When the medical community encourages people with disabilities to
undergo surgeries or use technological aids to become more “normal,” they are reinforcing the belief that disability is abnormal. One might argue this is merely a way to end the pain disabilities can cause or make a disabled person’s life easier, but that argument is problematic. Who decides that the life of a disabled person is difficult? And why does having a disability automatically make one’s life difficult? Why is pain automatically linked with disability? The problem, as I see it, is not the different body but societal reaction to that difference.

I would like to note that, while I agree it is a worthwhile venture to lessen or end pain, I do not support the automatic association of disability with pain, or the view that pain is always negative. Pain, like other aspects of human existence, is a complex and convoluted concept that cannot be easily forced into a good/bad dichotomy.

Rich also encouraged scholars to read and write from a place that is less heterocentric. I argue that people should also do this from a place that is less ableist, less white-centric, and so forth. With this encouragement, Rich provides a list of ways male power oppresses women. This list could easily be used in disability studies to look at how nondisabled people (men and women alike) oppress women with disabilities. I will now list these points, with the exclusion of any that do not apply to women with disabilities:

1) To deny women [their own] sexuality
2) Or to force it [male sexuality] upon them
3) To command or exploit their labor to control their produce
4) To control or rob them of their children
5) To confine them physically and prevent their movement
6) To withhold from them large areas of society’s knowledge and cultural attainments. (p. 635-636)
Women with disabilities are frequently denied a sexuality of any kind and usually have limited control over how their sexuality is defined, when it is acknowledged. However, although their sexuality is often denied, they still experience sexual assault and rape (Sobsey, 1994). Women with disabilities have difficulty finding employment, are frequently underpaid, and often live under the poverty line (Disabled World website, 2010). As mentioned previously, there is a long history of people with disabilities being exploited in freak shows for the sake of entertainment. There have also been forced sterilization programs and laws that prohibit marriage for people with disabilities in North America (U.S. Holocaust Memorial Museum, 2010, as cited in Jewish Virtual Library website, 2010). People with disabilities are often limited as to where they can go because of inaccessible buildings, roads, and a lack of assistive technology. And, lastly, many children with disabilities have been institutionalized, or segregated, in “special education” classrooms instead of being allowed to remain with children who are not disabled.

In her article, “To See and Be Seen: The Politics of Reality,” Frye (1989), another renowned lesbian scholar, claimed that lesbians, because of their oppression and invisibility in society, have the peculiar position of being something that does not, yet does, exist. Frye also stated that this vantage point offers lesbians a freedom from the constraints of “the conceptual system” (p. 77) and gives them access to knowledge that is inaccessible to non-lesbians, whose existence is too integrated in the system. This could also be true for women with disabilities, who are often marginalized and ignored. Following Frye’s theory, this would mean that women with disabilities might have access to knowledge and information that nondisabled women do not. However, I am wary of
this argument as it places women with disabilities on a pedestal and further separates people with disabilities from nondisabled people.

**Intersex identities.**

Moving beyond lesbian theories, there has been a lot written about the intersexed body, which is relevant to the disabled body. Holmes (2000), in the article “Queer Cut Bodies: Intersexuality and Homophobia in Medical Practice,” wrote that the intersexed body is viewed as a body that does not fit into Western culture and that this body has been figuratively and literally, “cut, bound, and sutured in order to appear, in a most violent paradox, ‘normal’” (p. 84-85). Like intersexed bodies, disabled bodies are often medically acted upon at birth and attempts to “normalize” the body are performed through surgeries. Holmes argued that the cuts and surgeries forced on intersexed bodies are attempts to force them to fit into dominant discourses about the body. By cutting up intersexed bodies, heterosexist hegemonies can be maintained.

For Holmes, most intersexed bodies are transformed into female bodies because female bodies are viewed as lacking and, therefore, easier to convert. But the main focus of this article is “bodies that do not fit” (p. 89), which I argue applies to physically disabled bodies as well as intersexed bodies. Both are bodies that exist outside of what Western society deems are the acceptable boundaries of what a body should look like, and both intersexed and disabled bodies have a long history of exploitation, oppression and medicalization. A notable quote by Holmes states: “most people are not built this way, because most people are not *built*” (emphasis by the author, p. 94). This quote can be effectively applied to both disabled and intersexed bodies.
Cultural race theories.

Another theoretical framework I would like to discuss is that of race and ethnicity. I begin with a look at critical Black studies and then turn to Aboriginal/Native/First Nation discourses before ending with a brief discussion on people who identify as Jewish. There is far more literature on race (and the body) than I could hope to cover in this thesis, so I have chosen to discuss only a few articles.

The bodies of Black people were deemed, at one time, to be so different from European and Western bodies that they were considered “deformed” and they were grouped with all the other “deformed” bodies (Garland Thomson, 2002). A well-known example of this is the exploitation of Saartje Bartmann, an African-American woman who was exhibited as a “freak” in nineteenth century Europe. Commonly known as the Hottentot Venus, her protruding buttocks and genitalia were displayed in freak shows (p. 7). There was no disability, as we define it today, in Saartje’s body. She was simply an African woman, but the standards of that time period dictated that her perceived ethnic characteristics were different enough from “white” characteristics to be labeled different.

During the early and mid-nineteenth century, racial theorists used two arguments to explain the differences between racialized bodies (Young, 1995). The first, called the monogenetic argument, stated that all humans, regardless of race, were descended from one source, as claimed in the Bible. In this theory, the thought was that racial differences were explained through degeneration, which placed the white male as the pure origin of mankind and “the universal mean and measure of all things” (p. 101). The second was the polygenetic argument, which claimed that different races were actually different species. The polygenetic argument was most often toted by those who wanted to uphold
extreme forms of racism and prejudice, such as slavery (p. 101). The medical model, which defined differences within the body according to a scale of pathology and the normal, was used in the polygenetic argument to explain how Black bodies differed from white bodies. The focus of these differences, however, seemed to concentrate mainly on describing and examining the female genitalia of Black women (Gilman, 1985), as was the case with the Hottentot Venus.

According to Cuvier (as cited in Gilman, 1985), one of the most influential figures in science during the early nineteenth century, the Black woman looked different and everything about her body, from her skin colour to her genitalia, labeled her as inherently different from white women. Not only was the Black female body viewed as possessing a primitive sexual appetite, but this excessive sexuality was thought to be shown through “abnormal” genitalia. By the mid-nineteenth century, the implication of this idea was that people believed the differences between white and Black bodies were inherent biological flaws (Gilman, 1985). This is similar to the belief put forward by the medical model that disabled bodies are biologically lacking or inherently flawed.

Moving beyond discussions of Black studies, when it comes to qualitative research, disability is not the only discourse made invisible. First Nation/Native-centred understandings of gender and sexuality are also forgotten and ignored. According to Driskill (2010), dialogues of gender and sexuality in Native research help to critique and deconstruct colonialism, queerphobia, racism, and misogyny. Driskill’s article,

\[5\] I am aware that the current acceptable term, when discussing First Nation/Aboriginal/Native communities and/or studies, is “First Nation.” However, since the author, Driskill, uses the term “Native” and “Native-centered” throughout her article, I have chosen to use the same term when discussing her arguments. In all other discussions, I will use “First Nation” or a hybrid of the two, “First Nation/Native,” dependent on the situation.

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"Doubleweaving Two-Spirit Critiques: Building Alliances between Native and Queer Studies" (2010), explained the absence of Native theory in queer studies, as well as its omission from most conversations about race, sexuality, and colonialism. Driskill argued that qualitative researchers need to include race theory in their work, especially Native-centred theory, because it opens up conversations about ongoing struggles of decolonization and the interconnectedness of our identities.

Driskill used the label of “two-spirit” to describe Native Lesbian/Gay/Bisexual/Transsexual/Queer (LGBTQ) individuals. The term comes from a Northern Algonquin dialect and gained popularity during the third annual spiritual gathering of gay and lesbian Native people in 1990. The term was selected because two-spirits, or niizh manitoag, indicate the presence of both feminine and masculine spirits in one person. The author claimed that two-spirit critiques are similar to queer critiques in that they challenge heteropatriarchy, gender binaries, and the repression or control of sexualized and gendered bodies; the difference is that two-spirit critiques are rooted in Native histories (Driskill, 2010).

For me, one of the most relevant parts of Driskill’s article is the discussion of doublewoven baskets as a model for articulating the interconnectivity of identity. Doubleweave has its origins in river cane weaving and is two complete baskets, one woven inside the other, with a common rim. In addition, doubling is often used as a Cherokee strategy in which two seemingly separate rhetorical approaches exist at the

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6 According to Walia (2012), decolonization is “as much a process as a goal. It requires a profound recentring on Indigenous worldviews. Syed Hussan, a Toronto-based activist, states: ‘Decolonization is a dramatic reimagining of relationships with land, people and the state. Much of this requires study. It requires conversation. It is a practice; it is an unlearning.’... Decolonization is the process whereby we create the conditions in which we want to live and the social relations we wish to have.” (http://briarpatchmagazine.com/articles/view/decolonizing-together)
same time, together. Using the doubleweave as a metaphor, researchers can conceptualize the intertwining of queer and Native concerns into a specifically indigenous creation. When visualized in this way, we are able to see the numerous “splints” in these interconnected theories, including Native politics, postmodern scholarship, grassroots activism, queer and trans resistance movements, and queer studies (p. 73-74). In a way, with the doubleweaving metaphor, researchers can move beyond intersectional politics, into a more complex and durable story that is both unique and rooted in Native history.

The practice of using the doubleweave as a metaphor could also be implemented in critical disability studies. Similar to Native and queer theory, researchers could use doubleweaving to connect sexuality, race, class, and gender under the common “rim” of disability. The conversations that could arise from this methodology may help increase the visibility of disability in critical studies and more easily show how and where our identities overlap and intersect.

Another discourse that has commonalities with disability studies is critical Jewish politics. Beck (1988), argued that because Jewish women have been omitted from the majority of feminist literature and critiques, it is difficult not to see it as a conscious and oppressive act. The author emphasized the point that she is referring only to the absence of writings about Jewish women and the nonexistence of Jewish women’s culture in feminist “multicultural” events, and not the exclusion of Jews themselves.

For Beck, the invisibility of Jewish women is a symptom of anti-Semitism, just as lesbian invisibility is a symptom of homophobia. In North America and Europe, anti-Semitism is being fueled by the growth of neo-Nazi white supremacists, neo-conservative
Christian fundamentalists, and extremists in the Nation of Islam (p. 96). These prejudices and racist attitudes have made it feel unsafe for Jewish women to bring Jewish issues into feminist discourses. Jewish women fear they might be attacked for their research, perceived as too demanding, or that they may be even further excluded if they speak up. Speaking and writing about Jewish themes also raises the worry that the work will be considered “marginal” and not widely read or discussed.

I believe that women with disabilities have similar concerns to Jewish women. Women with disabilities fear coming forward with critiques of disability discourses because they could be perceived as being too demanding or pushy. In addition, if women with disabilities complain too much, I argue they could be excluded altogether from qualitative research texts. The motto of “nothing about us without us” could lead scholars and researchers to simply omit all discussions of disability because of the “hassle” of inclusion.

Beck (1988) argued that the reason Jewish women are excluded from feminist frameworks is because, originally, feminism included critical analyses of sex, class, and race. While sex became sexual difference, and race became ethnicity, these categories failed to leave room for the Jewish identity, which does not fit easily into pre-defined categories. This argument can also be used among disability scholars as an argument for the invisibility of disability. Like Jewishness, disability does not fit under the label of sex, class, or race, so it is not easily inserted into feminist discourses – and yet it has the potential to intersect with all these identities.

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7 “Nothing about us without us” is a motto or mantra thought to have originated in South Africa’s disability rights movement. It was then adopted by many North American and European disability rights groups during the 1960’s and 1970’s. The motto demands that individuals with disabilities should be at the forefront of any decision or policy-making that affects their lives (Franits, 2005).
Although racial oppression is different from the oppression of people with disabilities, there are commonalities and overlapping histories, which is why I have chosen to include it in this research.

The theories I have included in this research are important for several reasons. First, I felt it important to use a new model of disability; one that incorporated all aspects of a person’s identity and did not rely too heavily on the medical model. Second, since I am looking at representations of women with physical disabilities in the media, it was imperative that I include feminism. Critical feminist theories about the female body, objectification, the media, and the gaze are integral parts of this research. But it is also vital to be aware of the gaps in feminist research; namely, the absence of disability in critical feminist studies. Third, because people with disabilities are sometimes included in advertising and fashion, it was worthwhile to look at that inclusion and its representations of the disabled female body. However, little has been written about the incorporation of the female disabled body in advertising and fashion, especially from a feminist perspective. Fourth, representations of people with disabilities found in the media are often based on stereotypes. Therefore, it was important to find out more about common disability stereotypes and look at those stereotypes from a critical feminist perspective as well as a critical disability perspective. Fifth, the photographic images constructed by the participants are, I argue, part of the disability arts movement. I also argue that the images are a type of performance. Because of this, it was important to briefly discuss the Disability Arts Movement as well as Disabled Performance Art. And, finally, I included discussions of race and sexual identity theories because of the overlapping histories and commonalities between them and disability.
In this chapter, I take an in-depth look at the methodologies and methods used in this research study. Specifically, I discuss feminist methodologies and questions about reflexivity, insider/outsider status, and arts-based inquiry. I also look at specific methods, including focus groups, photo elicitation, research interviewing, and transcription. Finally, I address ethical concerns, such as speaking for others, researcher/participant relations, and anonymity. I finish the chapter with a look at the specific research design used in the research.

Is There a Feminist Methodology?

Feminist and non-feminist theorists alike have long debated the question of whether or not a feminist methodology exists. According to O’Neill (1995), there is no single feminist way to do research. However, McDonald (2003) argued that feminist research is always engaged, instead of supposedly “neutral.” The topics that get researched, why they get researched, and who funds the research all affect the research process and outcomes. Even quantitative results need to be interpreted in a report for the public and funding bodies, and that report can be filled with biases and beliefs based on the researcher’s or funder’s position in society and their identities – e.g. their race, gender, sexuality, class, and body.

Reinharz (1992, as cited in McDonald, 2003) stated feminism is not a research method so much as a perspective. She explained feminist research is politically motivated and aims to: produce useful information for women, make women visible, and facilitate a potential for change while causing minimal harm to participants. Similarly,
Montell (1999) claims that feminist methodology also shares three distinct goals, to: a) bring women into the research process to discover what knowledge, about women is being ignored, censored, and suppressed; b) minimize harm, control, and exploitation in the research process; and, c) conduct research that is of value to women and will lead to social change or action that will benefit women.

Further, Cook and Fonow (1986, as cited in Montell, 1999) identified five principles they felt concerned feminist researchers: a) an attention to the importance of gender; b) a need to challenge the idea of objectivity in research, and the rigid separation of the researcher and the researched; c) an inclusion of consciousness-raising as a methodological tool; d) an emphasis on women’s empowerment and transforming patriarchal hierarchies; and, e) a concern for ethical issues within research.

I argue that this research is feminist because, first and foremost, I am a feminist and my work is strongly influenced by feminist discourses. Second, this project works to make women more visible and tries to create the potential for change without causing harm. Third, I am bringing women as active participants into the research process: the women are given the chance to critically analyze the representations of women with disabilities in the media and discuss the invisibility of disability in North American culture. They are also in control of their representations through the construction of new photographic images.

As shared decision-making and self-disclosure occurred, I tried to minimize any differences between the participants and myself, such as differences in social status, backgrounds, disability type, and so forth (Reinharz & Davidman, 1992). However, I
was not always able to completely erase the hierarchies of power that occur between researchers and participants in focus groups.

**Reflexivity in research.**

One of the more prominent feminist research concepts I utilize is that of reflexivity: the recognition that from where one speaks affects what one says and how one says it. No one can transcend his or her location because s/he is too deeply embedded within it (Alcoff, 2008). In other words, everything about my past and my identity affects who I am, what I do, what I say, and how I think. The analysis of one’s own positioning also becomes an important part of the research process.

According to Foucault (n.d., as cited in Jardine, 2005), human beings are formed by the system of knowledge and power into which they are born and raised. Even perceptions of what is around us are influenced by our position in society. “At every moment, step by step,” Foucault stated, “one must confront what one is thinking and saying with what one is doing, with what one is” (1983, as cited in Jardine, 2005, p. 8). Foucault also argued that there was no such thing as an absolute, pure, objective and perspectiveless “truth” and felt it was harmful to pretend there was. Similarly, Carr (1995, as cited in Greenbank, 2002) argued that researchers who claimed to carry out objective, value-neutral, research were deluding themselves and misleading others.

Ideologies work because they are hidden, and they become difficult to resist because they appear to be “natural” or “normal” (Darts, 2004). By acknowledging the existence of ideologies, a researcher can begin to reveal the taken-for-granted assumptions. Reflexivity helps us become more aware of our biases and beliefs by discussing them openly and honestly. A reflexive approach to research attempts to make
the entire process transparent by providing a clear audit trail (Hand, 2003). It demands that researchers continuously reflect on their actions and the respondents’ reactions, as well as how the data is collected, and how interpretations are made.

Knowing that there is no one objective and pure “truth” deepens our ability as researchers to critically examine how we are affected by the dominant cultural beliefs and assumptions in our everyday lives. Knowing how and why we are affected is the first step in figuring out what should be changed, what should be appreciated, and what should be maintained (Jardine, 2005).

With respect to reflexivity, I must now take a moment to position myself within this research. As I mentioned previously, I am a white female with a physical disability (Miller’s Syndrome). I am Canadian, relatively healthy, slim, heterosexual, non-religious, liberal, and middle-class. I use critical analysis in every facet of my life, from television and billboards to news articles and face-to-face conversations. I spent twelve years in post-secondary education and have been involved in women’s studies for almost eight years. I also have a professional background in photography, graphic design, communications, and research.

As the daughter of two left-wing liberal parents who questioned everything and accepted nothing at face value, I come from a relatively non-traditional background. My parents also firmly believed that in order to argue one’s point of view, you had to fully understand the opponent’s point of view. You did not have to agree with their point of view, but you had to understand it.

