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# A methodological approach to examining racial and ethnic minorities with disabilities: intersecting and interlocking race/ethnicity, disability, and gender

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A methodological approach to examining racial and ethnic minorities with disabilities:  
intersecting and interlocking race/ethnicity, disability, and gender

By

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A thesis submitted to the graduate faculty  
in partial fulfillment of the requirements for the degree:

MASTER OF SCIENCE

Major: Sociology

Program of Study Committee:  
Betty Dobratz, Major Professor  
Nancy Evans  
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Iowa State University

Ames, Iowa

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## DEDICATION

I would like to dedicate this thesis to all the wonderful people who helped me along this journey. I owe a significant debt to all of them. First, I would like to express my gratitude to Dr. Riyad Shahjahan. He was the first person who recognized my need and the importance of my being able to understand and express my internal struggles in order to gain a sense of inner peace. Because of Dr. Shahjahan, I was able to gain a deeper understanding of who I am and how my multiple identities connect with society. He helped me see myself as a whole person through my writing; so I am no longer a fragmented person. To Dr. Stephanie Bondi and Dr. Michael Benitez Jr., I wish to express gratitude for helping me along this journey and allowing me to be privy to your personal struggles to understand self and social justice. I feel privileged to know you both and to have you in my life. I wish to express my gratitude to Dr. Nana Osei-Kofi for challenging me to engage with social justice and Disability Studies in new ways that allow me to weave parts of who I am into this educational journey. To all, thank you for challenging me to see even the smallest insignificant details in a different light that keep reminding me to not take things for granted. Last but not least, to my mom, I wish to express the deepest gratitude for her helping me complete this task by spending hours and hours editing and giving me feedback that enabled me to turn my often convoluted thoughts into coherent thoughts. Thank you.

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## ABSTRACT

In the past several decades, disability, race, class, gender, and sexuality have been critically examined to determine how disability shapes and is shaped by society. That disability is interpreted and defined from a nondisabled perspective and continues to be researched, debated, and discussed in isolation from the other fields remains an issue. There is a need to problematize and complicate disability by enabling those with disabilities to voice their experiences. Drawing upon a phenomenological research approach and an intersectionality and normalcy framework along with conversations with five racial/ethnic minorities with disabilities provides the opportunity to demonstrate that disability is not an isolated experience but part of the everyday process by showing how disability is a social identity and social phenomenon. In order to continue to challenge the field of Disability Studies, there is a need to continually expand our understanding of disability through application of different lenses and intersecting race, class, gender, sexuality, and disability to gain new insights and move towards social justice and social change.

## CHAPTER 1: INTRODUCTION

### Introduction

In the past few decades, there has been an increasing demand to critically address the topic of disability. Disability is an ambiguous term that conceals a broad spectrum of physical and mental conditions ranging from slight to severe (Linton 1998). Disability contains multiple meanings: the lack of ability, differently abled, personal tragedies, medical and social problems, biological deficiencies, incompetence, adversities, and painful, accidental, troublesome, and inconvenient conditions (Barnes and Mercer 2010; Davis 1995; Michalko 2002; Striker 1999; Titchkosky 2006). The generalized meaning of disability echoes the negative undertone of being different from the general population. Due to disability's strong association with biological deficiency and personal tragedy in the 1960s, an increased global movement challenged the individual notion of disability and how social, economic, cultural, and political institutions excluded disabled people from inclusion and citizenship rights. It was not until the early 90s, when academicians and disabled people challenged what disability meant, that the prominent field of Disability Studies was established (Barnes and Mercer 2010; Johnstone 2001).

Disability Studies is an interdisciplinary field that explores the question: "what is disability?" Because Disability Studies employ multiple fields such as the arts, politics, economics, society, culture, philosophy, education, social sciences, law, humanities, medicine, psychology, and history in understanding the meaning and construction of disability (Ferri and Conner 2006; Gabel 2005; Johnstone 2001; Linton 1998), disability is considered a "social, political, cultural, discursive phenomenon rather than an individual or medical one" (Ferri and Connor 2006: 14-15). Answering the question of what disability is

reveals that there is no singular accepted definition of disability, just as there is no single homogenous experience of disability. Disability Studies provide grounds to understand disability culture, social change, and social justice (Johnstone 2001; Linton 1998). The fields of medicine, psychology, sociology, and anthropology defined disability as deviant from social norms and culture. Since then, individuals and groups of people with disabilities have come together to challenge disability as deviant by applying a socio/political perspective to disablement (Johnstone 2001). Over the past couple of decades, Disability Studies criticized the presence of the inaccurate representations of disability and the absence of problematizing disability.

Even with the strides Disability Studies have made, disability remains marginalized in both academic and general literature, and even with the increased awareness of disability issues, disability remains a taboo subject (Davis 1995; Linton 1998). There has been an increase of writers who push for a more critical and complex stance on disability such as Davis (1995; 1997), Gabel (2005), Linton (1998), Michalko (2002), and Titchkosky (2006). Multiple authors argue the need to consider the direction that Disability Studies must take to progress (Barnes, Mercer, and Shakespeare 1999). This is problematic because the failure to discuss disability and its continued marginalization perpetuates a dominant hegemony that disability is not a subject that needs to be critically examined or discussed; it assumes disability is not part of everyday life and fails to challenge or question normalcy and consequently takes normalcy for granted (Davis 1997; Linton 1998). While multiculturalism, classism, racism, sexism, feminism, queer studies, sexuality, and other subjects have been critically contested and overlapped, disability and the body remain uncontested and isolated reflecting the dominance of the ablest culture (Davis 1995). There

is a need to complicate disability by fusing the interpretations and experiences of persons with disabilities and Disability Studies through all institutions, rather than keeping it a segregated field, which only reinforces the notion of disability as a separate experience (Barnes, Mercer, and Shakespeare 1999; Gabel 2005). To complicate disability is to shift away from the simplistic notion of disability as a medical condition or a social construction in order to demonstrate that disability is a social identity, a social phenomenon, and part of the everyday process along with race, class, gender, and sexuality.

### Overview of the Thesis

The focus of this thesis is to explore the circumstances and attitudes of those racial/ethnic minorities with disabilities to not only restore the subjective everyday experiences of disability but also intertwine disability with the social categories of race, class, gender, and sexuality. Disability persists as a separate phenomenon that is not part of race, class, gender, and sexuality; and the fields of race, class, gender, and sexuality continue to expand without including disability as part of the picture. There is a need to overlap and crisscross fields in order to expand and challenge our understanding of all of the social categories and how they shape one another. More voices of those with disabilities must be incorporated into the academic literature. The general trend is to study persons with disabilities and the concept of disability as objects of research resulting in definitions and descriptions of the disability experience by the nondisabled. Moving towards a more inclusive approach requires that persons with disabilities be presented opportunities to vocalize their experiences rather than have them expressed on their behalf.

After describing the medical and social models of disability, which exert considerable influence in shaping disability concepts and Disability Studies literature, the subjective

experiences of racial and ethnic minorities with disabilities will be examined. Different approaches must be utilized to explore the question of “what disability is,” in order to understand why there is a need for a more holistic approach that includes the perspectives of racial and ethnic minorities with disabilities. Following the literature review, the theoretical framework and methodology chapters describe and justify the approaches this thesis implemented to explore the experiences of racial or ethnic minorities with disabilities. This thesis is a qualitative phenomenological study of the experience of ethnic and racial minorities with disabilities. The study consisted of in depth interviews with five college aged participants about their personal experiences of dealing with race, gender, and disability. It is important to recognize that this study emphasizes race, gender, and disability, but does not indicate exclusion of sexuality and class in aspect of intersectionality.