By taking a reflexive approach in this research, I hope to create a more equitable relationship between the participants and myself (McDonald, 2003). However, I must
remain aware that providing information about one's self, as a disclaimer of ignorance, without any critical interrogation, benefits no one (Alcoff, 2008). The goal of implementing reflexivity is to engage my beliefs and perceptions, and to challenge the ideologies that influence my world.

The insider/outsider conundrum.

Another issue faced by feminist researchers is that of the insider/outsider challenge. Whether a researcher is part of the group being researched (i.e., an insider) or set apart and separate (i.e., an outsider) affects the research process. The pros and cons of each position are often debated in critical feminist discourse.

McEvoy (2001, as cited in Hand, 2003) claimed there are four limitations to an insider perspective: a) a taken-for-granted viewpoint that makes it more difficult for the researcher to question the world s/he is familiar with; b) a lack of distance required to maintain a balanced and “objective” perspective; c) subjection to the constraints of group membership that usually causes the researcher to avoid asking questions about well-established social mores; and, d) a reluctance to ask about sensitive issues.

The first issue I take with McEvoy’s argument is that the author assumes an objective perspective is possible. The assumption that such a view can be obtained is, in itself, a limitation to the research process. McEvoy also ignores the point that being an insider can provide a researcher with the knowledge of exactly what the sensitive issues are and the researcher can then target those areas for discussion (Hand, 2003). Being an insider can also encourage a more open dialogue because the participants are more comfortable speaking with someone within their group (Anderson & Jack, 1998).
However, an insider position can also make participants so comfortable that they forget their words will be written down and this can lead to exploitation.

As the researcher in this project, I possess both an insider and outsider status. As I have mentioned, I am physically disabled so in that respect, I am an insider. I understand, first-hand, the experience of being physically disabled. I am also a woman and a feminist. Yet I am also the researcher who created the project and who is organizing its every detail. In this way, I am an outsider. No matter how inclusive my research is, or how hard I try to provide an equal footing between the participants and me, there will inevitably be an unequal distribution of power. This became crystal clear at the end of the focus group when one participant, Mary, asked, “Did you get what you wanted to get? Or what you thought you might get?” Prior to that statement, I had not thought that the participants were trying to give me what they thought I wanted. But once Mary asked if I “got” what I wanted, I began to worry I had pointed the participants in a specific direction without realizing it. Looking back at the transcriptions of the focus group, I quickly saw where I made my mistake.

At the beginning of the focus group, I informed the participants I would not be talking during the discussion(s) as I did not want to bias them. This research was about having their voices heard. However, immediately following that statement, I uttered the words: “So I’m Rachel Watters. I’m the researcher for this project.” Then I spoke about my academic and professional background for thirty seconds. In doing so, I established myself as an authority figure, which was not my intent. I was simply trying to stress my ability to conduct this research. But why was it so important to prove my worth to the participants? Upon reflection, I realize I often have to explain my abilities or prove I am
capable to others in my day-to-day life. I think I felt the need to do this with the participants as well. It is clear now that this was unnecessary. My presence, and my ability to organize the focus group, was sufficient evidence of my capabilities.

Talking about my background may have led the participants in a direction they otherwise might not have taken because they were aware of my academic and personal interests. I also clearly pointed out to the participants that I was an outsider because I was the researcher. In future research, I will keep the details of my background to a minimum in an effort to reduce the power relationships that can develop so easily in these situations. However, no matter how hard a researcher works to erase power hierarchies, they will always exist due to the inherent nature of the research project. As long as there are researchers and participants, there will be unequal balances of power. The key is to work diligently to reduce those imbalances.

**Arts-based Inquiry as a Form of Knowledge**

The goal of research is to investigate one’s theories and find meaning and validation in those theories (Estrella & Forinash, 2007). It is also about creating new knowledge and understanding more about the human experience and how transformation may be possible (Estrella & Forinash, 2007). But not all forms of knowledge or data representation are considered legitimate; knowledge creation is a fluid process, a temporary state, can be unnerving to many researchers (Eisner, 1997).

The written word is one of the more acceptable forms of data representation and many researchers tend to privilege it over other forms of expression. Lawrence (2008) argued that the problem with the written word is that it is a form of one-way
communication. He claimed that although words can provoke feelings, they leave very little open to interpretation because they dictate what the reader should feel. Instead, Lawrence (2008) argued for the incorporation of art in the research process. He believes art can open a space for interpretation and new knowledge. In arts-based inquiry, the arts are central to formulating the research question, generating and analyzing data, and presenting the research results (Knowles & Cole, 2008). By blending narratives with arts-based inquiry, researchers can explore the marginalized and disruptive perspectives that are often lost in more traditional research methodologies (Estrella & Forinash, 2007).

The value of including arts in the research process comes from the idea that artistic knowledge is different from intellectual knowledge, and this difference is the very basis of its value (McNiff, 1998, as cited in Simons & McCormack, 2010). By incorporating the creative arts into the research process researchers can engage with the data differently and see information in a new way (Simons & McCormack, 2010). The arts provide a tool that can break through, uncover, and reveal while also supporting, nourishing, and sustaining knowledge (Estrella & Forinash, 2007).

Simons and McCormack (2010) claim that when participants have the chance to express their experiences through art making, they often reveal insights they could not articulate in words. Visual images can make it possible for participants to form meanings that elude linguistic description (Casey, 2009). In other words, they provide another way for participants to have their voices heard and their opinions understood.

Art can also help to validate a participant’s experience and empower her through the construction of her own image (Estrella & Forinash, 2007). The inclusion of arts-based inquiry in this research gave participants a greater sense of control over the
research process, opened possibilities for counter-narratives, and challenged dominant ideologies potentially hidden within the written text.

Since the eighteenth century, artists have used their work to inspire, offend, and enrage audiences. The goal of many artists is to awaken the unconscious in order to communicate ideas and emotions that are otherwise difficult to express (Darts, 2004). Through its use of ambiguous texts and openness to interpretation, arts-based inquiry draws participants into a dialogue and opens up a space for a critique of existing social structures (Finley, 2005). Critically engaged art can also be a tool for exposing and addressing oppression, and encouraging social transformation (Darts, 2004). That is why I have included the construction of new photographic imagery and the use of photo elicitation as methods of arts-based inquiry in this research.

Photography.

Arts-based inquiry was used in this project through the construction of new photographic images and photo elicitation. As a form of representation, photography tends to carry more “truth” value than other visual mediums because of the belief that photographs mirror the real world. The consequence of this concept is that the influence of the photographer, who frames and takes the photograph, is erased (Sturken & Cartwright, 2009). But, like all representations, photographs are constructed and shaped through cultural ideals, biases, and preconceived ideas about what the subject should look like and where the photographer points the camera (Garland Thomson, 2001).

Modern medicine and photography appeared almost simultaneously during the nineteenth century, and quickly joined forces under the genre of medical photography. The medical community exploited photography’s supposed ability to tell the truth in
order to present an “objective” view of the body. The medical photograph, which was one of the first uses of photography (Millet, 2008), constructed what Michel Foucault (n.d.) called the medical gaze, which is a gaze that defines what is considered normal by picturing the deviant, or the deformed (Garland Thomson, 2001).

Over the last 150 years, the medical community has diagnosed, documented, identified, and pathologized disability through the use of photography (Garland Thomson, 2001). Images taken by the medical community of disabled bodies, in early modern medicine, often blocked the subject’s eyes with black boxes in an effort to preserve the patient’s dignity. Instead, this only served to shame the individual and impede any sort of return gaze from the disabled body (Millet, 2008).

This categorization of disability by the medical community was one of the reasons I decided to incorporate photography in my research. In medical photography, the individual being photographed has no control over his or her image. Individuals are told what to do and how to do it. I argue that this also denies an individual identity and, in many ways, a “humanness,” because of the black boxes covering the eyes. They are objects to be viewed; medical oddities that are talked about, but rarely to. Using photography allowed the participants in this research to take control of their images and become subjects, instead of objects.

**Case studies: Arts-based inquiry projects.**

When I first began my research, I was unable to find a disability study that used arts-based inquiry. What follows are a series of brief synopses for the projects I did find that utilized arts-based inquiry and assisted me in constructing my research project.
Hughes (2009), in his paper “Leadership, Management and Sculpture: How Arts Based Activities Can Transform Learning and Deepen Understanding,” looked at the use of arts-based activities for improving the quality of workplace practices. Participants were given blocks of clay and asked to make sculptures that represented themselves and their organizations in relation to personal and organizational change. The art making activity lasted two hours and involved four stages: thinking about the issues, reflecting on past experiences, making the sculpture, and a coaching event. The coaching was a one-on-one dialogue that focused on exploring the meaning of the art object. According to Hughes, many participants felt the workshop led to new insights and they acknowledged that the coaching process helped to clarify their thoughts.

Before I started this research, I wanted to incorporate more of a coaching element, similar to the one Hughes (2009) discussed above. I felt it was important for the participants to discuss the process of constructing their own photographic representations. I believed it could open up a space for a deeper dialogue as it did in Hughes’ study. Unfortunately, due to time constraints, I was unable to include the coaching element into the thesis, but I hope to utilize it in future work.

Casy (2009) looked at the methods, processes, and experiences of using arts-based inquiry in the context of undergraduate nursing curriculum in the article, “Arts-Based Inquiry in Nursing Education.” The essential attributes of contemporary nursing were explored through representations and analyses of student artwork, contextual discussions, and researcher field notes. According to findings from the research, the process of engaging in arts-based methodology fostered creativity and encouraged critical thinking among the participants. Although there were many benefits to using arts-based
inquiry, Casy found that there were also challenges. Working with arts-based methods forced participants to get used to a teaching and learning environment that was unstructured. This made some participants re-examine their firmly held beliefs, expectations, and practices.

While I am not sure if the participants in this research re-examined their beliefs or expectations, the act of creating new photographic images allowed the participants to think more critically about the media representations of women with physical disabilities. One participant, Katherine, made it clear throughout the process of designing and taking the photographs that she did not want her photographs to come across as weak. Her goal was to construct images of strength because she was tired of the pitying or victim stereotype that is so prevalent in the media.

Drawing on the use of children-centered visual research methods in Irish primary schools, White, Bushin, Carpena-Mendez and Laoire (2010) wrote an article entitled “Using Visual Methodologies to Explore Contemporary Irish Childhoods”. This paper compared the use of artwork and photography as visual research methods and looked at the theoretical framework within which data is produced and made meaningful. By drawing and taking photographs, the children in this study took some control over the research process and prioritized issues that an adult researcher might have seen as irrelevant.

Part of the reason I included photography in this research project was to provide a space for the participants to construct their own photographic representations. By designing their own representations, the participants became more involved in the research process and how they wanted to be seen. Using this method, I found that many
of the participants highlighted topics and issues that I, as the researcher, might have considered unimportant. For example, both Mary and Sophia were mainly concerned with taking a portrait of themselves. They wanted at least one photograph where their disability was not the focus, but simply one piece of “a nice portrait.”

Methods

Focus groups.

The focus group is often seen as secondary to other, more established, forms of research and academic study (Jowett & O’Toole, 2006). However, as a research method, the focus group can potentially open up a space for more detailed discussions of people’s thoughts and ideas, especially with regard to the social and cultural world.

Focus groups have much in common with the consciousness-raising groups that were a mainstay of the women’s movement in the 1960’s and 1970’s (Montell, 1999). Consciousness-raising is a feminist method that strikes at the heart of the women’s movement because it allows for the discussion of personal experiences and empowerment. The main difference between consciousness-raising groups and focus groups is that consciousness-raising groups are usually leaderless and meet frequently over an extended period of time. Focus groups, on the other hand, generally have a clear leader and may meet only once (Montell, 1999). Based on this definition, I held a focus group with consciousness-raising potential. The participants met only once, and I was the “facilitator” during the session. However, I attempted to create more of a consciousness-raising environment by encouraging the participants to discuss personal experiences in relation to the representations. I also exposed the participants to
representations they had never seen before and encouraged them to think critically about those representations.

Mies (1983, as cited in Montell, 1999), argued that a shift from personal interviews to group discussions allows feminists to gather more diverse data and helps women overcome structural isolation. Group discussion can also help women understand the social causes and shared nature of their oppression (Montell, 1999). As a group, people with disabilities tend to be segregated, not only from nondisabled people, but also from each other. As mentioned previously, due to the categorization of disabilities in the medical community, it is extremely difficult for people with disabilities to form a community. Thus, it became important in this research for the participants to meet face-to-face and discuss the representations as a group.

The focus group conversations enabled the participants in my study to gain insights into the oppressions and social situations of women with disabilities (Goss & Leinbach, n.d., as cited in Montell, 1999). They learned to look more critically at the representations they see in their day-to-day lives. As one participant, named Laura, commented, “I never thought about that….I never even thought about that.” Another participant, Mary, also remarked: “I had never seen any of these…books or anything. I’ll have to do some searching!”

Along with the positives, there are negatives to focus groups. According to Staveren (1997), the group atmosphere can sometimes inhibit trust and affect confidentiality. This meant I had to establish ground rules before the focus group began. In the consent form, which was sent to each participant, I stated that while I, as the researcher, am bound by ethical standards regarding anonymity and confidentiality,
information could potentially be discussed by members of the focus group outside the meeting space. I emphasized the importance of the participants maintaining confidentiality of what took place in the focus group. I am not aware of any discussions occurring outside the focus group, but that does not mean they did not happen.

Before the focus group, I had feared some participants' contributions might get lost in the wider debate going on within the group. There was a real danger that a participant could get censored, either by another participant or by holding back what she wanted to say in order to conform to a perceived consensus. A risk also existed wherein a particular participant could self-appoint herself as an "expert" within the group and try to coerce others to agree with her point of view. Finally, there was also a chance that participants would exaggerate what they said in order to impress others, or for "peace-makers" to want to try and create a mutual agreement within the group (Jowett & O’Toole, 2006). Since one of the goals of the focus group was to illuminate contrasting opinions and experiences, as well as provide a space for commonality and shared feelings, these possible hindrances could affect the information gathered.

While some participants were certainly more outgoing and talkative than others, there seemed to be no censorship or silencing among the women during the focus group. The participants also seemed quite comfortable having differing opinions on some of the representations we analyzed, and interesting debates occurred around certain topics. However, it is entirely possible that some participants may have remained silent, at times, out of a fear that they were not as informed on a subject as others, or because they were simply not comfortable in the group setting. This was one of the reasons I chose to
conduct an online questionnaire. The questionnaire gave the participants the chance to speak up in a more private manner.

The difficulties of transcription.

Scholars have recently begun to call the act of transcription – writing a verbal interview onto paper – into question. These scholars question the notion that a transcript is a “truthful replication of some objective reality” (Tilley, 2003, p. 751). Instead, as Green, Franquiz and Dixon (1997, as cited in Tilley, 2003) state: “a transcription is a text that ‘re’-presents an event; it is not the event itself” (p. 751).

When a researcher attempts to write verbal exchanges onto paper, claims Poland (1995, as cited in Tilley, 2003), the result is an immediate deterioration and loss of the context and emotional dynamics of the encounter. Some researchers, me included, when going back over their transcriptions, find discrepancies between their memories of the interviews and what was written in the transcript. This is because the transcript lacks the vocal quality and body language that was present during the interview (Anderson & Jack, 1998). Deciding where to put a comma, or a period, when someone is speaking becomes a judgment call (Tilley, 2003).

One possible way to combat this problem is to review the tapes while following the transcription in order to make notes about tone and vocal intensity, as well as correct the accuracy of the words (Tilley, 2003). Before I began this process, I had reservations about the process of transcription because I am hard of hearing. To account for this, I used two tape recorders, one at each end of the table, and a video camera. The video camera provided me the ability to read lips and gather data about body language during the focus group. I worried the video camera might make the participants self-conscious.
or uncomfortable so I positioned it in a discreet location. Within a moment or two, it seemed to me that the camera had all but disappeared from their thoughts. However, even with careful preparation and technology, there were still a few words I could not make out due to my hearing impairment.

Additionally, there was a discrepancy between my memory and the transcriptions. Following the focus group, I was certain the participants had been upset about a representation of disability by a woman who did not actually have a disability. But when I looked back over the transcription, and watched the video tape, there was no reaction at all to the nondisabled woman “pretending” to be disabled. It surprised me that my memory of events was different from the actual events and showed the importance of using technology in focus groups and interviews. Without audio, and video, I might have imposed my own perspectives on the research.

I would also like to take a moment to talk briefly about the length of time transcription can take. This was not something I had been expecting. Even using software designed for transcription, it took months to transcribe the entire focus group. Ten minutes of audio took approximately an hour and a half for me to transcribe. Transcribing also made me acutely aware of how my hearing impairment was a hindrance in this type of situation and I became resentful of the entire transcription process. This led me to avoid transcribing, which lengthened the time it took to complete the process overall.

The reason I transcribed the focus group by myself was to avoid possible errors or omissions others might make, and to save money. I worried someone else might misinterpret the tone of a participant and decided, since I was present during the focus
group, that I would remember the details. I realize now I should have hired someone to
do the transcribing anyway. Once they were done, I could have listened to the audio,
while reading the transcription, and corrected any mistakes I came across. This would
have saved me a great deal of time and frustration.

**Photo elicitation.**

Photo elicitation is the insertion of images into interviews to provide a more in-
depth conversation (Auken, Frisvoll, & Stewart, 2010). The term was first coined in a
paper published by photographer and researcher John Collier, a member of a Cornell
University’s multi-disciplinary research team, examining mental health in changing
communities in the Canadian Maritime Provinces (Harper, 2002).

Harper (2002) argued that images evoke deeper elements of human consciousness
than words. More specifically, Harper argues that words alone use less brain capacity
than processing images and words together. Visual methods of research facilitates layers
of investigation (Gauntlett, 2007 as cited in Bagnoli, 2009) and allows “a creative way of
interviewing that is responsive to participants’ own meanings and associations” (Bagnoli,
2009, p. 547).

According to Auken, Frisvoll, and Stewart (2010), there are two types of photo-
elicitation: externally driven and participant-driven. In externally driven photo-
elicitation, participants are asked to analyze or discuss images that have been preselected
by researchers. Since the researcher controls this method, it is often considered to be
close-ended and top-down. Participant-driven photo elicitation, on the other hand, lets
the participants choose the images that become the foundation of the interview. This
method allows photo-elicitation to break down barriers between researchers and participants, allowing participants to be more involved in data generation.

For this research project, I chose to use externally driven photo elicitation. Although it has aspects that could be considered problematic, I felt it was the best fit for this research because of the way I organized the images for the focus group. Instead of a random selection of images, I organized the visual materials into sections. First, as a group, we discussed stereotypes about people with physical disabilities. Then we analyzed images of people with disabilities in fine art, television shows, fashion photography, and so forth. I then asked the participants to provide, verbally, examples of women with disabilities they had seen in the media. I posed this question at the beginning of the focus group and, again, at the end. Both times, participants provided numerous examples of representations they had encountered, some of which were then used in the online questionnaire I distributed.

My selection of imagery for the photo elicitation required a great deal of online research, which I go into in more detail at the end of this chapter. Because women with disabilities are so rarely shown in the media, it was challenging to find enough examples for the focus group. In the end, I showed participants photographic images, television screenshots, advertisements, commercials, and video clips of women with disabilities found in the media. The end goal was to facilitate discussions about these representations. At this point, it is important to note that many of the representations shown contained words or text that added complex layers to the different representations. When it comes to media, what is said and how it is said becomes just as important as what is seen and how it is seen.
Methods of Analysis

There are many types of qualitative data analysis. However, due to the diverse nature of this research, I did not feel one specific data analysis method was adequate. Instead, I have utilized components from several types of qualitative data analyses for the discussion section. This is known as a mixed method (Schutt, 2012).

First and foremost, I take the position that texts are interpretative and can never be deemed absolutely "true" or "false." Because researchers come from a variety of backgrounds, the potential exists for multiple interpretations of the same text. This is considered a hermeneutic approach (Patton, 2002). Thus, the text in this research, and my interpretation of that text, is one possible viewpoint among many (Schutt, 2012).

Second, this research attempts to maintain a primarily emic focus through ongoing collaboration with participants. An emic focus is one where the research and interpretations are represented in terms of the participants and their viewpoints. In contrast, an etic focus means that the participants are represented in terms put forward by the researcher (Schutt, 2012). Instead of removing myself completely from the research or silencing the participants, I chose to incorporate a more conversational method of analysis and interpretation. This involved a back and forth exchange between myself and the participants, with a focus on making sure everyone’s viewpoints – including my own – were included in the research.

Throughout the research process, I kept notes on all the interactions I had with the participants. I regularly reviewed these notes alongside the original texts and transcripts, and looked for reoccurring concepts. When it came time to analyze the texts in more depth, I incorporated aspects of narrative analysis by attempting to preserve the personal
experiences and stories of the participants (Riessman, 2002). I read through the texts multiple times, each time making notes of common themes mentioned by the participants. The goal was to critically analyze the representations of women with disabilities that currently exist in the media through the inclusion of the participants’ observations and stories (Schutt, 2012). I then tied those themes into the theories discussed in the literature review of this thesis.

Research Design

I now offer a brief summary of the methods used in this research, followed by an explanation of each method. I began by conducting a focus group with six women. I then held an informal one-on-one meeting with each participant to discuss the construction of her photographic images. Following that, I worked with each participant to create the photographic images, and, finally, I involved the participants in the writing of the thesis by asking for their input on Chapter Four: Discussion.

My initial goal was to find up to ten female participants who would be willing and available to take part in the focus group. The criteria I established to decide who to include in my research were as follows: the participants must be female, over the age of consent in Canada (i.e., 18 years of age or older), identify as physically disabled, and located in Atlantic Canada. I stipulated that the physical disability must be visible because a non-visible physical disability may not affect a woman’s view of her body (or her identity) in the same way as a visible physical disability. I allowed the participants to self-identify as visibly physically disabled, instead of forcing definitions on them as to what I considered to be a visible physical disability. As Sutherland (as cited in Shapiro, 76
2004), stated: “it is for people with disabilities to decide how we chose to define ourselves, and few of us choose to do so according to the prejudices of people who consider themselves ablebodied” (p. 48).

I had some concerns that I would not be able to find enough participants to make the focus group worthwhile because I did not know how to reach the disabled community. As previously discussed, the disabled community is not as cohesive as it could be and reaching out to a subset of the disability community was even more difficult. I started by designing posters and invitations about the research project. These posters and invitations gave a brief overview of the research topic and provided my contact information. I then sent these posters and invitations to disability organizations across New Brunswick and Nova Scotia. I also emailed them to everyone I knew. From this first wave of emails, I received three responses. Of these responses, one woman agreed to be part of the project.

Next, I took a slightly different route. I contacted the local university newspapers to see if they might help me. The Aquinian, the St. Thomas University (STU) newspaper, and the Brunswickan, the University of New Brunswick (UNB) newspaper, ran a story on my research and me. Each article ended with a request to contact me if anyone wanted to participate. Using this strategy, I received four responses, of which only one panned out. However, at about the same time, a friend told me that she had been discussing my work with a woman she knew who had expressed interest in participating. My thesis supervisor also gave me the names of two possible participants. I contacted them all and each agreed to participate.
I now had five participants but still needed more. So, I emailed the posters and invitations to all the disability organizations once again and I put a write-up in “Art News,” a weekly email newsletter sent to the Fredericton art community. I also created an “edaily,” a daily digital email sent to the entire UNB community. From this second wave of communications, I received two more participants, for a total of seven. By this point, many months had passed and I needed to move onto the next stage of the research.

Once the participants had confirmed their availability, I emailed each of them a detailed sheet outlining the research as well as a consent form. I asked each participant to sign the consent form and either email it back to me or we could make arrangements to meet in person. Three participants emailed the form back to me; the other four gave it to me in person. I then went about selecting a location for the focus group. The room had to be wired for a projector and completely accessible. It also had to be near accessible parking and accessible bathrooms. My thesis supervisor helped me select a room on the UNB Fredericton campus that fit all these needs. I then had to select a day and time. To find a time when everyone was free, I used an online website called “Doodle” where you provided a list of days and times and individuals marked off whether they were available. Unfortunately, once everyone had submitted their availability, I discovered that one of the participants was not available for any of the days/times I had proposed due to a new job. In the end, I had only six participants for the focus group.

Once the focus group was arranged, I searched for images and video clips to show during the focus group. I used Google Image Search and Google Web Search to find my sources; they included images as well as video clips. The representations shown during the focus group included advertisements, fashion spreads, fine art images, television and
movie video clips, charity ad campaign posters, ebooks, and digital excerpts from print publications.

Once I had selected the images I wanted to use, I emailed each participant a list of questions and web links, including web links to video clips and photographic images. This gave the participants a chance to view the representations and formulate their responses without the pressure that comes from on-the-spot questioning (Hand, 2003). Several of the participants said they were glad they viewed the selected representations ahead of time as it helped them think about their responses and their own experiences as women with disabilities.

During the focus group, I used a PowerPoint slideshow to present the images to the participants. A detailed list of the images and video clips shown during the focus group is included in Appendix A. After each image or video clip was presented, I asked the following questions:

- How do you feel about this representation?
- Do or do you not relate to this representation? Why or why not?
- Is there anything you would change about this representation? Why or why not?

During the focus group, I allowed conversations to follow whatever path the participants chose to take. I did not redirect them back to the topic at hand when they went on tangents because I wanted the discussions to be open and free flowing. If the presence of an image encouraged the participants to deviate into a conversation on super heroines and disabilities, for example, that was a critical aspect of the research. The pathways and connections our minds make is just as important as the final destination.
also encouraged the participants to ask questions or offer other examples of representations of women with disabilities throughout the focus group.

Following the focus group, I moved onto the photographic stage of the research project. I met informally with each participant at her own convenience to discuss how she wanted to be represented in her photographs. The informal meetings occurred at local cafes. Each participant could create two photographs. We began the informal one-on-one meetings by discussing the first photograph.

As I mentioned previously, the first photograph was to be constructed entirely by each individual participant. It was her message and her voice about being a woman with a physical disability. I took the photograph and assisted in helping to create a “look” or “ambience” that best expressed the message about disability that the participant was after. I did not provide any suggestions to the participants for this photograph, even when asked directly, because I did not want to bias the participant’s message. Once the message for the first photograph was selected, we moved to the second photograph.

The theme I chose for the second photograph was fantasy or “make-believe.” I chose this theme because I wanted to play on the idea that only in a fantasy world could a woman with a disability control her own representation. The participants and I designed this photograph together during the informal one-on-one meetings. I started by asking each participant if she had a favourite or beloved fairy tale, fantasy, or sci-fi story as a child, teenager, or adult. If she could not think of anything, I probed with additional questions. I asked if she had a favourite story growing up; what she wanted to be, as a child, when she grew up; and, if there were any fairy tales or fantasies she disliked. Eventually, a story was formulated for each participant. From there we worked together
to design a photograph tailored to the story of that particular participant, but still under the theme of fantasy.

After the informal one-on-one meetings with each participant, I scheduled photoshoots. Grace had her first photoshoot in my own studio located in the lower level of my apartment. Her second photoshoot was held outdoors at a local place. Katherine, Mary, and Charlotte had both of their photoshoots in the student photography studio at UNB. Laura’s first photoshoot took place in my own studio located in my apartment. For her second photoshoot, I, once again, ventured to an outdoor location in town.

While the photographs were relatively problem-free, there were some issues. The first, and most troublesome, was the regular attempts by participants to have me make decisions for them about the photographs. During the design stage, when I met informally with each participant to plan out the photographs and decide on a message, all participants repeatedly asked what I thought they should do for their first photograph. Every time, I turned the question back to the participant and inquired, “What do you think you should do?” If they persisted, I explained that the first photograph was meant to be designed by them, and I repeated the question: “How would you like to be represented?” I believe this eagerness for my guidance stemmed from the participants’ knowledge of my professional photography background, and a desire to try and give me what they thought I wanted. Eventually, each participant was able to create her own design for the first photograph.

But the problem of asking for my help did not stop at the design stage. During the photoshoots themselves, the participants consistently asked me how they should pose, where they should look, and what they should do. No matter how many times I told them
it was up to them and encouraged them to position themselves in whatever way they wished, I could tell they were unsure of what to do. I also tried my best to not take control of the photographs but it was unavoidable. For example, while I let the participants pose themselves and construct the representations, I chose the angles, the focal lengths, the zoom, the lighting setups, and so on. Following the photoshoots, in an effort to give the participants more control over the new photographic images, I sent each participant five to 12 photographic proofs. I then asked each participant to select two images from the proofs.

Looking back, for the first photograph, I should have given the camera to the participants and told them to take the pictures themselves. Doing so may have helped to alleviate some of their deferrals to my “expertise” and given them more control over the first photograph.

I chose to take the photographs myself because I believed it was important to maintain a shared involvement in the photography section of the research, but I am no longer sure if that was necessary. I have begun to wonder if my desire to be involved, and share in the construction of the images, clouded my judgment about how the photography component should have been conducted. However, I still believe the second image was best photographed by me because, while it was tailored to the specific interests, experiences, and life stories of each participant, the overarching theme was my design. The first image, however, may have benefited from a different approach.

After all the photoshoots had been completed, I selected the best images to present to the participants⁸. There were hundreds of images so it was necessary to narrow

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⁸ Images were deemed to be “the best” if they fit several criteria, established by me. First, the participant could not be blinking or talking during the shot. Second, the image had to be in focus and
down the selection for the participants; otherwise they would have been overwhelmed with the options. Once I had a selection of five to twelve images for each participant, I emailed them an invitation to a website called Dropbox, where low resolution samples of the images were stored in individual folders. The participants were only able to see their own photographs. Once I sent the invitation to view the photographs, I asked the participants to select their favourite two images from each photoshoot. The participants then selected their images. I worked on editing these selected photographs (i.e. adjusting colour, lighting, contrast, etc.) and sent the final images to the participants for final approval. Once each participant had given final approval of her photographs, I included them in the thesis.

During the approval process, I also created an online questionnaire. I designed the questionnaire from scratch using LimeSurvey and hosted it on my own website (www.stillwatters.net). A detailed list of the images, video clips, and questions included in the questionnaire is located in Appendix B. The online questionnaire was sent to all the participants as well as to individuals who had wanted to take part in the focus group but were unavailable. I received twelve responses to the questionnaire; four filled out the entire questionnaire while six answered one to five questions out of thirty. Of the four who filled out the entire questionnaire, three were participants from the focus group and one was an anonymous person. The remaining six responses were anonymous and only partially filled out.

corrected exposed. Third, the image had to closely match the message the participant had expressed to me previously. Fourth, the composition of the image had to be appealing or interesting in some way.
Originally, I had wanted to hold a second focus group to analyze the new photographic images that were created, but was unable due to time constraints. I had also planned to present each participant with multiple drafts of the thesis as it was being written but found this impossible within the time limits I had set. Instead, I sent the participants the discussion and conclusion sections of the research once it had been drafted, but not finalized. When I sent these sections, I encouraged the participants to look over my interpretations and provide feedback. If they disagreed with an interpretation, their feedback was then incorporated into the interpretation in the thesis. I wanted to ensure that I did not speak for the participants, but with them. If there was a disagreement between a participant and me, about an interpretation(s), I included her feedback along with my original interpretation. This was done to give the participants and me, the researcher, equal footing in the research process.

Ethical Concerns

Speaking for others.

An issue present in many qualitative studies is that of speaking for or about participants, instead of speaking with them. But is it possible for researchers to interpret information gathered from interviews and focus groups without “othering,” exploiting, or silencing participants (Finley, 2005)? One solution offered by researchers has been to declare that they are speaking only for themselves. But this tactic avoids taking responsibility and accountability for the researcher’s effect on the study, and does nothing to erase those effects; they are simply ignored or hidden away (Alcoff, 2008).
Another possible solution is to maintain regular contact with participants throughout the research and to involve them in the research as well as in the analysis. A potential problem with this method, however, could arise if a participant disagrees with a researcher's interpretation. What does a researcher do in this instance – erase their own interpretation, or keep it and risk silencing a participant? After much deliberation, I decided that if a participant disagreed with an interpretation I made, I would include a statement noting the disagreement by the participant and explaining why they disagreed. I decided not to erase my interpretation because my voice as the researcher also has value. In this way, the participants and I are both heard in the research.

For Montell (1999), there is a problem with treating participants as “experts” because they may not be fully conscious of the forces acting upon them, or they may be unable to fully articulate their reaction to those forces. This is not to say that the researcher is more of an expert, but simply that the inclusion of knowledge from both the researcher and the participant is important. While it is critical that the voice of the researcher does not overshadow that of the participant, it is also not fair for the researcher to remain completely silent. Researchers and participants should work together, in partnership, to develop in-depth discussions within the research (Greenbank, 2002).

During the research process, I discovered that the participants were far more aware of the complexities inherent in the representations of women with disabilities than I had assumed they would be. They were also all more than capable of articulating their reactions throughout the process. The only time I noticed a struggle among the participants was when they came up against representations they could not easily categorize into “good” or “bad.” When faced with representations that they felt had both
positive and negative components, many of the participants had a difficult time articulating how they felt about the representations. What resulted was a back and forth discussion with several participants voicing contradictory views on the representations. Our conversations opened up all of our minds about the complexities of the representations of women with physical disabilities in the media.

**Anonymity.**

Due to the inclusion of photographic images, it was impossible to maintain complete anonymity. All of the participants were made aware of this concern in the project description, which was sent to each participant as soon as they expressed interest in participating. The full project description can be found in Appendix H.

Once a participant confirmed availability and consented to participate, they were assigned a pseudonym, which was used in place of their actual name throughout the written text. Additionally, in an attempt to preserve privacy, no names – not even the pseudonyms – were attached to the photographs. I also avoided any detailed descriptions of the participant’s disabilities because I did not want the viewer/reader to be able to connect the photographic images to a participant via the description of a disability.

**Researcher/participant relations.**

Throughout the research project, the issue of my association with the participants came up repeatedly. For instance, one of the participants was an acquaintance of mine prior to being part of this research. I was told she wanted to participate through a mutual friend. Throughout the focus group and construction of photographic images, I had to be careful not to exploit my position as her acquaintance/friend and ensure that I did not
include information that was told to me as a friend, and only include what was said to me as a researcher.

Another problem I ran into was that several participants wanted to add me as a "friend" on social media sites after the focus group. While this may not concern some researchers, I had reservations. While I think it is wonderful to become friends with participants, I realized if I added them to my social networks, I would have to be fully aware of what I was posting – especially if my posts were related to my thesis. However, I also realized not accepting their friend request could be viewed as an insult by the participant. In the end, I accepted the Facebook friend request a participant sent to me and “followed” the two participants who had previously followed me on Twitter. I also made a concerted effort for the rest of the research process to avoid any discussion of the thesis on these sites.
CHAPTER FOUR: COMPLEXITIES AND CONTRADICTIONS

In this chapter, I look at the topics that came out of the focus group, online questionnaire, and individual responses. After reviewing the texts and my field notes, I found three overarching themes within the research: the sexualization of the female disabled body; the complexities of representing women with disabilities; and the invisibility and hypervisibility of the disabled female body.

Disability and Sexual/ized Bodies

The issue of sexualization and exploitation of the female body came up repeatedly during the focus group, and in response to the online questionnaire. As I stated previously, when an individual has a disability, they are often denied a sexuality (Lloyd, 2001); they are not seen as viable sexual partners because of their disability (Zitzelbsgerger, 2005). This makes the issue of sexual objectification much more complicated for women with disabilities.

Before I began the focus group, I had no idea how the participants would respond to the images and I was not sure if they would bring up the subject of sexuality at all. I need not have worried. The subject was prominent among all the participants. Within the first five minutes Sophia raised the question of sexuality and women with disabilities:

Sophia: It’s—in effect though, it’s a person with a disability cannot have, you know, a meaningful life—

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9 For the sake of clarity, I would like to explain some of the ways I denoted pauses and abrupt stops when transcribing the focus group discussions. When a participant trailed off, or paused, during a sentence, I used three periods to imply a pause of a second or more. When a participant abruptly ended a sentence or changed what she was saying mid-sentence or mid-word, I used an em dash.
Mary: Yeah.

Sophia: —which typically would include having a family, you know, employment, um, those types of things. One of the biggest ones that I've seen from the healthcare perspective is that, you know, a woman with a disability, um, cannot, you know, have a sex life. That's a big one that exists.