I also included a chapter that discussed my own personal experiences because I felt it was essential for me to convey how my personal experiences motivated me to pursue this topic. Following the methodology chapter, the data results chapter is divided into three sections where the participants discuss their experiences, how they perceive and feel about their disabilities, how they perceive themselves in terms of race, class, gender, and sexuality, and how all of those identities influence their everyday lives. In the discussion chapter, I weave together the participants’ experiences and the theoretical framework to explain how disability is a social identity, a social phenomenon, and part of the everyday process. Through the discussion, I hope to convey the urgent need to complicate disability by shifting towards a more holistic approach to disability that enables those with disabilities to voice their feelings, thoughts and insights. Providing a space for the participants to express their knowledge allows the readers to see those with disabilities as whole persons with diverse

social backgrounds rather than simply as a disability, a medical condition, or a social construction; in other words, it puts a face back on disability.

## CHAPTER 2: REVIEW OF LITERATURE

### Introduction

The focus of this chapter is to give a comprehensive overview of the literature on disability that has been published in the past few decades. The field of Disability Studies presented different ways of understanding disabilities. In order to understand the evolving meaning behind disability, there is a need to understand the approaches utilized in explaining the ultimate question of “what disability is.” The chapter begins with the two pervasive implemented models: the medical model and the social model. The medical model influences the common idea of what disability is: the medical conceptualization of disability. The social model developed in response to the medical model by contesting that disability was not simply a medical condition, but it was a social construction shaped by societal forces. The social model also shifts away from the individualized disability notion by recognizing how social institutions shape disability. Through the lenses of the social model, we examine how disability is not just a social construction but also a form of oppression created by social institutions such as: education, family, housing, finance, employment, culture, and the built environment.

After the social model became well established, multiple authors argued the need to bring back the voices and personal experiences in order to broaden our understanding of disability. This involved seeing how disability is a construct that is continually shaped and defined through social interaction, understanding how those with disabilities perceive themselves, and how their disabilities influence their lives. There has been effort to complicate disability with race, class, gender, and sexuality. From this body of literature, there is recognition of the need for new paradigms, theories, practices, and policies that will

shift beyond the medical and social models of disability toward a more inclusive approach to disability that enables both collective and individual experiences to co-exist. Utilizing a more inclusive and intersectionality approach disrupts the notion that disability is an isolated, homogenous, and segregated experience.

### The Medical Model of Disability

Understanding the meaning of disability requires understanding the evolution of the two prevalent models of disability: the medical and the social models of disability. The medical model, the biomedical paradigm, or the medical-diagnostic explanation concluded that disability is impairment, a deviation, something that needs to be fixed, or a personal tragedy. In the 1980s, the field of Disability Studies provided a space for those who have experience with disabilities to critique and contest the medical concept of disability resulting in a distinction between the medical and the social models of disability (Barnes, Mercer, and Shakespeare 1999; Davis 1995; Johnstone 2001; Michalko 2002; Turner and Stagg 2006).

The combination of the nineteenth and early twentieth century's national movements, modern eugenics, and the advancement of medical science and technology were instrumental in the re-conceptualization of disability (Barnes, Mercer, and Shakespeare 1999; DePoy and Gilson 2004; Titchkosky 2006; Turner and Stagg 2006). During the 18<sup>th</sup> century, increased industrialization and urbanization changed the community, work force, and family life. Industrialization contributed to the ideology of ableness through the themes of production, progress, and strength. The rapid rise of industrialization involved a huge demand for bodies physically able to perform heavy labor, which indicated what was desirable and perpetuated the social norm of ableism. Those who were not physically able to participate in the industrializing workforce were not able to integrate into the rapidly urbanizing industrial

work force or contribute economically; consequently they became economically dependent social problems (Barnes and Mercer 2010; Davis, 1995).

This notion of ableism persisted through the 18<sup>th</sup> century by the proponents of Eugenics and Social Darwinism who perceived disability as a threat to civilization, and it contributed to “fixing” or “curing” disability with medical solutions (Barnes, Mercer, and Shakespeare 1999; Davis 1995; Turner and Stagg 2006). The rise of medical solutions in response to disability and increasing longevity resulted in an expansion of rehabilitation programs, medical services, and charitable acts in an attempt to improve the human race through advances in medical science and technology (Barnes, Mercer, and Shakespeare 1999; Barnes and Mercer 2010; DePoy and Gilson 2004). This is not to argue that those advancements and scientific knowledge do not have substantial impact on the quality of life (DePoy and Gilson 2004; Gabel 2005). What is apparent is that science and medicine play an influential role in the construction of disability.

The medical model dominates the understanding of the body and what is considered normal and abnormal, but only from a limited medical perspective (Michalko 2002). The medical model perceives disability as a biological or physiological impairment, a medical problem naturally requiring medical professionals because only they have the proper medical credentials and expertise (DePoy and Gilson 2004; Johnstone 2001; Michalko 2002). This legitimized the medical community’s right in creating guidelines defining what was normal and what was not, thus creating a distinct minority population that did not previously exist. In the mid 20<sup>th</sup> century, the term disabled was created when trying to determine eligibility criteria for social services and welfare benefits. There was a demand for explicit assessment and measurements of the individual’s functional limitations in everyday activities. The

measurements were based on the person's physical ability to toilet, dress, eat, and perform other daily tasks. The measurements and degree of eligibility continued to become more defined or broad as the definitions of impairment, disability, and handicapped expanded from simple physical limitations to any degree of physical, psychological, or physiological abnormality. In the medical model, disability became a functional limitation, an individual pathology, a biological deficit, an abnormality, or a personal tragedy.

In the late 19<sup>th</sup> century, medical domination legitimized the individual approach to disability (Barnes and Mercer 2010). The medical and rehabilitation approach to disability contributed to and maintained disability as individual ability-based criteria (Titchkosky 2006). Perceiving disability as solely a medical problem enables medical professionals, educators, and rehabilitation specialists to exercise considerable influence over what constitutes disability and the approaches used in curing or minimizing the effects of the impairment (Barnes, Mercer, and Shakespeare 1999; DePoy and Gilson 2004; Johnstone 2001; Michalko 2002; Turner & Stagg 2006). The medical model of disability emphasizes medical knowledge, objective diagnosis, treatment and measurement of recovery as the means of ending or minimizing the disability itself or enabling the person to return to the closest state of ableism as possible (Barnes, Mercer, & Shakespeare 1999; Barnes and Mercer 2010).

The medical community sees disability as either a need for human intervention or an accident of nature, thus an unnatural biological condition. Seeing disability as an unwanted biological condition implies a negative connotation, or in other words, that disability is not desirable. This creates an unnatural symbiotic relationship between suffering and disability, which in turn legitimizes the societal concept of a natural and healthy body. A complete and

healthy functioning body is considered normal; hence, limitations or impairments such as hearing loss, obesity, missing limbs, and blindness are indicators of abnormality. The medical model presents disability with a dual contrast, a stratified dualism; therefore, ranking disability as an abnormal medical problem justifies seeing disability as impairment or a social problem that needs to be cured or fixed (Johnstone 2001). Rehabilitation, social assistance programs, medical programs, and educational programs are oriented around enabling individuals to overcome or minimize their limitations in order to become whole functioning members of society; thus molding the notion of normality and abnormality (Michalko 2002). This framework creates the assumption that a normal body or sameness is considered desirable, which is reinforced by the growth in demand for medical rehabilitation programs and services. As Michalko (2002) stated, “Society will do its bit by providing medical, rehabilitative, and special education services as methods for transforming otherness into sameness” (63). These industries shaped not only the meaning of disability but perpetuated the social normalcy of wanting a wholesome body.