Grace: Some of us don't have one anyway.

Sophia: I'm — but I'm saying it's very pronounced.

Grace: You're right.

An interesting component that came out of the discussion on sexuality and disability was the difference of opinion between the younger and older participants. The younger participants, Laura, Charlotte, and Katherine — who were all under the age of thirty — agreed that sexualized representations of women with disabilities made them feel included and desirable; they liked the idea of being seen as a sexual woman. However, the other participants, Grace, Mary, and Sophia — all over the age of thirty — seemed conflicted. This tension was evident when we looked at two images from Marlene LeRoux's book, Look at Me, a collection of photographs of women with physical disabilities:

Mary: Well, the book, you said it was about sensuality or something, so they have to be dressed like this, for the book, but they could have a suit on or a lab coat or...

Grace: I mean, they're beautifully...posed and they wouldn't really...if you look from the waist up, this woman wouldn't look any different from what you might see in a Vogue magazine, right? And so I think they've done an amazing job making that woman look incredibly sexy, with whatever her disability happens to be.

Mary: I guess if she had clothes on you wouldn't be able to see her leg.

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10 The first image is of a woman leaning against a white brick wall wearing a revealing one-piece bathing suit and a leg brace. She is looking directly into the camera. This image was used as the cover of the book. The second image is of a woman sitting on a large rock, with her legs splayed open and her hands clasped together in front of her crotch area. There is a blue sky behind her and she is also looking into the camera. She has a prosthetic leg and appears to only be wearing a black blouse.
Grace: Right.

Sophia: I guess it does say —women with disabilities can be sexual beings.

[multiple participants make "mmmm" noise]

Laura: That's what I like about it, is that it's portraying them as sexual beings, even though in the media, women in general are portrayed as sexual, like, sexualized or demeaned or whatever, like, that's not a positive thing but it's kinda like taking women with disabilities and saying, like, you know, we can be really sexy too but like we had said before —the double edged sword, eh —like over sexualized but at the same time...

On the one hand, Grace, Mary, and Sophia, expressed a desire to cover up the woman’s body as they felt it was too revealing, while Laura and several of the other younger participants enjoyed the images because they liked that a woman with a disability was being shown in a sexy manner. Yet, at the same time, whenever a younger participant praised the revealing images, Grace, Mary, and Sophia all agreed that the women were sexy.

Another image that sparked a discussion about sexual objectification and women with disabilities was that of a woman in a bra, looking at the camera, with the lower half of one arm missing. The caption read, “Look me in the eyes...I said the eyes.” It was made for a campaign by a Belgian disability awareness organization called CAP48. Once again, Laura, Katherine, and Charlotte all seemed quite fond of the image, while Grace, Mary, and Sophia appeared bothered by the amount of skin shown:

Laura: I like that. [laughs]

Me: And it reads, "Look me in the eyes," dot dot dot, "I said the eyes."

Laura: Yeah, she looks happy and empowered to me.

Charlotte: Yeah.

Mary: Couldn't she have a shirt on though?
Katherine: But they’re—they’re—

Mary: Are they talking about look me in the eyes, like, don't look at my boobs?

Sophia: That's what I wondered!

Grace: Yeah.

Katherine: Yeah, well, that's—that's—that's what they're playing off of.

Mary: Yeah, I know but—

Grace: Couldn't she have a shirt on?

Mary: —she could also have a shirt on, and still say, you know, 'look at me in the eyes,' because people do stare, right?

Katherine: Yep.

Grace: mm hmm.

Katherine: Well, it's both, like they're—they're showing the woman as multi-faceted, right, she's a woman, so there's the sexuality, the gender, the blondeness, the—you know what I mean, right? I don't need to walk you through it.

[Mary nods]

Sophia: Yeah, I'd still like to see her in a shirt.

Once again, the fact that the model wore nothing but a bra seemed to bother Grace, Mary, and Sophia. The objection, for Sophia at least, seemed to stem from the question of whether it was necessary for the model to wear a bra. Sophia believed that this image would have been just as sexy if the woman had been in a shirt but Katherine responded that she felt this type of image presented the model as multi-faceted woman because she was sexual/desirable, feminine, and disabled.

I first noticed the differing opinions about the sexualization of women with disabilities’ bodies when I was transcribing the focus group discussions and I wondered
what the reason was behind it. One theory I had was that the participants over the age of thirty may have had more experiences or stronger connections to second wave feminism, which fought against the sexual objectification of women in the media and the public sphere (Krolokke & Sorsensen, 2006). Another possibility could be that the participants over thirty may not have felt these sexualized representations related to them because they were all younger models. Mature women tend to be underrepresented in the media, and when they do appear, they are often inaccurately portrayed as “past the most useful and important stages of life” (Miller & Simeth, 2007, p. 50). It would have been interesting to find out if the participants over thirty would have reacted more favourably to mature models in sexualized poses, or if their feelings would have remained the same.

Later in the focus group, I asked the participants to respond to two images\(^\text{11}\) from a reality BBC Channel Three television show called *Britain’s Missing Top Model*, where women, under twenty-four, with disabilities compete to become a model. Again, the participants raised the issue of objectification, but this time it was connected to the idea that even when disability is used sexually in the media, it still tends to uphold the stereotypical ideals of beauty. Grace commented:

> The only thing I might add is, statistically in Canada, 17% of the population has some form of disability and yet the only women in the media that you see who are profiled who have a disability, are these gorgeous women that are multi-talented and could be anything...they're never ordinary — to me — never ordinary people, as you say 'living their lives' — real, real people. It seems like if you have a disability, that's ok as long as you're 30, very attractive, preferably blonde, have

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\(^{11}\) The first image was from a promotional shot for the show. It shows six of the contestants together against a black velvet curtain that's draped behind them and under them. All of the women are wearing pink dresses and high heels. Four of the women are standing, two are sitting; all are looking into the camera. The second image is of the winner of the competition. It is a Caucasian woman in a fitted black dress with an arm that ends just below the elbow. She is looking into the camera and holding the ruffle of her sleeve over her chin in a coy manner.
long legs —ya know, really —so, the stereotypes aren’t any different to me than the stereotypical idea that they try to put forward about women anyway.

Grace made an important point in her comment, one that, I think, needs to be considered more deeply. After viewing several of the images, Grace came to an important realization that she shared with the group. For Grace, the only female disabled bodies that were deemed acceptable in the media were the ones that came as close to being nondisabled as possible. In other words, the closer a woman with a physical disability comes to the cultural body ideal of a woman, the more acceptable and desirable she is considered.

Following a short discussion among the participants, Grace continued with the idea that even when disabled, women still have to be as close as possible to what is deemed to be perfection:

Grace and Mary (at the same time): They’re all thin.

[Laura laughs]

Grace: Again, it’s how beautiful you are. Right? I mean, once again, these women are all beautiful.

Katherine: Mm hmmm.

Grace: Right? They’re all beautiful to start with and they may be, you know, missing a limb or in a wheelchair or —and I guess, maybe that’s just advertising, period. They’re only interested in something as close to perfection as possible.

This led directly to a conversation about the supposed importance men put on women to be beautiful. Most participants agreed that the majority of men expect women to be perfect and that, even today, men are not accepting of difference. However, one participant, Katherine, pointed out that women can also be guilty of doing this; women
regularly expect men to be strong and virile, and this expectation is often portrayed in the media:

Mary: I'm sure if I was younger and went into a bar in a wheelchair, nobody would probably even talk to me.

Laura: Do you think it's a generation thing though? Do you think with more—the more awareness of today that men my age might not...

Grace: I think men your age are more accepting of women with imperfections.

Charlotte: Nnnnooo. [said slowly]. I don't think so. They expect the perfect—

Grace: Do they still?

Charlotte: Yeah...

Katherine: I think both sexes expect the perfect image because when you think, you know, in your head of prince charming or whoever—

Laura: That's true.

Katherine: They they don't have, uh, you know, they're tall, dark, and handsome, whatever you picture. [laughs] You know what I mean? That issue of, "oh! right, well I want him to be, you know, bigger than me and I want him to, you know," and if they're — have a deformity or something you're like, "oh, well, can they you know and all that," er, even with like overweight, right? When women are overweight, men don't look at them either, or they fetishize them, same thing with the physical aspects. And the whole expectation of men, they are supposed to be more powerful and stronger, and if he has a disability, you know...it's complicated.

While the participants may not have agreed on the representation of women in images shown, they did agree that the images were not commonplace. The sexualized representations of women with disabilities were not plastered on billboards in Times Square or flashing across television sets. They were hidden away. In one instance, discussed earlier, the images were from a book entitled *Look at Me*. But this book is not readily available; it can only be bought through the website of the publisher, located in South Africa:
Mary: But it's in the book. We never ever see this.

Laura: True.

Mary: The average person would never see this, right?

The discussion of the sexualized female body also led to debates about whether any inclusion was better than none at all. As discussed previously, Garland Thomson (2002) claimed that incorporating disability into fashion or advertising does not lead directly to social progress, but she did feel that inclusion of any kind brought disability into the public sphere and opened up a space for conversation (Garland Thomson, 2005).

Below, Katherine and Laura discuss the complexities of inclusion for women with disabilities:

Katherine: I just think, the more visibility, uhhh, people with disabilities get, the better it is...in general [laughs].

Laura: I mean—

Katherine: Yeah, so I'm for it—

Laura: With mainstream, um, fashion magazines, television, portraying women in a sexualized manner— I don't necessarily believe —like, I don't support, that's - right. But to put women with disabilities, to showcase them similarly as the other women. I think that that's positive. Yeah, that makes sense?

Katherine: Yeah, it's like I don't necessarily believe in the fashion industry but I mean, I think you should be there, if it exists.

Laura and Katherine agreed, in the end, that if an industry existed, people with disabilities should be included, even if not all the representations were beneficial or positive. As a woman with a visible physical disability, I have often struggled with the feminist fight against the sexual objectification of women’s bodies. On the surface, the idea that women should never be sexually objectified without expressed consent seems straightforward. But it becomes more complicated when you are excluded from sexual...
objectification, and sexuality in general, because of your disability. For me, as I mentioned previously, the problem of sexual objectification is not about being viewed as a sexual object per se, but in not being able to control when you are objectified. For me, sexual objectification is not always harmful and oppressive; it is the lack of control over when it occurs that can cause the oppression.

The Complexities of Representation

During the focus group, I began to notice that most of the participants were having difficulty with the representations they were seeing. They seemed to want to be able to label a representation as unequivocally positive or negative, and struggled when faced with images that were not easily categorized. This often led to complex, and contradictory, statements from the participants as they came to terms with the multifaceted nature of the representations they were seeing. When dealing with complex representations that cannot easily be deemed positive or negative, one begins to wonder, how much do you put up with in order to just be seen? If a representation has both positive and negative aspects, should it be appreciated for the positive or challenged for the negative? Is it possible to do both at once?

For the women in this research, the deciding factor on whether an image was deemed "positive” or “negative,” seemed to fall on who had constructed the image. If it was created or organized by people who identified as nondisabled, the participants were not overly fond of the representation. However, if it was found to be designed by people with disabilities, or people connected to others with disabilities, there was a much more positive reaction to the image:
Laura: There’s a show, um, that I’m really into that’s called *Switched at Birth*... Oh gosh, I watch it every week. [laughs] Um, but, um, one of the girls in it, she's hearing impaired and the main act—a lot of the main actors in it either sign or are hearing impaired. And they actually feature different types of hearing impairment within the show. And I thought it—and it’s very funny too. And, um, what I thought was cool was how that they would incorporate, like, their daily routines into the show...like if she would get a text message, her phone would light up or, um, there would be a light when the door was being, like, when there was someone knocking on the door. Or, uh, just, you were seeing that kind of stuff as part of their everyday routine, in a show, so it was kind of, it was really interesting. And, I love it. And they, uh, kind of—not make fun of—but they definitely put a laughing spin on it, and most of them are women.

Charlotte: But, that's a laughing spin. These ones [screenshots from *South Park* and *Family Guy*], it's making them look—it's dehumanizing them, cause I watched-

Laura: In this —yeah—

Charlotte: —I watched *Family Guy*, and I've seen *South Park* quite a few times, and they pretty much dehumanize them with the jokes about their disability-

Laura: That's true. Yeah.

*One minute later...*

Charlotte: Whereas Nikki Payne, it's lighthearted and she's doing it herself and... it's not making her seem...

Katherine: Well, if it's funny then its good [laughs]. I mean, like, uh, because it opens up a conversation, right? It's —somebody will be like “what do you think about that? Do you think that's appropriate?” and the, which is, you know, fine, um, but, uh, but, yeah, I mean, some jokes are pretty tasteless you know what I mean? Like, there's a line where you draw... uh, I dunno.

Mary: Or, I can make jokes about myself-

Katherine: Yeah—

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12 *South Park* and *Family Guy*, both popular cartoons, have characters with disabilities. *Family Guy* has Joe Swanson, a policeman, husband and father in a wheelchair. *South Park* has Timmy, who has a stutter and walks with the help of crutches attached to his arms, and Jimmy, who uses a wheelchair to get around and can only say his name.

13 Nikki Payne is a Canadian comedian and actress. Born with a cleft palate, she is well known for incorporating her lisp into her comedy act.
Mary: —but I don’t know if I can take a stranger making jokes about it.

Charlotte: Yeah, my friends and I, kind of, we make jokes about [clears throat] my seizures or my tumor and it’s just lighthearted because that helps to ease the tension around it, and the stress around the fact that I’m getting sicker and things aren’t going well. So if we joke about it, it’s not always a depressing topic that I just spent two weeks in the hospital.

Katherine: Well, you’re, like, kind of included, right?

Charlotte: Yeah.

Katherine: People tease each other all the time—

Charlotte: Yeah.

Katherine: —so that’s just another part of, ya know, friendship.

Charlotte: It’s not like, with them, someone’s making jokes about them behind their back or the show is poking fun at them but with... the humour it’s kind of the inclusion of the person, and whether it’s dehumanizing or light hearted...

In the discussion above, the participants felt strongly that the person making the joke was the deciding factor in the joke’s acceptability. If a comedian made fun of people with disabilities and was himself or herself disabled, it was permitted and generally considered to be funny. But when someone without a disability made a joke about disabilities, the participants were less impressed. However, it is not always possible to know if the person behind a joke (i.e. the writer, director, or producer) has a disability or knows someone with a disability. I also think it is a slippery slope to declare that one person can joke about disability, but not another.

The secondary factor in the acceptability of disability as laughable was the joke itself. Although participants could not quite articulate what made a joke acceptable, they were all well aware of when a joke went too far.
Another area that sparked a discussion was the stereotype of “the supercrip,” which portrays people with disabilities working to overcome their disabilities in order to accomplish superhuman feats (Garland Thomson, 2001). This stereotype is meant to be an inspiration to those with and without disabilities, but the participants in this study felt the supercrip was a double-edged sword. On one side, the supercrip lets people with disabilities know they can be or do anything, and it also shows nondisabled people that disability does not equal uselessness. On the other side, it can create a sense of failure among those with disabilities who cannot do these superhuman things. As Sophia and Grace explained:

Sophia: I think it's really more of a double-edge sword. I mean, it's good in some respects, um, to have somebody that that young people can look up to and know that it's a possibility. But at the same time, that's a really long shot in terms of a possibility. If you look at, um, if you would look at the amputee population in Canada, the number of people that actually get to have artificial limbs, like that Aimee's wearing in her —in most pictures, or the men are wearing, is next to nil. Um, very few people can actually have them —the money —to be able to purchase those kinds of limbs. So, the possibilities are —aren't as equal for everybody. So, this becomes kind of a downer a too.

Grace: Yeah, I think it almost makes it like one more challenge that you have to overcome...how do you become...how do you look like that? [gestures to projector screen] Become a leader in your sport and an advocate?

Both Sophia and Grace recognized the tensions inherent in the supercrip representation for people with disabilities. On the one hand, supercrips provide positive role models for individuals to look up to; on the other hand, not all people with disabilities have the ability, the finances, or the access to technology to do what a supercrip does. In this sense, the supercrip can sometimes stand as a reminder that not everyone with a disability has the same opportunities.
During the revision period, Katherine asked that I include an additional note about the supercrip, which she felt was missing:

In the discussion on the supercrip, there is something I meant to say that wasn't quite grasped there. An additional nuance, if you will, is that it is more impressive to do certain things when you have a disability but it is nice to have the recognition for it too. For example, stats show that only 25% of work-aged adults with a disability have employment, so if you are one of the 25 that is...you are considered exceptional given the oppression. We have extra hurdles and obstacles for certain things, and so we work harder just to be average. So, you can seem average but you are really a high achiever.

Following this discussion, several participants commented on the assumption (by nondisabled people) that no matter how trivial an act, if a person with a disability is doing it, it is impressive and worthy of admiration and praise:

Katherine: Well, it's just like, um, every other person, there's, ya know, high achievers and, ya know, middle of the road, and there's underachievers...everyone, you know. Um, so, when you have a disability and you're a high achiever, people are like “WHOA!” Like there's this novelty to it, there's this, like, um —so if you're just, you have a disability and you're just, like, average people are still like “WHOA! You're awesome!” You know what I mean?

[laughter]

Charlotte: You've done so much, look at you! Go you!

Laura: Yeah.

Mary: Yeah.

Charlotte: I'm just, ya know, doing what everyone else does...

Katherine: But I think like, I say that too, but at the same time, I still kinda want that recognition, because it's like I spend a lot more time doing things that average people don't do, you know what I mean? It takes me more effort in a way for certain things, uh, to be just average. I mean, if you wanna be —if you want to be awesome, then, you, you know, [laughs] you gotta really [laughs]...you gotta really work for it.

[Laura nods]

Laura: Yes.
Here, Katherine explained how people who identify as nondisabled often give over-the-top praise to people with disabilities for doing everyday things. She pointed out that if a person with a disability is just an average individual, they are often seen as a high achiever because of his/her disability. At the same time, Katherine mentioned that she did not always mind the praise because sometimes it takes more effort to do everyday things, and it’s nice to be recognized. As a woman with a physical disability, I understand the complexities of this situation quite well. When people see my photographs online, without knowing I have a disability, I receive a decent amount of praise. However, as soon as they find out I have a disability, my photographs often become “amazing” or I become “exceptionally gifted.” I actually had someone tell me once that when he saw my work he was pretty impressed, but when he saw I was a photographer with a physical disability, he was “floored” by my abilities and thought my photos were “exceptional, especially considering you’re disabled.” While I take these “compliments” with a grain of salt, I do appreciate it when someone recognizes that certain everyday things take a little more work for me.

As Mairs (n.d., as cited in Rohrer, 2004) stated, “People with whole bodies sometimes mistake cripples for heroes. They forget that I’m doing what they’re doing, only more clumsily” (p. 48).

The sentimental stereotype, which one could argue is the reverse of the supercrip, positions the person with the disability as a victim to be pitied (Barnes, 1992). This representation proved to be another complex topic for the participants. While they did not want to be pitied, they did appreciate the help offered by charities and recognized the importance disability organizations play in the lives of people with disabilities:
Katherine: I don't know, like, there's a lot of, um, there's obviously — ya know—I have a disability, so sometimes I need things, and somebody can notice that I need things without actually me having to say it is kind of nice. But, ah, I don't like being, ya know, pitied, or thinking, “Uuugh, she'll never drive a car cause she can't see oh my god.” [Laura chuckles at Katherine’s motions] It's those sorts of things, but, um, I guess it gets — becomes complicated because, uh, a lot of the disability organizations are, uh, non-profit and fundraise, so, uh, it's kind of a charity. [laughs] So to have the services you sti — you gotta have -play that charity card but appropriately, you don't, you know, it's awkward.

Grace: You're right, you're absolutely right...about non-profits, you know, having to, not glorify the disability, but raise awareness and create sympathy so the people will give money, so that they can just meet the basic needs of whatever their organization is.

Later in the focus group...

Sophia: I think that, to me though, that doesn't necessarily speak to a charity. I think there's lots of great charities out there, but me, as an individual, I don't want people giving me pity [Grace nods and leans back in chair] or thinking that they need to go out of their way to help me. And I'd rather figure out ways and the means to be able to figure out things. [Grace nods again]

Mary: It's nice to have a little help though.

Sophia: It is nice to have help. Yeah...

While all the participants appreciated receiving help, and agreed that charities usually had good intentions, none of them liked being pitied or seen as helpless. In the discussion above, Katherine and Grace subtly point out that charities sometimes resort to exploitative tactics to raise money for disabilities because they’re not well funded. In order to convince others to donate, charities often create sympathy or pity for the person with the disability. The assumption is that this is the best tactic for getting donations. The participants did agree, however, that disability charities and non-profit organizations used young children far too often and that this created a stereotype wherein people with disabilities were seen as childlike and helpless.
This issue came up again when, during the focus group, I played a commercial called “Saboteur,” which shows a woman setting “booby-traps” in a house. The ending reveals that the woman setting the traps is in fact the owner of the house and she has muscular dystrophy. The message conveyed is that muscular dystrophy can attack one’s body at any time without warning. Mary, Grace, Charlotte, and Laura took a moment to discuss the commercial:

Mary: That— that ad's for muscular dystrophy and I've never seen an adult in a muscular dystrophy advertisement, always kids.

Grace: Mm hmm.

Charlotte: It's because disabled adults don't exist in the world, it's always kids. [said with slight sarcastic tone]

Mary: People people ha— feel more pity for the kids.

Charlotte: Yep.

Laura: Yeah.

Mary: They're more helpless, right?

Grace: For sure.

Sophia: But I think what that sets up as well is that we can't do anything on our own. We need to have that charity.

The participants noted that the use of children in charity advertising seems to be a tactic to elicit more pity from the public and raise more money. But it has the potential consequence of stereotyping people with disabilities as helpless and childlike. Sophia then suggested that some charities portray people with disabilities as not being able to take care of themselves, and by doing this, charities become a necessity instead of simply a source of help. For the participants, pity had no place in the act of helping others.
In the midst of this discussion, Charlotte, made a comment about how some charity campaigns seem to want to raise money and awareness in order to “fix” a disability. She explained:

*I — Autism Speak, the group in the States. It’s like a cure beaker, that’s what they call it, and they want to cure everyone with Autism. They want to be able to fix them and make them better, when there’s people on the spectrum who are completely high functioning level on their own. And that’s all they want to do. Just cure people with whatever, um, specifically with, um, mental health or cognitive disabilities, they want to cure them when maybe they don’t want to be cured.

Charlotte’s observation is notable because it ties in with the medical model discussed in a previous chapter. The medical model seeks to cure or fix a disability, which it positions as a flaw. This point of view also suggests that there is no value or happiness in being disabled and that all people with disabilities would choose to be nondisabled if they could. But, as Charlotte points out, not everyone with a disability wants to be “cured.” It is important to recognize that being disabled does not mean one’s life has no value or that happiness cannot come from a disabled life. Indeed, I argue having a disability can be the source of happiness and value.

The stereotype of the villain also entered, albeit briefly, into our conversation. This stereotype shows people with disabilities as cruel and evil, and their evilness is usually directly connected to their different bodies (Shapiro, 2000). The potential consequence of this stereotype is that it can teach people that physical beauty equals purity and goodness, and disability symbolizes evil.

It was actually quite difficult to find examples of women with disabilities for this stereotype. The more common examples were of men. This connects back to the earlier discussion of Haller and Ralph’s article (2006), entitled “Are Disability Images
Advertising Becoming Bold and Daring? An Analysis of Prominent Themes in US and UK Campaigns.” Previously, I said that it seemed men were allowed to transcend bodily ideals and appear in the media as visibly disabled, but women were not. The stereotype of the villain stands as evidence of this theory.

Because of the difficulty in finding examples of women with physical disabilities as villains, I showed an image of Ursula, the sea witch from the Disney cartoon *The Little Mermaid*, who is half woman and half octopus. I also showed a photograph of Freddy Krueger, from the movie series *A Nightmare on Elm Street*, who has a badly burned face, and a photograph of Two-Face from the *Batman* movie series, who also has a badly scarred face. A brief, but interesting, point the participants made was that they did not feel Ursula was disabled; she was simply “deformed.” I found it curious that Katherine, Laura, Grace, and Mary differentiated between a physical disability and a deformity:

Katherine: So she's an octopus, is that a disab—like, I dunno, is that... [laughs]
Laura: I guess.
Grace: She's evil—
Mary: I don't think she has a disability.
Katherine: Yeah, she's just deformed.
Laura: Yeah, a deformity.

Following this exchange, the participants did not clarify what made a disability different from a deformity. If I had caught these comments during the focus group, I would have asked follow-up questions, but due to my hearing impairment I did not notice the comments until the transcription process. Based on the comments above, it seems that some of the participants saw disability as a physical limitation, whereas deformity,
for them, implied a physical difference, like a scar. I have come across this distinction before in disability communities and groups, where individuals disagree on what falls under the label of “disabled.”

In the focus group, the villain stereotype was not discussed in much depth. I attribute this to the fact that most of the representations I showed were men. So, for the online questionnaire, I took the time to find additional examples of women with physical disabilities who were villains. In the end I was able to find two new representations. One was a character named Venom from a popular online web series, called *The Guild.*

This character uses her disability, being in a wheelchair, to her advantage and manipulates those around to get what she wants. The other example I found was a character from the children’s cartoon, *Captain Planet and the Planeteers.* In this cartoon, there is a villain named Dr. Blight who has a large scar across her face.

In the online questionnaire, Laura, Mary, and Katherine made the following comments about the villain named Venom from the web series, *The Guild:*

Laura: Honestly, in movies and on television, people of all ethnicities and bother [sic] genders are portrayed as both good and evil so I do not think portraying a woman with a disability as the villain is wrong or any different. If anything it is a good portrayal because it shows anyone can be wrong or evil.

Mary: She uses her disability to get to the head of the line and into the store. She should be wanting to be treated like an equal and wait in line with everyone else. She plays on the pity of the store clerk for her because of her disability. By the guy saying she was “hot”, I feel that it is a stereotypical thing to happen in the movies or on tv for any hot individual.

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14 *The Guild* is an American comedy web series. It premiered on YouTube on July 27, 2007. The show revolves around the lives of a gamers’ online guild, The Knights of Good, who play countless hours of a fantasy MMORPG video game entitled *The Game.*

15 *Captain Planet and the Planeteers* is an American animated environmentalist television program. In the cartoon, a group of teenagers work together to encourage environmentally responsible behaviour and can summon a superhero (Captain Planet) to deal with ecological disasters.

16 All the responses from the online questionnaire have been written verbatim. I did not edit or alter any of the answers, including punctuation and grammar.
Katherine: I don't like how I feel when I watch this, I mean I get it's a villain and I
am not suppose to like it but it rubs me the wrong way, that doesn't happen in real
life and pointing that out like its some advantage is disgusting. Interesting they
get a person who has a disability to play a person with a disability though.

The first example clearly touched on a sensitive subject for Mary and Katherine.
It seemed the "realness" of the character and her "evil acts" made an impact on these
participants and they were bothered by the fact that Venom used her disability to get
ahead in the situation. I think it is worth noting, however, that Laura, one of the younger
participants, saw the representation as an uplifting one. She liked the portrayal of the
woman with a disability being evil because it showed that people with disabilities can be
"bad," just like everyone else.

The second example, Dr. Blight from the children's cartoon, Captain Planet,
brought about different comments from the participants in the online questionnaire:

Laura: it is kind of strange that you do not know the origin of her scar and that she
hides it considering she talks so confidently about herself.

Mary: Her disability/disfiguring scar makes her look scary to kids watching the
cartoon. Since these kids see her with a disability scary they would see disability
in their real life scary too

Katherine: this does not offend me I mean I think nothing of it, a scar to me is not
a disability, but it is such a cliché that villains have scars.

The participants had quite different opinions on this representation. Katherine
mentioned that she does not see a scar as a disability; to her, it is simply a scar and
nothing more. Because of this, she wasn't offended by this representation. Laura felt it
was odd that Dr. Blight would talk so confidently about herself in the video clip but used
her hair to hide her scar most of the time. And, finally, Mary feared that this clip might
make children afraid of people with disabilities or scars because it was so scary. She
worried about the connection between scars and fear, especially in a children's cartoon.
Based on the answers and discussions provided by the participants, it is clear that most felt a deformity or scar was not the same as a disability. For the participants, it seemed a limitation had to be present for a deformity to be considered a disability. While I understand that point of view, I think deformities and scars can cause limitations, especially in North American culture where bodily perfection is held as the ideal. Even though there may not be physical limitations or restrictions, people with deformities and scars may still suffer from, what I call, social limitations. That is, they may have to deal with stares, judgments, stigma, social ostracization, and assumptions about their abilities based on the way they look. There may be elements of pain involved, whether physical or emotional, which one could argue are also limitations. On the other hand, if I remove the characteristic of limitation from the definition of what constitutes a disability, it could be a slippery slope. Perhaps this is why the participants were quick to differentiate between a deformity and a disability; they wanted to avoid blurring the definition of disability and making it too vague.

Invisibility and Hypervisibility

At the beginning of the focus group I asked the participants to provide examples of women with disabilities they had seen in the media. After about fifteen seconds of silence, I got this response from Katherine:

Katherine: Okay, um, that they're not there? [Laughs]

Grace: Yeah.

Katherine: That they don't exist. [chuckles] I dunno.
Garland Thomson (2001) argued that keeping the disabled body invisible allows people who identify as nondisabled to think they will never become disabled. She argues that the disabled body causes nondisabled people to realize their ablebodied-ness is merely temporary, which makes them decidedly uncomfortable. Thus, disabled bodies are made invisible to continue the belief that the human body is immune to change.

Many disability scholars write about the issue of visibility because, even today, people with disabilities are not visible in our culture (Bruggemann, White, Dunn, Heirfferon, & Cheu, 2001). But there is a paradox to the invisibility of the physically disabled body in that it is, at once, hidden and hypervisible (Kuppers, 2001). Physical disability, while invisible in mainstream media, is, in the real world, instantly recognized and categorized by others. People with physical disabilities may not see themselves represented in the media very often, but they are regularly defined by their physicality when they appear in public (Kuppers, 2001).

While the participants did not directly address the issue of hypervisibility, they did talk about how some of the participants’ disabilities were more visible than others. At one point, Mary talked about an encounter where a stranger had assumed she was depressed because she was in a wheelchair. When the individual discovered she was happy with her life, he expressed surprise:

Mary: I get a lot of comments, like, "why are you so happy?"...why not?

Grace: mm hmm.

Mary: I met somebody at my husband's work last week for the first time, and he came to my husband this week and said, "Your wife is so happy!"

[Laura chuckles]
Laura: Are you supposed to be depressed because you're in a wheelchair? [Chuckles]

Mary: Apparently.

Grace, who has a hearing impairment, talked about being a student in online classes. She said that she loved enrolling in online classes because, for once, her disability was completely invisible. Grace explains:

Grace: I can't hear at all. It's like online classes. Oh! [clutches her hands to her chest, near heart]

Katherine: [laughs, mimics Grace’s hand movements]

Grace: I'm just like everyone else in an online class. It's nice.

As you can see from this discussion, many of the participants have been defined by their physical disabilities at some point during their lives. When they appear in public, they are placed on display by others who stare at their differences. The prevalence of this is shown by Grace’s desire to escape her hypervisibility through online classes; in a virtual world, she is just like everyone else.

Another aspect of the invisibility of disability is that, when it does appear, it is almost always the focus of the representation. As Sophia, Katherine, and Grace pointed out, you cannot have a disability in the media and just be an “average” person; you have to be almost superhuman:

Grace: Yeah, you can't just be a woman with a disability—

Sophia: No, you just can't be a woman with a disability—

Grace: You have to be the head of something, or you have to be the crime solver or you have to—

Sophia: But you can't be on like Entertainment Tonight and be a host or anything like that.
Grace: Oh!

Sophia: I've never seen anybody with a disability in that kind of a role.

Katherine: You never see us anywhere, period. Like, [chuckles] like, there's, like, maybe 0.5% of the time you see someone with a disability, and you're like, "oh wow!" Like, and then you get, like, 10 seconds of them and that's all people remember. Right? So—

Charlotte: The token person.

Katherine: Yeah, you almost feel grateful that they're on the air, you're like, "Oh look!" [chuckles]

Laura: There it is!

Katherine: Oh!

Laura: It's like finding Waldo.

Charlotte: I'm on TV, I exist! 10 seconds but-

Katherine: [laughs]

Charlotte: I'm there.

The other point made in the discussion above is that when a person with a disability does appear in the media, it is expected that people with disabilities will be happy about it, regardless of what the representation entails or how long the image is shown. As I discussed earlier, many of the participants felt that any inclusion was better than none at all, but they also recognized that not every representation of disability was a positive one. Once again, inclusion, in this respect, became a double-edged sword for some of the participants.

When considering the representations of women with disabilities in the media, it becomes difficult to find a representation where the disability is not central to the representation itself. As Sophia mentioned, women with physical disabilities are rarely,
if ever, shown as "normal" women. Either the disability is something they have
"overcome," or it is the reason for their problems, or it is the consequence of a tragic
event. We could not think of an example where a woman's disability was simply a part
of her, and not her sole defining characteristic.

Chapter Summary

While the participants differed in their responses to the sexualization of the
disabled female body in the media, they did agree that the young, thin, Caucasian bodily
ideal upheld in North American culture for women was disturbing. They also noted that
this bodily ideal did not seem to transcend gender, as there were far more representations
of men with physical disabilities than representations of women with physical disabilities.
Further, the representations of women with physical disabilities that did exist, more often
than not, came as close as possible to the bodily ideal mentioned above. Women whose
bodies did not adhere to this ideal were far less represented in mainstream media. This
discussion of the female disabled body also led to a discussion on whether any inclusion
was better than none at all. In the end, the participants felt some inclusion was good but
struggled with completely agreeing that any representation was acceptable.

This led into a look at the complexities inherent in many of the representations of
women with physical disabilities in the media. As discussed previously, many of the
participants wanted to label the images they were seeing as "good" or "bad," and had
difficulty when this was not possible. In the end, the deciding factor on the acceptability
of a representation seemed to depend on who constructed the representation, especially
when it came to comedy involving disability. When they could not determine who
constructed the representations, the participants often wound up making contradictory statements about the representations.

Finally, the participants noted that the representations of women with disabilities were few and far between, especially compared to the abundance of representations of women who are nondisabled. The participants also told personal stories that suggested when a disabled body appears in public, the disability often becomes the defining characteristic of the individual’s identity. This suggests that although the representations of women with physical disabilities are rare in the media, disability as a category of identity in everyday life can overshadow all other parts of one’s identity.
CHAPTER FIVE: NEW PHOTOGRAPHIC REPRESENTATIONS

In this chapter, I discuss how and why I chose to construct new photographic representations. I also present each photograph and explain the story or message behind it, as explained to me by each participant.

The new photographic images created by the participants for this research are a perfect example of the Disability Arts Movement. Through the construction of their own representations of women with physical disabilities, the participants in this research have challenged how they view disabilities and how disabilities are viewed by others. They also illustrate how they would like disabilities to be viewed in mainstream society. The photographs provide a space for a critical reflection of visual culture and create potential roads to empowerment (Barnes & Mercer, 2003).

The goal of constructing these new representations was to allow the participants to speak for themselves through the art-making process. According to Lawrence (2008), the arts are a powerful way to motivate people to work for social change. However, as Barnes and Mercer (2003) caution, the inclusion of disability in art must always be careful not to cross the line between challenging the representation of disability in visual culture and encouraging voyeurism.

Although this research is not a performance piece, it is fusing the visual with the narrative by including photographic images in the written text. One effect of presenting the disabled body before a viewer, says Garland Thomson (2000), is that the “display” will generate a stare, which I discussed previously. Thus, in a way, the photographs “display” the participants each time the thesis is read. Instead of allowing the stare to control the encounter, however, the participants in this study have challenged the stare by
designing their own images. The participants have constructed how they wish to be seen. Also, by agreeing to partake in the photography section of my thesis, the participants are giving permission for others to stare, thus controlling when and how the stare occurs.