There is also an unnatural association between disability and personal tragedy (Michalko 2002). Paul Hunt (1966) interviewed twelve individuals to learn how their impairments influenced their relationships with normal able-bodied people. Hunt noted that disabled people are perceived as unfortunate because they are not able to fully enjoy marriage, parenthood, social status, independence and freedom, or employment, thus personal tragedies. This reinforced the notion in the 18<sup>th</sup> century that those who could not contribute to the economic household were deemed useless. Those who were disabled were isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled (Davis 1997). Davis (1995) argued the importance

of considering the normalization of negative or violent responses towards the stigmatized body. An intact body is healthy when detailing no missing limbs or senses. Suffering and disability are associated with “bad,” “negative” or “pitiful” emotions, a state no one wishes for, and this is also reinforced by the growth and expansion of medical services and programs to prevent suffering from disability (Michalko 2002; Newman 2004).

Positioning disability as a focal point of a person demonstrates the saliency of disability as a person’s problem, an individual problem as reflected in the medical interventions and rehabilitation emphasis on the person’s ability to eat, dress, and toilet independently in order to overcome the disability (Barnes, Mercer, and Shakespeare 1999; Barnes and Mercer 2010). This definition creates a choice: individuals may choose to suffer with their disabilities or to choose to overcome their disabilities. A society that views illness and impairment as a health issue that needs to be prevented, treated, and cured reinforces the notion that illness and impairment are not desirable. In other words, “to have a disability is to have something wrong with you” (Oliver 1996b: 30). The accepted norm of ableism and medical solutions connotes the assumption that all people with disabilities will make every effort to strive to be able-bodied (Barnes, Mercer, and Shakespeare 1999).

Medical professional domination revolves around their physical and social control over illness, such as normalizing the response that illness requires biomedical treatment and is legitimized through stories of those who overcame their illnesses or disabilities, which in turn reinforces the normalcy of the medical response and the desirability of having an able body (Barnes, Mercer, and Shakespeare 1999; Michalko 2002). To repackage one’s ability to overcome illness as individual empowerment and accomplishment disguises the domination of medical and professional institutions over impairment and disability. This is

not to criticize medical and technological advances, but to recognize the individual's inclination to undergo rehabilitation and adjustment and the absence of considering social factors such as stereotypes, prejudice, discrimination, and oppression (Abberley 1993; Barnes and Mercer 2010; Shakespeare and Watson 1997).

The problem is that the individualized medical model remains the dominant ideology. Distinguishing disability as medical abnormality changes impairment into an individual problem that excludes economic, political, historical, social, and cultural factors, which play a role in the construction of disability (Michalko 2002; Titchkosky 2006). This approach shifts the focus towards understanding and fixing the deviation through science and medicine but excludes social and environmental factors. This philosophy is what the Disability Movement came to challenge in the 1960s (Barnes and Mercer 2010).

#### The Social Model of Disability

Before the 1960s, there was limited literature that challenged the negative stereotypes and prejudices towards disability or disability as social deviance. After the 1960s, people with disabilities, activists, and writers unified to protest against disabling attitudes and social barriers in education, employment, income and financial support, housing, transportation, sexuality/reproduction, and the built environment. This signaled a shift from disability as an individual problem or personal tragedy to a social, structural, and institutional construction of disability, or in other words, a social model of disability (Barnes, Mercer, and Shakespeare 1999).

As a framework, the social model was developed to oppose the medical model by complicating disability. The central distinction between the two models is that the medical model sees disability as an individual problem, while the social model sees disability as a

product of social construction (Davis 1995; Gabel 2005; Michalko 2002; Titchkosky 2006). This framework complicates the notion of disability by shifting away from the biological body that needs to be fixed to the external institutional components (political, economic, social, historical, educational, and cultural components) that frame the concept of disability. The social model explores how these external institutional components frame the concept of disability and how the medical model reinforces an inaccurate image of disability by devaluing the experience of disability and focusing on fixing the problem (Barnes, Mercer, and Shakespeare 1999; Davis 1995; DePoy and Gilson, 2004; Gabel 2005; Johnstone 2001; Michalko 2002; Titchkosky 2006; Turner and Stagg 2006).

Expanding beyond disability as a medical condition allows one to see how disability is a part of everyday experience. Maintaining and reinforcing the notion of disability as a medical condition and not one that is socially constructed conveys that disability is “unexpected, undesired, asocial, apolitical, [and a] bodily condition” (Titchkosky 2006: 155); therefore the field of Disability Studies requires considerably more critical social research and political action from the lens of those who have experience with disabilities. Disability is not a new social phenomenon but a social construction that has been continually reconstructed throughout history by political, economic, social, historical, and cultural factors (Davis 1995; Titchkosky 2006).

Shifting away from individual limitations by focusing on the structural causes of disability is the main difference in the approaches of the medical and social models of disability. The social model of disability critically examines the social barriers that construct everyday experiences with disability emphasizing the importance of society’s organizational institutions such as economics, politics, and culture that oppress those with disabilities

(Barnes, Mercer, and Shakespeare 1999; Barnes and Mercer 2010; Johnstone 2001). The social model separates impairment and disability in an effort to be distinguished from the medical model. That does not mean that impairment and illness do not have limitations or that treatments are not valuable. To shift away from experiences and the impacts of impairment allows the social model to refocus on disability and social institutions that would shift towards social structural changes rather than focus on individual personal accounts of impairment (Barnes and Mercer 2010; Finkelstein 1996; 2002; Johnstone 2001). The personal tragedy approach or individual focus does not allow one to see the bigger picture of how social institutions play a role in the disability experience (Oliver 1986).

The social model stresses theorizing and tying disability to political actions while addressing citizenship rights, equal opportunity, inclusion, and social justice. This approach allows those with disabilities to not just voice their experiences with disability, but to gain understanding and control over their lives (Barnes and Mercer 2010; Johnstone 2001; Oliver 1992). The significance of the social model is to collectively work towards constructive solutions through understanding why the societal barriers exist in the first place and to pursue collective political action and social change to tear down those social barriers (Barnes and Mercer 2010; Johnstone 2001; Swain, French, and Cameron 2003).

The social model has been useful in generating new literature on disability, but there is considerable debate over the social model's exclusion of impairment in order to focus only on disability and the roots of social barriers in order to distinguish itself from the medical model's approach (Abberley 1987; Barnes and Mercer 2010; Gabel 2005; Shakespeare 2006; Tremain 2002; 2005). Some argue that it is wrong to exclude the significance of impairment. The issue with this approach is that the social model (as well as the medical model) creates a

generalized homogenous concept of disability that excludes disabled people's experience of dealing with the impairment. To consider only social institutions such as economics, capitalism, industrialization, culture, society, medicine and politics as social factors that shape disability is open to analytical reductionism. Disability is not a homogenous universal experience. Thus in order to fully understand disability, there is a need to complicate the disability and impairment experiences. There is an increasing rejection of the divide between impairment and disability because they are not singular or separate experiences. Disabled feminists argue that there is a need to bring impairment and disability back together because disabled people do not normally separate the two in their actual experience; and personal experiences are also significant (Barnes and Mercer 2010, Crow 1996; Morris 1991). To ignore the impairment or the body experience is to indicate that physical differences and restrictions are based solely on social creation (Morris 1991).