I now present the final photographic images constructed by each participant, along with a brief discussion of the goal or message each participant wished to express. I have chosen not to delve into a critical analysis of the photographs because I want the images to stand on their own and I do not want my interpretations to overpower the voices of the participants.
She paid a lot of money for this set...

...of hearing aids.
This photograph was designed entirely by the participant; she was inspired by an image presented during the focus group. The image, mentioned previously, was created by the charity organization CAP48 and showed a model with an amputated arm wearing a bra. The caption under the image reads, “Look me in the eyes...I said the eyes”. In this image, the participant wanted to play on the idea that, for most people, her chest or body might be the focal point, not her disability. The caption, “She paid a lot of money for this set...of hearing aids,” plays on the idea that people will initially think the participant is referring to her breasts. But she is actually talking about her hearing aids. This is made clear by the second half of the caption. The photograph looks at the sexualization of the disabled female body and challenges the viewer’s gaze.

To emphasize her disability, the participant points at her hearing aids. She also chose a simple white t-shirt that flattered her figure but was not overly revealing. Her goal was to be pretty but not overly sexualized.
For the participant's second photograph, which was a collaborative effort between
the participant and myself, I asked what her favourite fairy tale was as a child. Through
an in-depth discussion, I discovered that she had been a pageant queen in her youth.
While she was very proud of all abilities, her parents chose to focus on her pageant
success. She said that she always felt she was "more than this crown" and wanted to
express that in her second photograph. She was wanted to put that part of her life behind
her, and expressed a desire for others to also let it go. She did not want to be known as
the pageant queen anymore.

In this photograph, the participant sits in the middle of a forest in a white gown,
holding a tiara. The tiara symbolizes her pageant crown and is purposefully not on her
head. Instead, it is in her hands because she is about to put it down and walk away from
it. At this point, she can barely look at the tiara because she is tired of being tied to one
piece of her past. This photograph is meant to capture the moment before she puts down
the crown and moves on.

But, on another level, this image also represents the participant's feelings about
her disability. This participant is proud and does not try to hide her disability. But, at the
same time, she wants people to realize that her disability is not representative of her
entire identity. She is more than her disability, and more than her crown. Yet both of
these things remain an integral part of who she is, even as she moves on with her life.

During the revision process, the participant had the following to say about this
photograph:

I just have one little correction that probably occurred because of both of our
"hearing" or "not hearing" maybe. What I had said about [town name] and the
beauty pageant...was really this:
In [town name], growing up, girls wanted to be Miss [town name] and boys wanted to be hockey players - that was the ultimate goal and to this day, people still talk to me about "remember when you were Miss [town name]," etc, and I think part of that is because in a small town we tend to really focus on "town accomplishments" like.....being Miss [town name] or being a hockey star. I have had some pretty amazing accomplishments since [year] but to many of my family members and people in my community, being Miss [town name] was the biggest accomplishment I have achieved! Maybe I should start looking at like......wow...I was Miss [town name] EVEN though I am [disability name]!
This photograph was designed entirely by the participant. After the focus group, this participant wanted to take a photograph that highlighted her disability in a sensual way. The participant had noticed, during the focus group, that women with disabilities in the media are often not seen as sexy. If they are, it is despite their disability, not because of it. The inspiration came from a photograph of the singer and actress Miley Cyrus, where she is posed with her back to the camera and a bedsheets is wrapped around her body. The image is sensual but artistic.

To highlight her disability, represented by the scar on her back, the participant selected clothing that was cut low. She also asked that the photograph be sensual, not sexualized or exploitative. The participant wanted to be in charge of her sexuality. She wanted to show others that women with disabilities are sexual beings and that the disabled female body is sensual.
The second photograph for this participant was a collaborative effort based on the idea of a wood nymph. When I asked the participant what her favourite fairy tale was, she said she had always been fascinated by nymphs; both forest and water. For her, nymphs symbolize sensuality and playfulness, and that was something she wanted to emulate in her photograph. This touches on the theme of her first photograph, where she also wanted to be seen as a sensual woman.

In this photograph, the participant is a wood or forest nymph. Her clothes symbolize her connection to nature, the changing seasons, and the mother earth. At the same time that she is leaning sensually against a tree, there is also a playfulness in her eyes. As if she could, at any moment, play a trick on the viewer. Her stare invites the viewer to look at her, yet challenges that look with a return stare. Yet her stare will never change or end, because it is locked in a photograph.
This photograph was designed entirely by the participant. The inspiration for this photograph came from a black and white image of Aimee Mullins, disability advocate, model, and athlete, shown during the focus group. In the original image, Aimee Mullins is in the starting position for a race wearing her prosthetic legs. Mullins is wearing minimal clothing in the image.

This participant wanted a simple photograph that showed off the new legs she had recently purchased. She was proud of the legs and wanted to show them off in the photograph. But she did not want to imitate Aimee Mullins’ pose exactly because the participant was not an athlete and did not think she could get her body comfortably in the same position as Aimee Mullins. She also was not comfortable wearing revealing clothing like Aimee Mullins. So, instead, the participant decided to sit on a stool and asked me to take a portrait showcasing her beautiful new legs.
The second photograph for this participant was a collaborative effort based on mystery novels and stories. When I asked the participant what fairy tales she was interested in, she explained that she had never really been into fairy tales as a child. Through a series of questions, I learned that fairy tales had not been a big part of her life but, for as long as she could remember, she had always loved mysteries and solving things. The participant also mentioned that, as a woman with a disability, she often had to problem solve to enter a building or seek accommodations that suited her needs.

This photograph was designed to emulate an old-time detective show or novel. The participant is the detective and she is at her desk, thinking hard about the mystery she is been assigned. The picture is meant to challenge that women with disabilities, on television and in novels, are rarely given roles such as a detective. One of the only female detectives with a disability I could find on television is Sue Thomas from the television show, *F.B. Eye*. Sue Thomas is deaf and has a canine companion to help her as she works.
This photograph was designed entirely by the participant. For her first photograph, this participant wanted to have her fiancée in it because, in her own words, “I can’t represent my disability without including her.” She went on to explain that her fiancée was her best friend and that they supported each other equally.

The participant was also adamant that I not photograph the fiancée holding the participant up in any way. She wanted to show them holding the weight of her disability together, equally, as they do in life. The love and support each woman gives each other is clear in this photograph, and both are on equal footing with each other.
The second photograph, a collaborative effort between the participant and me, was inspired by the Harry Potter series\textsuperscript{17}. Harry Potter is a series of seven fantasy novels written by the British author J. K. Rowling. When I asked the participant what fairy tales she was into, she said she loved fantasy stories that were a bit dark and gritty; things that were somewhat surreal. I then discovered she was really into the Harry Potter movies and books. She said that she wished she could go to Hogwarts, the mythical and magical school in Harry Potter. She loved the idea that she could escape this world and be somewhere magical like Hogwarts. I also argue that her desire to go to Hogwarts may stem from it not being a big deal to be disabled in a fantasy scenario because everyone is different.

During the revision period, this participant asked that I clarify and explain her love of the Harry Potter world more clearly:

My only thing is, I don't think it was really conveyed that I love Hogwarts and the idea of this magical world because these disabilities don't exist, or they aren't a big deal. No one is "sick" in a way that they are in the muggle world. If I was a wizard, I wouldn't have [disability name] or [disability name], because it would be cured, but I would have other problems, like Voldemort and curses to face, but it would be so different and less damaging to my physical body.

\textsuperscript{17} The books follow the adventures of Harry Potter, a wizard, and his friends Ronald Weasley and Hermione Granger. All of them are students at Hogwarts School of Witchcraft and Wizardry. The main story arc is Harry's quest to overcome the evil wizard, Lord Voldemort. The books were also made into a series of popular movies.
This photograph was designed by the participant. For this photograph, the participant said she wanted a beautiful portrait or glamour shot. She said she wanted to be shown smiling and happy, because that is how she really is. The idea, that a woman’s disability does not impede her happiness in any way, is one that is difficult for non-disabled people to understand. They assume that anyone who is disabled must also be unhappy. This participant wanted to make sure people understood that she is as happy now as she was before her disability, and that her life is very full.
The second photograph, a collaboration between the participant and myself, was inspired by the participant’s past as a dancer. When I asked what or if she had a favourite fairy tale or fantasy at any point in her life, the participant responded, “None that I can think of.” So I decided to follow up with questions about her hobbies and activities as a child and teenager. I found out that she had taken dance classes, such as jazz, throughout high school. She also used to go downhill skiing and swim. From this, we came up with the idea to try and capture the participant surrounded by movement and motion. We felt it would be an interesting way to represent her past as a dancer and athlete, and her life today as an active woman with a disability.

In the photograph, we used fabric cascading in different directions to represent the movement we were trying to capture. The different shots of fabric were then manipulated into one image. Once again, the participant wanted to show herself smiling and to showcase her wheelchair.
Disability Awareness

Sometimes you need to look at it from different angles.

Let's get the ball rolling.
This photograph was designed by the participant. For this photograph, the participant wanted to create a disability awareness poster. In the poster, she wanted her cane to have a different purpose than the one most people expect. She had several ideas for this and eventually she settled on using the cane as a pool cue because the game of pool requires sharp vision and the ability to see and predict/calculate angles on a pool table.

The participant talked about wanting others to realize that her cane was not a tool she needed to use in order to see; she could see well enough without it. She mostly used her cane as a back-up, just in case she needed it. She also used the cane as a way to alert others to her disability. But often, people would see the cane and assume she was completely unable to see, which is not the case.

In this poster, the caption reads, “Disability Awareness / Sometimes you need to look at it from different angles / Let’s get the ball rolling.” The caption is meant to encourage the viewer to think about disability in a new way and look at it from a new vantage point. The participant also wants people, both disabled and non-disabled, to start a conversation about disability and talk to each other about the stereotypes that surround disabilities.
This photograph was designed as a collaborative effort between the participant and myself. When I asked the participant about her favourite fairy tale or fantasy story, she said she had always admired the strength of the television character, Xena. Xena is a fictional character from the 1995 television show called Xena: Warrior Princess. Xena is the main character of the show, and the series shows her on a quest for redemption for her past sins as a ruthless warlord. She seeks redemption by using her formidable fighting skills to help people. Xena's signature weapon is the chakram, a razor-edged throwing weapon which she often uses for ranged combat. The interesting thing was that this participant had not actually watched the series, but she knew about the character and what she represented. For the participant, Xena represented a strong, intelligent, warrior woman who let nothing stand in her way.

Together, the participant and I created a photograph inspired by everything Xena represented. In the photograph, the participant is holding a sword and a chakram. However, while the participant wanted to be shown as a strong female character, she also wanted to retain her femininity. To create this effect, the participant chose an image where she is looking downward, at a fire that she has cast. The idea is that while the participant is strong and ready to fight, she also has a softer side. The fire is meant to represent the fire and passion inside her.
CHAPTER SIX: CONCLUDING THOUGHTS

In this chapter, I discuss briefly the complexities of representing disability and highlight some of the discussions that came out of the research, including interconnected identities, inclusion, equality, and the value of disability. I end this chapter with suggestions for the media and recommendations for future research.

It never ceases to amaze me that disability is so hidden in Western and European cultures, especially considering that it affects so many people. For something that is so hypervisible, disability is remarkably well hidden in critical discourses and the media. When disability is represented, it is often mired in stereotypes and causes conflicting opinions in people with disabilities and people who self-identify as nondisabled. As I stated in the beginning of this thesis, the representations of women with disabilities is a complex issue that requires deep analysis and discussion.

The Complexities and Contradictions of Disability Representations

The participants in this research frequently contradicted each other and themselves throughout the focus group. They would often begin a discussion praising a representation, but then, a few moments later, they would draw out a negative aspect about the same representation. For example, charity advertisements brought about many mixed feelings, with the participants uncertain about whether they liked or disliked the representations.

It seemed as though the participants had difficulty responding to representations of women with disabilities that they could not easily categorize as “good” or “bad.” When faced with a representation that included aspects they liked and disliked, the
participants often attempted to make a final decision in one direction or another. They appeared to struggle with the concept that representations could be complex and contain both positive and negative components.

In my opinion, it is difficult to declare a representation “good” or “bad” because many representations contain both positive and negative aspects based on one’s position in society. Who you are affects how you respond to the representations of women with disabilities.

**Interconnected Identities**

As I stated above, the analysis of the representations of women with disabilities shown to the participants in this study were heavily influenced by the identities of the participants. What I mean is, the participants were not just disabled; they were female, Caucasian, of a certain age, from a certain financial background, and so forth. They also had different life experiences and personalities, which affected how they looked at and responded to the representations.

Each participant expressed her unique identity through the use of personal stories. During the focus group, Charlotte told a story about a childhood friend who asked his classmates to paint his wheelchair wheels to make them “look cool.” This was in response to a discussion about how to make disability fashionable. Another participant, Mary, told a story of when her husband encouraged her to wear high heels even though she was in a wheelchair. Her response was, “Why? It wouldn’t be for me.” This comment came out of a talk about the hypersexualization of the bodies of women with disabilities.
No one has just one identity; we are all made up of hundreds of pieces that work together to make us who we are. That uniqueness should be acknowledged and appreciated, especially in critical studies research. The past experiences of each of these participants affected their responses to the images they saw, so it is important to acknowledge those experiences instead of focusing on only their disabilities.

Inclusion or Exclusion?

When it came to the idea of inclusion and exclusion, the participants differed slightly on their opinions. The specific examples given were fashion and advertising, because those industries have been including women with disabilities more frequently over the last few years.

Grace, Mary, and Sophia did not feel that any inclusion was better than none at all. While they did agree that seeing women with disabilities in fashion and advertising was a positive move, they felt the women being shown were still adhering to impossible beauty ideals. The models with disabilities were still young, slender, hypersexualized, and Caucasian. In contrast, Laura, Katherine, and Charlotte liked seeing women with disabilities represented in these areas because it made them feel included. They also liked that women with disabilities were being shown in a sexy way, as far too often, the sexuality of women with disabilities is stripped away. But, at the same time, Laura, Katherine, and Charlotte disliked the hypersexualization of women’s bodies and the pressure to be thin. In the end, all the participants agreed that inclusion in fashion and advertising was, at the very least, a start; although there is still much work to be done in this area.
Different, But Equal

It is important for people with disabilities and those who self-identify as nondisabled to work together to find ways to understand, and discuss disability in a new way that is not oppressive and does not imply that difference is inferior (Garland Thomson, 2002). A mantra I have adopted in my personal life is that of "different, but equal." Zitzelsberger (2005) talked about this idea in her article, "(In)visibility: Accounts of Embodiment of Women with Physical Disabilities and Differences." The author commented that her participants, all female, had rejected "the 'gaze' of dominant cultures" and had "constructed their own views of their bodies as different from but not an inferior form of what is generally socially constituted as a normative body" (p. 398). The author then included a specific quote from a participant that I feel is relevant here: "Difference can be seen as a good thing and you do learn to...view difference as a source of power instead of looking at it as a negative thing. I feel a lot of power in that" (p. 398).

My physical disability sets me apart from others. I am different. To try and erase my difference is to try and erase my experiences and part of who I am. But my difference does not make me inferior. It makes me different. North American culture has an extremely difficult time with the concept that something can be different, but equal; there is a tendency to order categories in a hierarchical manner. But it is not necessary to do this. We can allow something to have value, without positioning it above us. In short, we can be different, but equal.

I would like to explain what I mean by "equal." Picture a long flat horizontal line with seven billion dots on it; each of these dots represents a person. All the dots are lined
up beside each other, none higher or lower than another; they are all equal to each other. But they are also different because they are not the same dot. So, when I say people with disabilities are “different, but equal,” I mean that they exist as dots on the same horizontal line as everyone else in the world; they just occupy a different space.

Re/presenting the Value of Disability

I argue that the act of ignoring the disabled body, or turning it invisible, creates shame. By hiding the disabled body, people with disabilities learn that their bodies are not worthy of being seen and they can sometimes feel they have no value. Taking the shame out of disability and making others realize being disabled is not a fate worse than death is, I believe, essential for critical disability studies. An important place to start that change is in the media. By portraying women with disabilities in varied ways, we can broaden the way others see and feel about the disabled body.

Another way to add value to disability is to encourage scholars and researchers to move away from the medical model of disability. The medical model, discussed previously, positions a disability as a flaw or deviation from the norm. It also strives to “fix” or “cure” those with disabilities so they can be “normal.” This view leaves no space for the possibility that disabilities provide value, joy, or happiness. The medical model portrays disabilities as something to avoid at all costs. But there is value in disability. It is not a fate worse than death; it is a life worth living.

An example of the view that being disabled is a fate worse than death occurs in the move The Butterfly Effect. In this movie, the main character, named Evan, is able to

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18 I am only giving a brief synopsis of the movie in this conclusion and have decided not to delve into the backstory or details of the movie, as I do not feel they are relevant here.
travel back in time and change a tragic event from his childhood. He attempts to change the event several times, trying a new tactic each time, but he winds up making the future worse for everyone he loves each time. In one instance, however, when he goes back to the present, he has lost his arms and his legs are disabled. But everyone else is happy and successful. The scenes that follow show him in abject misery at his fate of being disabled. There is no space in these scenes for happiness or joy.

This idea of happiness being outside the grasp of those with disabilities came up briefly during the focus group. Earlier, I noted that one of the participants, Mary, explained how, after meeting her, one of her husband’s co-workers exclaimed to him incredulously, “your wife is so happy!” It is clear that the co-worker was surprised by Mary’s happy nature. This suggests that he was previously under the impression that people with disabilities were, in general, not happy about their situation. And he was clearly taken aback enough to comment about it the following week to Mary’s husband. One way to combat this assumption that people with disabilities are unhappy, or that disabilities have no value, is to provide more non-tragic and non-medicalized representations of disability in the media.

Suggestions for Media

Throughout this research, the concept of stereotypes was discussed at great length by the participants. Although many of the participants felt there were positive aspects to many of the stereotypes we considered, they were still often one-dimensional representations. One way to combat this would be to give characters with disabilities
more complex and well-rounded personalities, as is done with nondisabled characters. Show them being happy as well as being sad; failing and being successful.

I now offer some suggestions to the media about how to handle a few specific stereotypes based on feedback from the participants. For example, the “supercrip,” presents the person with a disability overcoming their disability to accomplish an almost superhuman feat (Wendell, 2006). While the participants agreed that this stereotype showed people with disabilities being successful and strong, they also felt it suggested that in order to be successful, one had to “get passed” his or her disability. The disability is still positioned as a hurdle or lack. For the participants, the first step to combating the negative aspects of this stereotype was to change the language associated with it. The media must stop saying that the person with a disability did something despite being disabled or that they accomplished a difficult feat by overcoming their disability.

The second stereotype is the sentimental, which views the person with a disability as a helpless victim who needs assistance and protection in order to survive (Garland Thomson, 2001). This stereotype is usually used by charities and telethons. While the participants understood the value of charities and appreciated the good they did in raising money for services, they disliked the often exploitative heart-string tugging tactics used in the advertisements. First, and foremost, the participants were tired of being pitied and seeing advertisements that encouraged that viewpoint. My suggestion would be for charities to explore the use of adverts that do not use the victim stereotype. Why not create campaigns that are more positive? For example, President’s Choice has created disability adverts that show a smiling child with the caption, “You’re helping. Make a
difficult life a little easier."\textsuperscript{19} Although this is certainly not a perfect campaign, it is much improved on the scare-tactic Muscular Dystrophy posters shown during the focus group\textsuperscript{20}.

The third, and final, stereotype derives humour from the disabled body, with the humour typically being focused on the limitations of the disability (Clark, 2003). It was clear that all of the participants felt the most important part of this stereotype was the person making the joke. For example, if someone with a disability made fun of disabilities, the participants generally felt that was acceptable. But when someone without a disability mocked disabilities, the participants felt it was completely inappropriate and cruel. For them, the difference was "a laughing spin" versus outright mockery. My suggestion for the laughable stereotype is to approach it carefully, as it is complicated. If the media chooses to combine humour and disability, the first thing that should be done is to consult with, or include, people who have disabilities in the construction of said humour.

It is important to note that while I can make suggestions for the media to take into consideration when representing people with disabilities, I cannot make conclusive recommendations for improvement. My participant group was small, and even they had difficulty agreeing on some representations and stereotypes. Because of this, it is not possible for me to make grand declarations of what is acceptable and what is not. But I can make suggestions.

\textsuperscript{19} This advert can be seen at the very end of Appendix A.
\textsuperscript{20} As noted previously, a full list of the images and video clips shown during the focus group, and in the online questionnaire, can be found in Appendix A and Appendix B.
Recommendations for Future Research

A broader study should be conducted that looks at the representations of people with disabilities and includes both men and women with disabilities. It would be interesting to learn how men and women with disabilities feel about the representations of people with disabilities in the media. Researchers may also want to think about including nondisabled people in the discussions of disability in order to build bridges between the disabled and nondisabled communities. However, one must be extremely careful not to allow one community to overpower the other. The goal should be to work together to find ways to end the oppression of people with disabilities and remove the stigma of being disabled. However, it should also not be left entirely up to individuals with disabilities to “teach” everyone else about disabilities. The growth and learning has to happen together.

In addition, a study that includes disabilities that are not physical would be a worthwhile venture. It could help start conversations about the invisibility of developmental and intellectual disabilities, how invisible disabilities affect one’s life, and how they are represented in the media.

A research project that looks specifically at the inclusion of women with disabilities in fashion and advertising could also be a thought-provoking project. It would be interesting to see how women with disabilities, and those who self-identify as nondisabled, reconcile the hypersexuality and exploitation of the female body with the representation of disability. This research could potentially provide a space for a dialogue about feminism, the female body, and critical disability studies.
More research on the interconnectedness of women’s identities should be initiated. It is important to consider how one’s identity overlaps and interacts with others. This thesis touched on the topic, but it would be beneficial to examine the intersectionality of identity from a feminist and critical disability perspective.

Finally, researchers who are interested in doing research with people who have disabilities might consider using a methodology known as photo voice. Photo voice is a method of using photography to engage participants in explaining how they make sense of their world. Rather than simply asking participants to find images, photo voice provides participants with cameras and asks them to take pictures of their surroundings or everyday activities (Miles & Huberman, 1994). Using the art-making process, participants may find new ways of expression that they would not have access to through the written word. This methodology also allows researchers to play a much larger role in the research process.

The Value of Arts-Based Inquiry

A large portion of this thesis involved arts-based research as a form of methodology. I included the use of photo elicitation in the focus group and online questionnaire, and I worked with the participants to construct new photographic representations of each of them. By designing their own representations, the participants were able to express themselves in a non-lingual manner. In addition, because the art created is open to interpretation, arts-based inquiry draws the participants, the researcher(s), and the viewer(s) into a dialogue and creates a space for a critique of social structures (Finley, 2005).
As I discussed earlier, utilizing photography allowed the participants to challenge the stares they receive on a daily basis and control how they are seen by others. The photographs are, in a sense, a reverse stare; even if the participant is not looking directly at the camera in the image, I argue the mere act of creating the photograph is a type of stare. Each photograph focuses the stare back onto the viewer and forces the viewer to look at the disabled body on the participants’ terms. By controlling how, and when, they want to be seen, the participants bring the stare out of the shadows and force the viewer to think about how, why, and when they look at the disabled body.

Further, the creation of photographic imagery in this thesis brings the research into the realm of the Disability Arts Movement, which I discussed previously. The photographs explore the experience of living with a disability through the inclusion of women with disabilities, and provide a critical response to the social structures, both positive and negative, that surround disability. One of the main goals of the Disability Arts Movement is to build a more positive group consciousness and identity (Barnes & Mercer, 2003), and, in my opinion, the photographic images produced in this research do just that.

In Conclusion

I think this research has taken a step toward bringing disability out of the shadows, but there is still a long way to go. The goal of this research was to shed light on the invisibility of disability and let women with disabilities be heard in critical discourses. This thesis also provided an opportunity for women with disabilities to come forward and take an active role in the research process through discussions, feedback, and
the construction of new photographic representations. Too often people with disabilities have control taken away from them; it is time to give that control back.
BIBLIOGRAPHY


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APPENDIX A: VISUAL REPRESENTATIONS SHOWN IN FOCUS GROUP

1A: This image shows South African runner, Oscar Pistorius, who became the first disabled runner to compete in the Olympics when he ran in the 400 metres, beating Arab horse Maserati in the 'run like the wind' race. Source: http://www.heraldsun.com.au/sport/more-sports/blade-runner-oscar-pistorius-outruns-horse-in-race/story-e6frf1f-1226535801683
Aimee Mullins was born without fibulae and had both legs amputated below the knees as an infant, but athletics still has been a foundation in her life. Mullins became the first adaptive athlete to compete against able-bodied NCAA athletes by running track and field for Georgetown (1995-98). She competed in the 1996 Paralympics and worked as a fashion model and actress. Mullins shared her story with attendees at the NCAA Inclusion Forum on Tuesday. Source: http://www.ncaa.org/wps/wcm/connect/public/NCAA/Resources/Latest+News/2013/April/Overcoming+obstacles+is+normal+for+Aimee+Mullins
2A: A cartoon image of Ursula, the sea witch from The Little Mermaid. Ursula is the main antagonist of Disney's The Little Mermaid and its spin-off television series. She is voiced by Pat Carroll in all of her appearances. Over the years, Ursula has become one of the most popular and famous of all Disney villains and is one of the franchise's official members. Source: http://disney.wikia.com/wiki/Ursula

2B: A screenshot of Freddy Krueger's face from A Nightmare on Elm Street. Frederick Charles "Freddy" Krueger is a fictional character created by Wes Craven, and is the main antagonist and a killer from the slasher film series A Nightmare on Elm Street. When he was burned to death in 1968 by the citizens of Springwood, he was offered the spot as "Dream Killer" from the demons that live in the depths of hell. He uses this new career of his to his advantage to murder the children of his killers in their dreams. Source: http://horror-movies.wikia.com/wiki/Freddy_Krueger
2C: A promotional poster for a Batman movie featuring the villain “Two-Face.” Harvey Dent was Gotham City’s heroic and kind-hearted district-attorney and one of Batman’s strongest allies until Sal "Boss" Maroni threw acid in his face, hideously scarring him. It also fractured his mental state, causing him to become Two-Face, a schizoid criminal-mastermind obsessed with the number two. His former good luck charm, a "two-headed" silver dollar, was damaged on one side during the attack that ruined half his face, and Dent has seized on it as a reflection of his half-scarred visage. He flips it to decide the fates of his victims. Source: http://batman.wikia.com/wiki/Two-Face

3A: A drawing of Joe Swanson from the cartoon Family Guy. Joseph "Joe" Swanson is a macho paraplegic police officer in the Quahog Police Department who is at many times subject to intense anger problems. He is married to Bonnie Swanson and has two children; Susie and Kevin. Source: http://familyguy.wikia.com/wiki/Joe_Swanson
3B: A screenshot of Jimmy and Timmy from the cartoon South Park. Jimmy is a fellow classmate of the boys, originally introduced to us when the boys were in Boy Scouts. He is "Handi-Capable" and enjoys using his disabilities as an advantage during his stand-up comedy routines. The boys usually come to him for jokes and advice, as he tends to have a super positive outlook on life. He briefly took steroids to train for the Special Olympics. Source: http://www.southparkstudios.com/guide/characters/jimmy-valmer. Timmy Burch is male fourth grader at South Park Elementary. He is voiced by Trey Parker. He is handicapped, uses a wheelchair to get around, and has a limited vocabulary consisting only of his own name and a handful of other phrases. Source: http://southpark.wikia.com/wiki/Timmy_Burch

3C: A promotional photograph of the cast from the TV sitcom Malcom in the Middle, including the wheelchair bound character, Stevie Kenarban. Stevie Kenarban, played by Craig Lamar Traylor is Malcolm's best friend, Stevie first meets him in the pilot; they are
in the same accelerated class through middle school and most of high school. They originally met on a play date and took a liking to each other through a mutual interest in comic books. Stevie is a wheelchair user and has severe asthma, and only one lung; as a result, he speaks softly and can only say one or two words on each breath. However, despite these handicaps, Stevie seems to be a normal teenager and does not let his physical disadvantages keep him from having a relatively normal life and even uses his handicap to his advantage. Source: http://malcolminthemiddle.wikia.com/wiki/Stevie_Kenarban

4A: A charity poster for Multiple Dystrophy with a young child in a wheelchair in a field. Above the image is the caption, “He’d love to walk away from this poster too.” This poster, made my J. Walter Thompson, is a recreation of a famous disability advert made 33 years ago by Lord Snowdon. Source: http://www.guardian.co.uk/media/2010/feb/01/muscular-dystrophy-advertising-campaign
4B: A charity poster for Enable Scotland, featuring a person with a disability and the caption, “If i ate out of a dog bowl would you like me more? Believe it or not animal charities receive nearly double the donations of disability charities.” Source: http://news.bbc.co.uk/2/hi/uk_news/scotland/6247725.stm
5A: A vintage black and white photograph from a travelling “freak show” featuring a tall man holding two people with disabilities. Source: Unknown.

5B: A screenshot from the TLC special, Big Tiny, about two primordial dwarf siblings. Big Tiny is a 2012 The Learning Channel (TLC) reality show featuring the smallest known siblings in the entire world. Bridgette “Bri” and Brad Jordan are Guinness Book of World Records holders for their small stature. Bri Jordan is 27-inches-tall and Brad Jordan is slightly taller at 38-inches. The pair of twenty-something siblings will star in Big Tiny which premiered on August 13, 2012. Source: http://www.inquisitr.com/299268/big-tiny-reality-show-on-tlc-features-worlds-smallest-siblings/
Two documentaries on her life were shown on TLC. On October 2009, she passed away. Following her death, TLC aired another special about the last six months of Shiloh’s life. Source: http://www.thaindian.com/newsportal/world/mermaid-girls-moving-story-to-be-shown-on-tlc_100287895.html
6A: A photograph of “Life As An Amputee” Young Abu, 7, buttons his father’s collar in the family’s shelter in an amputee camp, northwest of Freetown, Sierra Leone. Source: http://www.visionthisworld.com/photo/life-as-an-amputee/
6B: A black and white photograph of a Sierra Leone amputee. Source: http://www.diamondboycott.com/
7A: A photograph of a woman leaning against a brick wall while wearing a revealing outfit and a leg brace. This is the cover image used on Marlene le Roux’s book, “Look at Me.” “Look at Me” is a photographic showcase of 23 disabled women and their incredible stories, challenging conventional beliefs about beauty and sensuality. This book was first published in South Africa and continues to exhibit internationally. Source: http://joho.bookslive.co.za/blog/2009/08/13/marlene-le-rouxs-look-at-me-exhibition-set-for-uct-programme/
7B: A photograph of a woman sitting on a hill with a prosthetic leg. This image is also from the book “Look at Me.” “Look at Me” is a photographic showcase of 23 disabled women and their incredible stories, challenging conventional beliefs about beauty and sensuality. This book was first published in South Africa and continues to exhibit internationally. Source: http://joho.bookslive.co.za/blog/2009/08/13/marlene-le-roux-look-at-me-exhibition-set-for-uct-programme/
8A: Photograph of a woman in a wheelchair with a birdcage around her head and arm braces. By photographer, Christopher Voekler. Christopher Voekler is an American photographer. Source: http://www.voelkerstudio.com/
8B: Photograph of a woman in a long black dress posed gracefully in a wheelchair with studio lights around her and the silhouette of a film camera. By photographer, Christopher Voekler. Christopher Voekler is an American photographer. Source: http://www.voelkerstudio.com/

Tops and bottoms.
9A: An image from a series of photographs that parody the American Apparel ads, featuring model Jes Sachse who has Freeman-Sheldon syndrome. ‘American Able’ intends to, through spoof, reveal the ways in which women with disabilities are invisibilized in advertising and mass media. The photographer chose American Apparel not just for their notable style, but also for their claims that many of their models are just ‘every day’ women... The model, Jes Sachse, and the photographer intend to reveal the hidden stories of disabled women by placing her in a position where women with disabilities are typically excluded. Source: http://thesocietypages.org/socimages/2010/05/06/american-able-challenging-depictions-of-women-with-disabilities/

Meet Jes.

9B: Another image from the series of photographs parodying American Apparel.
10A: Photograph of model Nadja Auermann with a fashion leg brace and a cane at the top of some stairs. Taken by Helmut Newton for a Vogue magazine fashion spread. Source: http://loveisthenewblack-loveisthenewblack.blogspot.ca/2010/08/blast-from-past-empowered-woman-vogue.html
10B: Photograph of a model with two walking canes being helped up some stairs by two men in suits. Taken by Helmut Newton for a Vogue magazine fashion spread. Source: http://loveisthenewblack-loveisthenewblack.blogspot.ca/2010/08/blast-from-past-empowered-woman-vogue.html

11A: A promotional photograph of the contestants from “Britain’s Missing Top Model,” a reality TV fashion show featuring women with disabilities. Source: http://www.bbc.co.uk/programmes/b00cfhhb
12: A series of video commercials about disability awareness by Aardman Animations, entitled “Creature Discomforts.” Real voices and experiences of people with disabilities were matched with Claymation creatures. Source: http://www.creaturediscomforts.org/
13: A disability awareness poster by Belgian charity, CAP48, featuring a beautiful amputee model wearing only a bra. The caption translates to, “Look me in the eyes...I said the eyes.” CAP48 is the leading Belgian charity working for the integration of handicapped people. The ad depicts the glamorous model smiling to camera, evocative of Eva Herzigova’s Wonderbra campaign. Source: http://adsoftheworld.com/media/print/cap48_look_me_in_the_eyes
14A: A screenshot from a commercial about Multiple Sclerosis with a woman hiding behind a door as the same woman enters the home unaware that her body may attack itself at any moment. MS Australia commissioned this commercial, called ‘Saboteur,’ which shows a woman sabotaging her own home. In the ad we see a woman break into a home and rig up a series of sinister traps. It is only at the conclusion that we find out why. Source: http://theinspirationroom.com/daily/2007/multiple-sclerosis-saboteur/
14B: A photograph of a charity advertisement for President's Choice, featuring a smiling child, a hand drawn sun, and the words, "You're helping. Make a difficult life a little easier." Source: Located in the Atlantic Superstore in Fredericton, New Brunswick.
1A: The image above is Sarah Reinertsen, the first female leg amputee with a prosthetic limb to complete the Ironman Triathlon World Championship in Kona, Hawaii. In October 2009, Sarah was featured on 1 of 6 different covers for the inaugural Body Issue of ESPN Magazine.
Qian Hongyan, 16, from the Yunzhinan Swimming Club for the handicapped, climbs onto a platform during a daily training session at a swimming centre in Kunming, southwest China's Yunnan province.
1C: Aimee Mullins is an America athlete, actress, and fashion model best known for her athletic accomplishments.

2A: Video clip about a character named Venom, a paraplegic from The Guild, which is an American comedy web series that revolves around the lives of a gamers' online guild. Video source: www.youtube.com/watch?feature=player_embedded&v=9ARiBPFLTss#at=192
2B: A screenshot of a villain from the cartoon Captain Planet, named Doctor Barbara Blight. She is a scientist who has blonde hair, which is styled to hide the scar on the left side of her face.

3A: A clip from a comedy special hosted by Nikki Payne, a Canadian comedian and actress. Born with a cleft palate, she is well known for incorporating her lisp into her comedy act. Video source:
www.youtube.com/watch?feature=player_embedded&v=g7YRk9Di7Xg#

3B: A video clip of 'I'm Spazticus', is a 30 minute prank filled show on BBC's Channel 4, made by a disabled cast. Video source:
www.youtube.com/watch?feature=player_embedded&v=QX8Dy10JzTY

4A: A Video clip called the ‘Saboteur’, where the female character is a metaphor for the way the body attacks itself with Multiple Sclerosis (MS). Video source:
www.youtube.com/watch?feature=player_embedded&v=WXFa8uJqOUU
4B: A print ad of a naked woman sitting alone on the floor with the words “use by” written across her body. Caption: “When you have Multiple Sclerosis you never know what will expire next.”
4C: The Arc San Francisco is a non-profit service and advocacy organization for adults with autism, Down syndrome, cerebral palsy, intellectual and developmental disabilities and their families living in San Francisco and San Mateo counties. This poster is a promotion for their "We can do it!" program.
4D: Thirty-five-year-old Tanja Kiewitz has recreated Eva Herzigova's famous Wonderbra ad with the caption, "Look me in the eyes...I said the eyes," but this time around, Kiewitz isn't selling lingerie. Instead, she's posed for Belgian handicap awareness group, CAP48, showing off her left arm that ends below the elbow.