It is important to note that societal barriers and social attitudes do play a role in the shaping of one's experience and that social change cannot completely erase the experience of the impairment itself. For instance, blindness and hearing loss will continue to influence one's ability in everyday activities and interactions regardless of societal barriers, so the personal and subjective experiences of disability cannot be ignored (Barnes and Mercer 2010; Crow 1992; French 1993; Scott-Hill 2004; Shakespeare 2006). When considering disability and Disability Studies, one needs to think about how the bodies are represented while noting 'the significance of material and cultural context' (Barnes and Mercer 2010; Shilling 2003; Turner 2001). In other words, impairment and disability are neither socially or culturally neutral nor segregated (Barnes and Mercer 2010; Shakespeare 2006).

Impairment and disability are two concepts that are difficult to extract or separate because of

the intertwined biological, psychological, cultural, social, and political elements that shape both. It is important to understand that the social model does not explain what disability is, but how disability is shaped by social institutions (Barnes and Mercer 2010; Oliver 1996b). As a model the goal is to generate social theory that provides explanations and understanding of disability that shift toward social and political change and that improve the lives of those with disabilities by examining how family, education, income, financial support, employment, housing, transportation, and the built environment impact those very lives (Barnes and Mercer 2010; Oliver 1996a).

### Disability and Social Institutions

Increasing amounts of literature have expanded on disability as a cultural and social product by examining disabled people's experiences with inequalities in their families, housing, education, finance, employment, culture, and the built environment. The heightening demand to politicize disability issues and equal rights contested the medical industry's influence over impairment and demanded disability be critically addressed as a form of social inequality (Albrecht, 1976; Barnes, Mercer, and Shakespeare 1999; Barnes and Mercer 2010; Blaxter 1976; Bowe 1978). Using the social model of disability enabled the researcher to analyze the structural barriers (economic, political, employment, family, built environment, education, housing and cultural barriers) to understand the factors that prevented those with disabilities from achieving lifestyles similar to those who are not disabled. The social model of disability questioned the existence of social barriers that play a significant role in one's ability to succeed and called for further research on social barriers to understand how the intersecting and correlating social divisions and social barriers

complicate disability and consequently shifted away from the individual concept of disability (Barnes and Mercer 2010).

### Education and Disability

Within the educational literature, the discussion focuses on the impact of segregated special education on those with disabilities and their livelihoods. There is a strong association between special education and disability due to the historic perception of disabled children as ‘not intelligent’ and their placement within a segregated education system (Barnes, Mercer, and Shakespeare 1999; Barnes and Mercer 2010). Since the 19<sup>th</sup> century, specialized segregated schools have catered to specific disabilities such as physical disabilities or sight and hearing impairments (Barnes and Mercer 2010; Winzer 1993). It was not until the 1990s, when the education system questioned the implication of segregated education on disabled children’s ability to succeed within society (Barnes and Mercer 2010). The disability theorists’ main argument is that the structure of special education constructs and maintains the oppression of disabled people (Barnes, Mercer, and Shakespeare 1999). Some studies demonstrate significant correlation between the gap in education and employment opportunities due to segregated education (Barnes and Mercer 2010). The studies revealed how special education generally focuses on social life skills rather than work skills development for future employment (Barnes, Mercer, and Shakespeare 1999).

To rectify this issue, there were three means of integrating the students with disabilities into mainstream education. The first was a segregated classroom within in the mainstream school environment; the second was to present opportunities for social interaction with the rest of the school population, and the third was to provide the opportunities for students with disabilities to take part-time or full-time classes with the rest

of the school population. The biggest challenge of integrating those with disabilities into mainstream schooling is that the education system implements a standardized curriculum and testing methods that do not address the needs of those with disabilities to succeed academically. The schools stressing high standardized test scores and repressing inclusivity, accessibility, and limited educational opportunities outside of the school for those with disabilities maintain and perpetuate the dominant discourse of academic success and ableism (Barnes and Mercer, 2010).

Regardless of segregated special education and the dominant mainstreamed education system, there has been a gradual increase of disabled students continuing their education beyond secondary school, but there is still a gap in their transition from education to employment opportunities. The studies point out that social disadvantages including finances, home environment, cost of medical treatment, segregated school curricula, and the lack of school facilities and resources all contribute to the gap between education and employment (Barton 1995; Barnes and Mercer 2010; Wade and Moore 1993). Segregated school facilities for those with disabilities continue and generate debates about the benefit of being around others with similar disabilities to the detriment of academic success with social isolation. Segregated school systems are able to present more accessible environments that have the technology and trained faculties that are able to help disabled students succeed academically. The problem with segregated education is the limited opportunities for students with disabilities to deal with the rest of society leading to socially awkward graduates. There is a demand for more inclusion and a broader curriculum that allows those with disabilities to learn along with their nondisabled peers and to interact socially with a wider population (Barnes and Mercer 2010).

## Employment and Disability

In employment and finances, people with disabilities experience various yet consistent degrees of exclusion, marginalization, and powerlessness (Barnes, Mercer, and Shakespeare 1999). Studies demonstrate that those with disabilities encounter societal and personal barriers obtaining and maintaining employment in order to become financially stable (Barnes and Mercer 2010). Among the people with disabilities, there are higher rates of unemployment, even with policies established to foster more employment opportunities. Unemployment rates are higher for minorities with disabilities (Barnes, Mercer, and Shakespeare 1999). There is a greater percentage of those with disabilities that are at or below the poverty line compared to the general population primarily due to limited access to resources such as employment insurance, pensions, housing, and other benefits. There is also a need to consider the cost of disability including the cost of medical equipment and adaptive equipment for treatment and transportation. Considerable debate centers around whether the benefits provided by welfare and social security are actually benefiting those with disabilities or holding them back (Barnes and Mercer, 2010).

Disabled workers encounter difficulty finding employment due to a workforce that perpetuates a dominant ideology of ableism and individualism preventing those with disabilities from becoming financially independent. Since 1945, the number of disabled people in the work force is significantly below the average for the general population. In addition, people with disabilities experience higher numbers and longer lengths of unemployment (Barnes and Mercer 2010). Those with disabilities tend to be clustered in less skilled employment, but since the 1990s there has been an increased number clustered within

managerial and senior official positions and professional careers (Barnes, Mercer, and Shakespeare 1999; Barnes and Mercer 2010).

Considering gender, the studies demonstrate that disabled women experience fewer job opportunities in those areas, and are more likely to be clustered within the less skilled jobs. Overall, those with disabilities are six times more likely to receive negative comments on their applications and evaluations regardless of adequate performance with minimal assistive technology (Barnes, Mercer, and Shakespeare 2010). Some argue that people with disabilities have difficulty finding employment due to employers not wanting to hire disabled people because they do not meet the educational and job requirements, that they require the extra cost of accommodations, or that disabled individuals do not apply for higher positions. The government attempts to present a solution by offering incentives for employers to hire disabled workers.

A changing workforce that is shifting toward flexible hours, increasing accessible technology, and home-based work could potentially lead to more opportunities, but creating barrier-free work environments is another hurdle that must be overcome (Barnes, Mercer, and Shakespeare 1999; Barnes and Mercer 2010). Others have argued the digital divide will work against those with disabilities and a percentage of the population, especially those with greater medical and support demands, will be excluded and more isolated (Abberley 1996; Barnes and Mercer 2005, Barnes and Mercer 2010). There is a growing awareness of the need to create employment opportunities and solutions by addressing the societal barriers those with disabilities encounter (Barnes and Mercer 2010).

## Family and Disability

Recently family studies have begun to explore how disability influences the lives and relationships within the family. Much of the research revolves around families with a disabled child, while it is limited with reference to parents who have disabilities. Parker's (1993) study noted that women with disabilities are vulnerable within gender roles because they earn less and are subjected to indirect discrimination. The studies recognize that whether mothers have disabilities or not, the mother is the primary caregiver. Other studies conclude that families with a disabled child living at home have increasing demands for community-based services.

Additional studies indicate that caregiver roles marginalize people with disabilities. Carol Thomas's (1997) study revealed three consistent themes within families with disabilities: pressure to be good mothers, mixed feelings about receiving help, and being perceived as a risk of passing on the disability intensifying the presence of genetic counseling and prenatal screening or other diagnostic or "normalizing technologies." The studies have indicated how disability can influence one's capacity to maintain a 'normal' lifestyle or whether a family with a disability can ever uphold the notion of normalcy. Inadequate social services may actually hinder the person's ability to reach the state of independence (Barnes, Mercer, and Shakespeare 1999).

## Accessibility in Built Environment and Disability

Accessibility within the built environment, housing, and transportation must be considered when promoting social inclusivity. Studies have demonstrated that the variety of disabilities hinders the development of accessible solutions, because one solution may be hazardous for someone with another disability. For example, "dropped kerbs favoured by

wheelchair users can be a hazard for people with visual impairment” (Barnes and Mercer 2010: 117). Nevertheless, physical access is gradually improving, but it is important to recognize that most architectural designs are for able-bodied people, and the ambiguousness of some disabilities hinders the development of barrier-free environments (Barnes, Mercer, and Shakespeare 1999). Most housing structures are designed for able-bodied persons and most architects do not consider the needs of those with disabilities unless instructed, resulting in limited available housing that provides accessible accommodations. As with work environments, adjustments and accommodations in housing are expensive, so owners are reluctant to make those accommodations (Barnes and Mercer 2010). Also, disabled people have lower incomes and buildings with built-in accessibility tend to be more expensive. Lower cost housing tends not to be accessible, putting those with disabilities in a bind (Barnes, Mercer, and Shakespeare 1999). There is a slow shift towards designing and building accessible housing (Barnes and Mercer 2010). Recently there has been a shift towards Universal Design as the result of the Disability Movement advocating for laws that required accessibility to public buildings, public transportation, and other public services. Universal Design involves designing accessibility within the architecture of the public facilities rather than following an add it on later approach.

Transportation to and from work and social activities plays a key role in social inclusion. Most of the disabled population is heavily dependent on public transportation due to limited economic resources. Studies have noted that the biggest challenge is getting to and from the public transportation sites and stops and getting in and out of public transportation vehicles. Environmental factors influence health, poverty, social activities, and relationships; multiple barriers make independence for those with disabilities generally less likely (Barnes,

Mercer, & Shakespeare 1999). Increasing awareness of the demands of those with disabilities has led to more accessibility friendly transportation including accessible doors and entryways for wheelchairs and both digitized and speech announcements for the hearing and visually impaired (Barnes and Mercer 2010). With increased awareness of disability issues gradual strides in all areas of accessibility have occurred to make the built environment, housing, and transportation more user friendly for everyone. It is important to acknowledge that the disability movement played an significant role in getting the legislation to implement accessible transportation.

### Culture and Disability

There has been considerable literature generated that explores the representation of disability in culture. Disability is strongly associated with personal tragedy due to persistent negative disabling stereotypes perpetuated by numerous factors throughout history (Campling 1981; Hunt, 1966; Shearer 1981). Since the Middle Ages, the public has been fascinated by and curious about those that are different, which is evident by the increasing numbers of public displays of those with abnormalities especially during the 19<sup>th</sup> century. The themes of disability continue to orient around passivity, victims, dependence, unproductiveness, health care, social welfare, and the triumph of overcoming disability, while excluding love, sex, and relationships. The problem with these representations is that they not only normalize how people perceive disability, but also influence how they interact with disabled people (Barnes and Mercer 2010; Johnstone 2001). In other words, the representations of disability are like a map that helps nondisabled individuals navigate the unfamiliar grounds of disability (Titchkosky 2006). The limited or missing portrayals of disability not only reflect social attitudes towards disability but also shape people's responses

to disability by affirming and normalizing that the normal reactions to disability include disgust, shunning, and fear of conditions that are different or abnormal (Barnes and Mercer 2010; Johnstone 2001).

During the 1960s and 1970s, the disabled community challenged the narrow representation of disability as a personal tragedy (Barnes and Mercer 2010). The disabled community challenged both the negative depiction of disability and the absence of critical challenges to the acceptance of disability as a natural biological condition that went awry, thus naturally unfortunate (Barnes, Mercer, and Shakespeare 1999). The disabled community pushed for positive roles and role models to counter the negative representation of disability as personal tragedy (Barnes and Mercer 2010). Some authors noted that this is a challenging goal due to conflicting ideas of what roles are considered positive.

In terms of gender, the portrayal of females involved vulnerable, passive, and dependent traits, while females with disabilities are stripped of those traits and portrayed as tragic but saintly (Barnes and Mercer 2010; Morris 1991). Fine and Asch (1988) noted that the media does not place disabled women in the traditional female roles of wives and mothers. To strip disabled females of nurturing and loving roles triggered a sense of degradation and stripped disabled females of their womanhood (Kent 1987). The portrayal of masculinity is associated with strength and ability, but that was not the case for disabled males. For disabled males, the stories and representations focused on their triumphs in overcoming their disabilities. This was not the case for disabled females except for the rare portrayals of Helen Keller's and Lisa O'Nion's stories (Barnes and Mercer 2010; Johnstone 2001; Morris 1991). The issue is that if the media portrays disabled males and females in stereotypical roles, then that perpetuates gender stereotypical roles. To challenge only the

stereotypical representations of gender fails to consider why disabled females and males are not presented in those stereotypical roles (Barnes and Mercer 2010). There is a need to shift away from the homogenous and singular representation of disability by complicating the representation of disability with the diversity of disabled experiences.

In response to the medical model's limited representation of disability as a biological condition, there has been substantial literature exploring how social institutions construct the meaning of disability by presenting a different view of disability. The literature reflects the importance of considering how disability is a form of social oppression as opposed to an individual problem. Seeing disability as social oppression enables a shift towards creating constructive solutions that aim to improve the lives of those with disabilities. Both models of disability present insightful literature that broaden our understanding of disability but still hinder Disability Studies and the concept of disability itself. The problem with the medical model is the emphasis on the individual that excludes environmental factors. Also, in response to the medical model, the social model problematizes or complicates disability by criticizing the medical model and demonstrating how disability is a social construction shaped by the social institutions that oppress those with disabilities. In other words, the social model reacted to the medical model by focusing on social institutions rather than individuals in order to resist the medical model's concept of disability. Consequently, the social model disregards the subjective experiences of disability in an attempt to shift the focus to how social structures influence the construction of disability. The problem is that creating another model in response to a model that is not agreed upon such as the medical model does not allow the flexibility to explore disability in an open-ended manner. Rather, disability is explored within a limited dichotomous lens: disability as a medical or individual

issue or disability as a social issue or social oppression. In the next section, a series of authors have attempted to entwine disability with personal experiences and observe how disability influences everyday experiences and interactions in response to the limitations of the two models of disability and the absence of the subjective disabled experiences.