5A: Shiloh was born with a rare condition called sirenomelia, or Mermaid Syndrome. "[The condition is] two legs that are stuck together to make one whole leg," Shiloh says. "It's the way I was made when I was born." Video source: http://www.youtube.com/watch?v=8okYhcRwrgY

5B: Born with a rare genetic disorder known as Sacral Agenesis, Rose had severely deformed legs with feet pointing in opposite directions. There was no feeling in the legs and, as a child, she was in danger of harming herself. When she was two years old her mother, after consulting with the doctors at the hospital, decided that the best course of action was to have the legs amputated. Video Source: http://www.youtube.com/watch?v=yFYnZKYQi5E
Abigail Loraine Hensel and Brittany Lee Hensel (born March 7, 1990) are dicephalic parapagus twins, meaning that they are conjoined twins. Each has a separate head, but their bodies are joined. They are highly symmetric, giving the appearance of having just a single body with little variation from normal proportion. Video source: http://www.youtube.com/watch?feature=player_embedded&v=N5AzjA0jY

In February of 2002, the LRA attacked Abia, searching for food, supplies and children to abduct. Mildred was inside her home with her six children when the rebels set fire to all the thatched roofs in the camp. The civilians were then forced to choose between staying inside their burning homes, or being shot by the rebels while attempting to escape. After she and her children were burned, Mildred’s husband left her and found another wife.” Photograph by Heather McClintock (2006).
6B: This picture, called The Music Of Love, was taken in Tenganan Village, Bali (2010). Tenganan is the most famous Bali Aga (original Balinese) village and is located close to Candi Dasa in East Bali. A man was playing bamboo music to entertain a disabled child who was not his son, but he loves this child like he loves his own son. (Photo by Ario Wibisono).
7A: Based on a true story, Sue Thomas: F.B.Eye follows the adventures of Sue Thomas at the FBI in Washington, D.C. She's one hard-headed, soft-hearted, woman whose talent for reading lips helps crack crimes and bag the bad guys in places listening devices can't penetrate. With her hearing-ear dog, Levi, Sue's a glutton for jeopardy - and there's almost nothing she won't do to bring notorious criminals to justice.
Video source:
http://www.youtube.com/watch?feature=player_embedded&v=jmMApNy48Sc

7B: After an experimental bio-weapon is released, turning thousands into zombie-like creatures, it's up to a rag-tag group of survivors to stop the infected and those behind its release. Cherry Darling is a Go-Go dancer with big goals. One night, Cherry is fed up with her dead end job and decides to search for greener pastures. Her travels lead her to a small BBQ and her lost love. Cherry is then wounded and has her leg amputated by zombies. A semi-automatic gun is then attached to her leg.
7C: Marlene le Roux sought to change perceptions with her book, Look at Me, which showcases the sensuality, strength and courage of 23 disabled women. The photographs in Look at Me, were taken by Lucie Pavlovich. Some of the women were born with their disability; others got it through an accident or illness later in life.

Tight.
American Able (first image) is a project that catches your eye and then asks why you’re staring. The series depicts twenty-five-year-old model Jes Sachse, who has the genetic disorder Freeman-Sheldon syndrome, re-enacting a range of American Apparel advertisements (second image) notorious for featuring barely clothed women.
7E: In 1995 Helmut Newton captured supermodel Nadja Auermann at the peak of her career in a controversial spread for American Vogue titled "The Empowered Woman." The model, Nadja, is not disabled.

7F: Britain's Missing Top Model was a British Reality TV modeling show for disabled women, aired on BBC Three. The premiere episode aired on July 2008. The show followed eight young women with disabilities, who competed for a modeling contract. Aired over a period of five weeks, the women lived together and competed in a series of challenges and photo shoots. Each week at least one contestant was sent home. Video Source: http://www.youtube.com/watch?feature=player_embedded&v=Q2WG-ZyrxrI

7G: By combining the real voices and experiences of disabled people, with the creativity of Aardman Animations, Creature Discomforts explores the barriers and attitudes faced by disabled people every day. Video source: http://www.youtube.com/watch?feature=player_embedded&v=l5gwcAy65Bo

7H: Push Girls is an American reality television series on the Sundance Channel. The series officially premiered on June 4, 2012. The series follows the lives of four women who have been paralyzed by illness or an accident, and displays the day-to-day challenges and triumphs they encounter. The series is set in Los Angeles, California. Video source: http://www.youtube.com/watch?feature=player_embedded&v=C--6tZGVDAs
Horizon follows three people with disabilities to see if, within their lifetime, they can be cured. After a car crash, Sophie was left paralyzed from the waist down; Anthony’s leg was amputated after a rugby accident; and Dean has a damaged heart. They’ve all read the headlines about the astonishing potential of stem cells to heal the body. Now they’ve been given access to the pioneering scientists who could transform their lives. Video source: http://www.youtube.com/watch?feature=player_embedded&v=HeyAsZY5Y9U
APPENDIX C – PREFOCUS GROUP EMAIL

SENT: Thu, Mar 22, 2012 at 10:42 PM

Hello Everyone,

Below, I have provided links to some videos and articles. I have also listed a few questions to consider. Visiting these links, watching the videos, and considering the questions are completely optional. If you choose not to view these links/videos (or simply don't have the time), it will in no way adversely affect you during the focus group.

Enjoy!

Links and examples:

1) This is a documentary entitled "Shameless: The Art of Disability." This documentary is 71 mins and 30 secs long. Here's the official description: "Art and activism are the starting point for a funny and intimate portrait of five surprising individuals with diverse disabilities. Packed with humour and raw energy, this film follows the gang of five from B.C. to Nova Scotia as they create and present their own images of their disabilities." http://www.nfb.ca/film/shameless_the_art_of_disability/

2) This an short advert from Bulgaria promoting diversity in media. This group emphasizes the motto, "We're people first, then we're different". http://www.youtube.com/watch?v=vpP-zO-H7zI

3) This is a blog post about an episode of "Say Yes to the Dress: Atlanta," which featured a soon-to-be-bride in a wheelchair: http://www.beautyability.com/2.0/2012/03/03/3312-say-yes-to-the-dress-atlanta-features-wheelchair-bride/. I also found a video clip of the episode (please excuse the advertisement at the start of the video): http://www.huffingtonpost.com/2012/03/02/say-yes-to-the-dress-atlanta_n_1316918.html

4) This is a TED Talks video by Aimee Mullins. The official description is: "The thesaurus might equate "disabled" with synonyms like "useless" and "mutilated," but ground-breaking runner Aimee Mullins is out to redefine the word. Defying these associations, she shows how adversity -- in her case, being born without shinbones -- actually opens the door for human potential. A record-breaker at the Paralympic Games in 1996, Aimee Mullins has built a career as a model, actor and advocate for women, sports and the next generation of
Questions to think about:

1) What are some of the most common stereotypes about women with disabilities present in the media?

2) What kind of roles do women with disabilities play in the media?

3) What are some of the myths about disabilities that the media creates?

4) Can you think of a few examples you’ve seen of disabled women in the media (in magazines, movies, television, etc)? What did they look like and how did you feel about them?
Seeking Participants

Are you a female, 18 years or older, with a physical disability?

I am a female graduate student at UNB with a physical disability and I’m working on a project about the representations of women with physical disabilities in the media.

I am seeking participants who will work collaboratively with me, the researcher, to analyze these representations in a focus group setting, and challenge them through the construction of new photographic imagery.

If you are a female with a physical disability and would like to participate, or want more information, please contact:

Rachel Watters, Researcher
Phone: (506) 260-1081
Email: rachelwatters@gmail.com

This project has been reviewed and approved by the Research Ethics Board of the University of New Brunswick and is on file as REB 2011-123.

Thank you for your consideration.
I am a female graduate student at UNB with a physical disability and I’m working on a project about the media representations of women with physical disabilities.

Participants will work collaboratively with me, the researcher, to analyze these representations and challenge them through the construction of new photographic imagery.

If you are a female with a physical disability and would like to participate, or want more information, please contact:

Rachel Watters, Researcher
Phone: (506) 260-1081
Email: rachelwatters@gmail.com
I understand that I am being asked to participate in a research study conducted by Rachel Watters, a graduate student in Interdisciplinary Studies at the University of New Brunswick. The results of this study will be used in Ms. Watters’ Master’s thesis, as well as subsequent presentations and publications.

I understand that if I have any questions or concerns about the research, I can contact:

**Rachel Watters**, Graduate Student/Researcher, University of New Brunswick
Phone: 506-260-1081

**Dr. Linda Eyre**, Faculty Supervisor
Phone: 506-453-5161

**Dr. Ed Biden**, Dean of Graduate Studies
Phone: 506-458-7154

I also understand that, if I so wish, I can withdraw my consent at any time and discontinue participation without penalty. I understand that I am not waiving any legal claims, rights or remedies because of my participation in this research study.

This project has been reviewed by the Research Ethics Board of the University of New Brunswick and is on file as REB 2011-123. If I have questions regarding my rights as a research participant, I may contact:

**Research Ethics Board**
R. Steven Turner, Chair of the Research Ethics Board
Renée Audet-Martel, Secretary
Sir Howard Douglas Hall, Room 212
University of New Brunswick
P.O. Box 4400, Fredericton, NB
Canada E3B 5A3
Tel: (506) 453-5189
Fax: (506) 453-3522
E-mail: ethics@unb.ca

You will be given a copy of this consent form and the project description to keep with your records.
CONSENT FORM

My signature below indicates that I have read the project description and that I agree to participate in Ms. Watters' study on the representations of women with physical disabilities in the media.

_________________________________________  ____________________________
Signature of Participant                     Date

_________________________________________
Printed Name of Participant

_________________________________________  ____________________________
Researcher's Signature                       Date
I, ________________________ , do hereby give to
__________________________ (the Photographer), permission to use my photograph
ONLY for conference presentations, publication in journals, and in the photographer’s
Master’s thesis. All other publications of my photograph are not permitted unless I give
written permission prior to publication.

I also agree that the Photographer owns the copyright to my photograph and I cannot sell
the images, or works derived therefrom, for profit or publish them without credit to the
photographer.

I am of full age and competent to sign this release. I agree that this release shall be
binding on me, my legal representatives, heirs, and assigns. I have read this release and
am fully familiar with its contents.

Participant: ________________________ Signed: ________________________

Contact Information: ________________________

Date: ____________, 20 ____
APPENDIX H – PROJECT DESCRIPTION

PROJECT DESCRIPTION
Title of Project: “Look at Me”: Disability, Representation, and the Female Body

PURPOSE OF STUDY:
This study will explore the representations of women with physical disabilities in the media then subvert and challenge those representations through the construction of new photographic imagery. The goal is to allow women with physical disabilities to take part in the research process, work collaboratively with the researcher, and challenge how women with physical disabilities are typically represented.

I will organize two focus group sessions with ten women in New Brunswick who have physical disabilities. Through in-depth discussions we will interpret and analyze images of physically disabled women in the media. Up to five of the participants will also work with the researcher to create a series of photographs that subvert these representations.

There are three main questions in this study:
1. How are women with physical disabilities represented in photographic images found in the media?
2. How do women with physical disabilities respond to these images? How do the images contribute to the construction of their identity, or sense of self?
3. How would women with physical disabilities represent themselves?

The information and insights collected in this study, as well as the photographic images made in connection with it, will appear in the researcher’s M.A. thesis. In addition, the findings and photographs may also be used by the researcher in future scholarly publications, presentations and reports.

PROCEDURES:
If you volunteer to participate in this study, you will be asked to do the following:

Focus Group
The first step of the research process involves being part of a focus group with ten women who have physical disabilities. This group will meet on two separate occasions:
1. The first focus group session will discuss photographic images of women with physical disabilities found in the media, including those in advertising, fashion, the art world and so forth. During this session,
participants will be asked to choose five women from the group who will work collaboratively with the researcher to construct new photographic representations of physically disabled women. This session will take approximately 2 to 3 hours to complete. Refreshments will be available.

2. The second focus group session will take place after the photographs have been completed. In this session we will discuss and analyze these new visual representations. The second focus group will take approximately 1 to 2 hours to complete. Refreshments will be available.

Prior to the first focus group session, you will receive questions that encourage you to think about the subject matter being discussed. You are also encouraged to bring your own questions, if you so desire.

Please note: Because the researcher has a moderate hearing impairment, each focus group session will be audio and videotaped. The resulting audio and video footage will be stored in a secure and locked cabinet for a total of one year, then destroyed. The footage will not be used for any purpose outside this study, unless written permission is obtained from the participant.

Photographs
During the first focus group, you and the other participants will work together to choose five members from the group who will work with the researcher to create two photographic self-portraits. Participation in the photographs is optional and voluntary.

If you decide you would like to be photographed, the first photograph will be constructed entirely by you— it is your message and your voice. The researcher, who is also a professional photographer, will take the photographs and assist in creating any “look” or “atmosphere” you wish to convey.

The second photograph will be a collaborative effort between you and the researcher. You will work together to construct an image, and a message, under the theme of “fantasy”. This theme was chosen in order to play on the idea that only in a fantasy world could a disabled woman control her own image.

Collaboration
Once the focus groups and photographs are completed, the researcher will work on analyzing the information obtained. During this time, the researcher may contact you to gain clarification on an issue or ask a follow-up question.
Toward the end of this project, you will also have the opportunity to look at how the researcher has interpreted and represented your contribution(s) and suggest appropriate changes to the final text and/or your images, if applicable. It is up to you whether you wish to respond.

QUALIFICATIONS:
You must be female, or self-identify as female, 24 hours a day.
You must be at least 18 years of age.
You must have a physical disability.
You must currently reside in New Brunswick, or be willing to travel to New Brunswick.

POTENTIAL RISKS:
There are no risks in participating in this research beyond those experienced in everyday life. You have the right to refuse to answer any questions, and you can choose to leave the focus group at any time without consequence.

EXPENSES:
All equipment, if applicable, will be provided.
You are responsible for organizing your own transportation to and from the focus group sessions.

CONFIDENTIALITY:
Every effort will be made to ensure confidentiality of identifying information that is obtained in connection with this study.

At the beginning of the study, you will be assigned a pseudonym that will be used throughout the thesis. Your real name will never be used and all other identifying information will be removed from final paper. Additionally, your identity will not be revealed in any future publications or presentations of the work.

Since this study includes a focus group, you should be aware that your identity, and any opinions you express in the focus group sessions, may not remain completely confidential as they will be known to other participants in the group.

The researcher will maintain complete confidentiality but it may not be possible to hold others in the group to the same pledge. However, at the beginning of both focus group sessions, the researcher will impress upon all members of the group the importance of
keeping both the identities and opinions of other group members confidential and ask that they respect this request.

PLEASE NOTE: Participation in the photography section of this study may also make it difficult to maintain complete anonymity. Since your image will be displayed in the thesis there is a possibility that someone may recognize you.

Also, although your pseudonym will not be attached to any photographs, your disability will likely be described in the thesis, which may allow readers to link a disability to a photograph. But, as previously mentioned, no other identifying information will be used and all efforts will be made to preserve your privacy.

All audio and videotapes will be kept in a locked filing cabinet in the researcher's home during the study. Upon completion, the original audio or videotapes will continue to be stored in a locked filing cabinet for one year, at which point they will be destroyed. No one aside from the researcher will hear or see the audio and videotapes without written permission from the participants.

PARTICIPATION AND WITHDRAWAL:
Participation in this study is completely voluntary. You may withdraw at any time without consequence. You can end your participation at any time by telling the researcher, the faculty supervisor or the Dean of Graduate Studies.

If you choose to participate in the photography section, you will have an opportunity to approve your images before they are presented at the second focus group session. If you are not completely happy with one, or both, of the photographs they can be altered, redone or removed.

This project has been reviewed by the Research Ethics Board of the University of New Brunswick and is on file as REB 2011-123.
ACADEMIC CURRICULUM VITAE

RACHEL WATTERS
500 Riverside Drive, Unit 12, Fredericton, N.B. E3A 8C2 | 506-206-2706 | rachelwatters@gmail.com

EDUCATION
New Brunswick College of Craft and Design, Fredericton, NB
**Diploma in Graphic Design** 2009
Graphic Design, Fine Arts

NSCAD University, Halifax, NS
**Bachelor of Fine Arts** 2004
Photography, Fine Arts

RELATED EXPERIENCE
Still Watters Photography, Fredericton, NB
**Owner/Photographer** 2007 – 2013
Started a professional photography business in 2007 that offers pet portraits, portfolio work, fine art photography, real estate photography, and more.

Development and Donor Relations, UNB Campus, Fredericton, NB
**Stewardship Writer & Researcher** 2010 – 2011
Researched information on students, staff members, and donors; compiled information into easy-to-read reports; wrote correspondence, congratulations, and condolence letters on a weekly basis; researched and wrote grant proposals and news articles.

New Brunswick College of Craft and Design, Fredericton, NB
**Research Assistant** 2009 – 2010
Researched art education and leadership methodologies; assisted in marketing and web site management; assisted in the creation of curriculum materials; created templates for organization of academic information.

Fredericton Community Foundation, Fredericton, NB
**Research Assistant** 2009
Researched and created a “brag book” of past award recipients; redesigned website; compiled tax information about local non-profit groups; designed a how-to guide on non-profit governance.

New Brunswick Advisory Council on the Status of Women
**Research Assistant** 2005
Researched topics related to women’s issues including spousal abuse; wrote summaries of articles, documentaries, and reports; compiled research into concise and easy-to-read reports for senior staff members.

Communications New Brunswick, Fredericton, NB

**Photography Assistant** 2003

Assisted the on-staff photographer with stock photography, portraits, and on-site shoots; Assisted in the maintenance of the CNB image databank.

**PUBLICATIONS AND PRESENTATIONS**


**PROFESSIONAL DEVELOPMENT**

Visual Design with Freeman Paterson 2011

NBCC Grant Writing Workshop 2010

**LANGUAGES**

English – native language