Including a detailed summary of the literature allows me to justify why I utilized the two approaches I implemented in the theoretical framework.

### The Shift Back to Personal

Due to the medical model's tendency to commercialize disability and the social model's exclusion of impairment, research interest shifted toward exploring subjective meanings developed during social interaction such as why certain attitudes, behaviors and attributes are labeled as deviant (Barnes and Mercer 2010; Becker 1963; Downes and Rock 1998; Goffman 1963; Rock 1979; Scheff, 2009). These approaches enabled disabled individuals to voice their experiences of living with impairment and to describe the effects that impairment had on their social relationships and themselves (Barnes and Mercer 2010; Edgerton 1967; Strauss 1975).

Erving Goffman (1963) wrote an influential piece that explored the phenomenon of stigma: an attribute that transforms a person into a repulsive object, which is reinforced through the interaction of language usage and body language. In the process of social interaction, Goffman (1963) identified three main techniques of passing, covering, or withdrawing from society that disabled people implemented in the attempt to maintain control over their presentation. The significance of analyzing social interaction reveals how both stigmatized (disabled) and non-stigmatized (nondisabled) individuals take part in upholding social norms by distinguishing which behaviors, attitudes, and attributes are

acceptable or unacceptable. Other authors noted the importance of seeing how different social factors such as class, gender, age, ethnicity, sexuality, and race influence social interaction as well (Barnes and Mercer 2010; Freidson 1970; Link and Phelan 2001). In addition, some argue that disabled people present themselves as physically different rather than socially deviant (Davis 1961).

The timing of disability, family reactions towards disability, hospitalization and education experiences, inaccessibility issues, and the choice of being able to reveal their disability on their own terms are other factors that influence how disabled persons define disability and perceive themselves. Disabled people frequently encounter difficulties and stress, and make continual attempts to control their presentation in everyday social interactions in order to conform to the medical concept of what is normal (Barnes, and Mercer 2010; Davis 1961; Goffman 1963). Disability is a continuous process of negotiation and renegotiation of identity, so to understand the meaning of disability, one has to deconstruct the social interactions and language used to create the meaning. This analytical stance on disability challenges the single dimension of disability as unfortunate and the disabled as passive victims of personal tragedies by demonstrating that the meaning of disability is continually constructed in everyday interactions (Barnes and Mercer 2010).

The negotiated and interpretative approaches explore how persons with disabilities understand their position and participate in society by analyzing lived experiences. The focus shifts from awareness of something that went wrong to understanding what went wrong and calculating how to reconstruct the identity they lost when they became ill or disabled (Anderson and Bury 1988; Barnes and Mercer 2010; Frank 1991; Strauss 1975). A tremendous amount of literature examines the effects of chronic illness on individuals such

as how does the illness impact everyday activities such as self-care, social and family relationships, and employment?

The negotiated and interpretative accounts explore how the illness or disability affects not just one's independence, but one's identity as well. Studies also considered how medical treatment affects everyday activities and social identity including how simple to drastic interventions impact one's life and how the preoccupation with the symptoms impact one's ability to engage with other people (Anderson and Bury 1988; Strauss 1975). Two common responses to illness are to normalize the illness by working around it or to resist and cling to their former able selves (Corbin and Strauss 1985; 1991). Part of the problem is when individuals examine how they experience their disabilities, they tend to shift to the personal tragedy focus and fail to see how social barriers play a role as well. Thus, interpretative accounts become too subjective, and the idea of disability as a social production resulting from the relationships between the individual, the social environment, and institutions are forgotten (Barnes and Mercer 2010).

Post-structuralists approached disability by examining culture and the body. This approach differs from previous approaches by shifting away from critically examining the medical model and medical professionals for instituting medical domination over illness and disability to considering the body itself and what the body represents culturally. Multiple sources of literature challenged the materialist stance on disability (Davis 1995; Garland-Thomson 1996; 1997; 2006; Linton 1998; Mitchell and Snyder 1997; 2000; 2001; Wendell 1989; 1996). The body is viewed as a discourse of social knowledge and power relations that reflect social and cultural values. For instance, physical attractiveness is highly praised by general society and reinforced not only by the mass media, but also by the growing industry

of health and fitness and medical procedures that enable people to achieve the ideal physical beauty. Trying to mold our body image into what is considered attractive not only conforms to societal norms but also maintains the institution's power and influence over what is considered a healthy, normal, and attractive body. The creation of an image of a healthy, normal, and attractive body in turn defines the opposite; therefore reinforces what is not desirable, healthy, or normal. The issue when examining the representation of the body alone is that experiences and individual meanings are no longer part of the picture.

The issue with these approaches to disability that shift away from the medical and social models is the tendency to skip over the materialist analysis of disability and impairment while emphasizing the cultural lens of disability. The authors challenge the materialist stance by noting the importance of considering how culture, language and discourse construct disability and the disability experience. Considerable amounts of literature examine how medical and scientific vocabularies shape the meaning of disability with language. Focusing on social interaction, personal experiences, and the representation of the body enables one to present an alternative perception of disability and impairment, but does not present constructive solutions to address the societal oppression that people with disabilities encounter. This is not to argue that these perspectives are not worthwhile, since they present an argument that challenges the idea of what is considered normal and enables a space where disabled people can voice and apply their own experiences. The literature offers insights as to how subjective experience ties in with the power of social discourse and the significance of material and cultural contexts (Barnes and Mercer 2010). There is still a need to complicate disability with other social factors such as race, class, gender, and sexuality to

reflect how disability is not an isolated experience segregated from those social circumstances, and to reinforce the notion that disability is part of the everyday process.

#### Incorporating Disability with Race, Class, Gender, and Sexuality

Expanding our understanding of disability (as with race, class, gender, sexuality, and other social factors) requires a multi-level analysis that examines the individual, the structure and social construction of disability, and how disability intertwines with power and inequalities (Barnes and Mercer 2010). Considerable literature has been generated to explore how social institutions shape the meaning of disability and the disability experience. The research that focuses on disability and social institutions risks alienating disabled individuals. The medical model shaped disability into personal tragedies, medical conditions, and biological deficiencies, which erases the face of the individual while focusing on fixing and curing the disability. The social model erases the individual by focusing on how social institutions oppress the disabled. Disability research has been problematic due to the continuing practice of treating disabled people as objects of research. Disabled people criticized disability research because of the exclusion of their voices, their experiences, their needs, and the failure to improve the quality of their lives. The problem with the medical and the social models is there is no space for the personal experiences and voices of the disabled population. To define nondisabled as positive, good, normal, and universal in experience and nondisabled as a negative homogenous experience perpetuates the notion that disability is only a social construction or a medical condition that hinders the ability to consider disability as part of the human experience that influences and shapes everyday interactions and experiences (Barnes and Mercer 2010; Johnstone 2001; Morris 1992).

The other problematic issue with the models and approaches is viewing disability as a Cartesian dualism, or an either/or lens where one is disabled or not disabled. This dichotomous approach to disability conveys an illusion that the disabled experience is a singular homogenous experience (Davis 1995; Goffman 1963). With the labels and master status, whoever has the power to state the meaning of the label is also privileging one label over another and perpetuating the dominant hegemony through ranking, misconceptions, and simplistic categories. The labels non-disabled and disabled are problematic because of the simplistic associations and dichotomous meanings such as blind or not blind because they reduce the broad spectrum of vision into two categories (Gordon and Rosenblum 2001; Linton 1998; Michalko 2002 Titchkosky 2006). Davis (1995) raises the question of why the concepts of disability continue to be broken into fixed polarities. Regarding disability as contradictory to normalcy also conveys a notion that one is superior to the other. Disability is the representation of inferiority and stigma and is consistently reinforced in all domains of social institutions and social interactions. This is evident from the emotions that disability triggers: avoidance, fear, and hostility to the representation of disability itself: pitiful, miserable, dependent, biologically deficient, dumb, unisexual, and weak, along with advancing medical interventions such as eugenic and bio-genetic engineering and segregated education and housing (Davis 1995; Gordon and Rosenblum 2001).

The current literature raises the question of why the research on disability persistently focuses on disability as an isolated phenomenon. Disability is not just a condition, but an ideology that normalcy continually reshaped and reinforced. In other words, disability is always present in everyday social interactions, social identities, and social institutions. So why does disability research persist in examining disability by itself sustaining the notion

that disability is not part of everyday existence? What do we have to gain by including disability with race, class, gender, and sexual orientation? Incorporating disability with the other social identities prompts the question of which identity is more prevalent in everyday interactions, thus, there is a need to expand and complicate disability theory and to cease segregating disability from the other social identities (Gordon and Rosenblum 2001).

To present disability as a singular representation such as an individual medical problem, a victim, an object of fear, or a source of trouble is to erase the face of that very person. Disability needs to be part of the whole package to avoid stripping a sense of humanity from the person but also to complicate disability. Multiple authors have challenged the homogenous concept of disability through studies incorporating disability with gender (Deegan and Brooks 1985; Fine and Asch 1988; Morris 1991; 1996; Thomas 1999; Wendell 1989; 1996), with race and ethnicity (Ahmad 2000; Bell 2006; Begum, Hill, and Stevens 1994; Stuart 1992; 1993), with sexuality (Gillespie-Sells, Hill and Robbins 1998; McCarthy 1999; McRuer 2006; Shakespeare, Gillespie-Sells, and Davis 1996; Tremain 1996), age (Priestley 2003; Zarb and Oliver 1992), and with social class (Jenkins 1991). It is important to note that race, class, gender, sexuality, age, and disability are not separate social identities, but rather simultaneous social identities that intersect and impact one another and influence everyday experiences and perspectives (Barnes and Mercer 2010; Collins 2004; Gordon and Rosenblum 2001; Morris 1992).

There has been incremental progress linking disability with race, class, gender, and sexuality in the academic literature. Multiple authors have taken different approaches to complicate disability. Some write from personal experiences, while others write to understand the connection between their experiences and the social divisions and structures.

The one goal they all have in common is the desire to address a gap in the literature and to theorize about disability through different lenses in order to challenge their readers to see disability in a new light.

### Gender and Disability

The analysis of the relationship between gender and disability has gradually emerged due to the feminists with disabilities and the absence of their voices in both the disability movement and in feminism studies. Jo Campling (1981) looks at personal relationships, sexuality, motherhood, education, employment and culture on an individual level amidst the female gender and disability. Michelle Fine and Adrienne Asch (1985, 1988) explored how women with disabilities experienced discrimination similar to other women, but because they were not able to assist with household finances or reproduce offspring, they were doubly oppressed. They argued that disabled males had more opportunities to overcome their stigmas so are more likely to conform to male role norms (Barnes, Mercer, and Shakespeare 1999; Barnes and Mercer 2010). These studies reveal how knowledge, ideologies, and discourses legitimize the exclusion or marginalization of those with disabilities. The empirical evidence has demonstrated that women with disabilities encounter different disadvantages than disabled men and nondisabled women and further excludes them from the workforce, which is evident economically, socially and psychologically. In addition, disabled women tend to be portrayed as a “childlike, helpless, and victimized” (Barnes and Mercer 2010: 86). Due to that representation and the struggle of fighting for stronger female role models, non-disabled feminists are less likely to incorporate the experiences of disabled females (Barnes and Mercer 2010; Fine and Asch 1988). Because of the ideologies and discourses of Western femininity, a person in a wheelchair encounters difficulty reclaiming

and conforming to the ideals or expectations of Western femininity (Barnes, Mercer, and Shakespeare 1999).

Morris (1991) criticized feminism for the exclusion of disabled women's experiences and their inability to conform to Western standards of femininity, and the irony is that they fought for stronger women's roles and rights, while concurrently perpetuating disabled women's representation as personal tragedies (Barnes and Mercer 2010). Begum (1992) noted that disabled women frequently express frustration about the imagery of disabled women: passive dependency and non-existent sexuality (Barnes and Mercer 2010). There also have been studies revealing that disabled women were encouraged not to embrace motherhood and to avoid reproducing, because they might pass on defective genes or the impairments while also questioning whether they could possibly be good mothers (Barnes and Mercer 2010; Finger 1991; Thomas 1997; Wates and Jade 1999).

In spite of feminism, disabled women have implemented feminist literature into their pursuit for justice and equality. They have embraced the notion that personal is political. This body of knowledge contributed to the expanding literature examining disabled women's experiences of living with a disability (Abu-Habib 1997; Campling 1981; Deegan and Brooks 1985; Morris 1989; 1996; Thomas 1999). There is a small yet increasing amount of literature that explores disabled males' experiences of negotiating their daily lives (Gerschick and Miller 1995; Robertson 2004; Smith and Sparks, 2004). The main argument is for the need to expand disability theory to include more personal experiences in order to advance the understanding of disability.

There is sparse literature on the intersection of race with ethnicity and disability. A common argument is the need to complicate disability with race, ethnicity, and racism in order to obtain a more complex understanding of oppression and racism. As with gender, there is a strong argument against seeing race and disability as a double oppression. Both race and disability have a dominant presence in social interactions because they both are visually apparent. This positioning prompts the question of what it means to be a racial minority and disabled (Stuart 1992). Multiple authors have argued that being a racial minority and disabled is not double oppression, but rather simultaneous oppression that impacts lives personally, socially, and institutionally (Stuart 1992; 1993; Begum, 1994). Double oppression indicates that oppression can be ranked in terms of race, class, gender, sexuality, and disability. For instance, double oppression raises the question of which one is more oppressive: being black or being a woman. This leaves the impression that oppression can be broken up according to social identities, and there is a ranking system between being a female, male, black, white, Asian, Hispanic, homosexual, heterosexual, upper class, middle class, or lower class. The problem with double oppression is the hierarchy among oppressed groups, and that the additive framework of oppression does not convey the complexity of oppression. The additive framework argues that oppression is compartmentalized rather than a collective experience (Barnes, Mercer, and Shakespeare 1999; Barnes and Mercer 2010, Begum 1994; Stuart 1992). This is not to argue that certain social identities are more prevalent in everyday experiences.

Simultaneous oppression enables individuals to see how all their identities intersect and overlap in structuring their oppression and privileges. Being both black and a female can be conceived as more oppressive than being a white female, thus presenting a more complete

picture of the individual rather than breaking her up into singular social identities. In addition, simultaneous oppression enables individuals to see how their oppression and privileges plays out not only on an individual level, but on a societal and institutional level by seeing how their social identities influence their experiences on multiple levels. For instance, black disabled people not only experience resource discrimination, but are also marginalized in the black community, the family, and the disabled community. Begum (1994) also noted that those with racial minority and a disabled status tend to employ complex survival strategies not only to survive, but also to negotiate their membership within mainstream and disabled societies and their racial communities. For an individual who has two master statuses of race and disability intersecting, it is logical to assume that they encounter additional complications obtaining employment, housing, education, and social services (Stuart 1992). Begum's (1994) studies also indicated that those who have multiple minority statuses, such as non-white, disabled, and homosexual, experience simultaneous oppressions rather than one dominant type of oppression.

Understanding oppression, racism, heterosexism, sexism, and ableism involves acknowledging multiple intersecting and interlocking layers of social circumstances (Stuart 1992). Simultaneous oppression is the key to understanding disabled black people's experiences, which Stuart (1992) saw as a distinctive form of oppression due to encountering social isolation associated with being black and disabled, as well as resource discrimination and marginalization from the black community. Other authors have noted that disabled Blacks and their experiences of double discrimination have been studied in the context of institutional racism. This form of discrimination involves marginalization from the white dominant society and the black community as well (Barnes, Mercer, and Shakespeare 1999;

Barnes and Mercer 2010; Hill 1994). The same applies to the label “multiple oppressions,” which implies that oppression can be categorized separately. Exploring the intersectionality of disability with other social factors reveals the need to shift away from the dichotomous imagery of the oppressed and the oppressor, because the reality is much more complex (Collins 2004).

As noted previously, the medical literature focused heavily on adjustment to the disability and disability as a medical condition. Multiple authors have tried to complicate disability and race by implementing different angles and approaches in order to offer new insights and to fill the gaps within the Disability Studies literature. Hernandez (2005) utilized a different focus that enabled those with disabilities to express their personal experiences with their disabilities rather than regarding them simply as medical conditions. He conducted a qualitative study of minorities with violence-related spinal cord injuries due to the absence of disability identities of racial minorities and violence-related disabilities. The study presented positive self-image alternatives to the personal tragedy images along with introducing the need to consider how race, ethnicity, and disability shape one another in an individual’s experience (Hernandez, 2005).

Madigan (2005) noted that there is an absence of examining gender issues within special education. When Madigan (2005) conducted a study with a small group of Latina special education students, she came to realize that additional studies of Latina females in special education are needed to understand the relationship between race and gender in special education. Stuart (1992) argued for the need to explore how identity influences the perception and isolation of racial minorities with disabilities. Identities are symbols or indicators that distinguish one person from another. Essentially, Stuart (1992) argued the

need to see disability as part of the identity. To understand how identity isolates black disabled individuals is to learn how identities are part of the broader power relationships in society. Within race studies, racial groups have been found to develop common languages, religions, cultural norms, and social expectations. The diversity among the racial groups contributes to the gap between the majority and minorities. Blending disability into the mix addresses not only the need to see how disability is an identity, but also one of the sub-groups within a racial category. Stuart (1992) noted that black disabled people were outsiders even within their own ethnic minority community. This study addressed the need to complicate race with disability in order to shift away from the pervasive black and white approach to race, racism, and racial issues. There is a need to incorporate the voices of racial minorities with disabilities into the literature in order to avoid perpetuating their invisibility or the erasure of their social roles or images.

Other authors have attempted to draw lines between social divisions in order to bring other perspectives to the current literature or debate. The general argument is that Disability Studies have as much to gain as race, class, gender, and sexuality studies do by intersecting and cross-fertilizing those fields. Noting the relationships between disability, race, class, gender, and sexuality allowed authors to present alternative arguments that are absent in the current literature. Ahmed (2000) attempted to execute a network demonstrating the connections between multiple social divisions. Tying together the relationships between ethnicity, disability, chronic illness, and caring, Ahmed (2000) demonstrated the need to overlap the fields of race, oppression, health care, and chronic illness to understand how all of those social factors structure one another, and how they influence an individual's experience.

Special education and mainstream education are other disciplines that are linked to disability. One of the common debates is the over-representation of racial minorities in special education programs (Ferri and Connor 2006; Harry and Klinger 2006). Again, as in this case, multiple authors have argued the need to overlap the fields of disability, race, education, racism, normalcy, and critical race theory. Ferri and Connor (2006) noted that to understand the current education situation, there is a need to see how the classroom is a product of race, disability, culture, history, and society in order to see why there are so many racial minorities in special or segregated education. Ferri and Connor (2006) explore how ableism and racism share common historical roots and how they overlap and undermine the IDEA (Individual with Disability Education Act) and the Brown v. Board of Education desegregation efforts.

Bell (2006) presented alternative means of examining how Disability Studies are actually White Disability Studies, highlighting the importance of tying race and disability together. Using various literature sources, Bell (2006) demonstrated how there is an obligation to critically examine Disability Studies in terms of who the researchers are and their motives, noting that those researchers must continually self-reflect on their positions. Normalcy and whiteness are taken for granted and challenged by academic scholars; there is a need to link those concepts together and critically examine how Disability Studies may unintentionally implement whiteness and normalcy.

Reid and Knight (2006) argued that incorporating ableism with institutional racism, classism, sexism, inequality, discrimination, and exclusion provides insights on how even the simple labels of learning disabled, mentally retarded, emotionally disturbed, and dyslexic reveal much about society and the educational system and reinforce a system of power. This

connection is not apparent until the complex webbing between ableism, racism, classism, and sexism is revealed, but together they enable further understanding and complicate the simplest concept by adding data to the bigger picture (Reid and Knight 2006).

### Sexuality and Disability

Considering sexuality and disability, there is a pervasive theme that those with disabilities are perceived as non-sexual or heterosexual. Throughout history, sexual activity among those with disabilities was strongly discouraged in order to stop the spread of inferior genes, and the suitability of those with disabilities to be parents was questioned. As noted previously, both males and females with disabilities are portrayed as asexual. In addition, the disability literature contributed to this misconception by emphasizing the disability while ignoring all the other identities thereby perpetuating the notion that disability overrides all other identities (Sherry 2004). There is a need to recognize and complicate the disabled identity by intersecting race, class, gender, and sexuality in order to shift away from this overly simplistic dichotomous concept of disability.

Limited literature explores the themes of sex, love, relationships, sexual rights and expressions, and the experiences of those with disabilities who are bisexual, gay, and lesbian. Multiple authors used firsthand accounts to explore the themes of sex, love, and relationships (Abbott and Howarth 2005; McCarthy 1999; Shakespeare et al. 1996; Tremain 1996). There is a need to challenge the notion taken for granted that those with disabilities are asexual and to understand what they mean by sexuality, sex, love, and relationships (Shakespeare et al. 1996). To incorporate disability with sexuality raises different questions to consider: what does sex mean and how do society and culture construct and shape the meaning of sex and sexual citizenship (Abbott and Howarth 2005; McCarthy 1999; Shakespeare et al. 1996;

Tremain 1996). This involves the need to create a space where those with disabilities are able to express and explore their understanding of sexuality, which in turn will broaden disability and sexuality studies (Abbott and Howarth 2005; McCarthy 1999).

To fail to contest the assumption that disabled people are asexual is to perpetuate the notion that heterosexuality is normal but also to sexually oppress the disabled population (McCarthy 1999; Shakespeare et al. 1996). This oppression addresses the importance of protecting sexual rights, sexual expression, and sexual citizenship of those with disabilities. Personal narratives reflect that the barriers disabled people encounter are often more social than biological. Their inability to pursue love and passion has less to do with biological function and more to do with social, political and cultural issues as reflected in the social Darwinian desire to minimize the spread of “inferior genes.” This issue is illustrated in today’s over-generalization that those with disabilities should not engage in sex. They are discouraged from marrying and having children and their qualifications to be adequate parents are questioned as well as the narrow concept of what is attractive (Shakespeare et al. 1996). It is also important to recognize and complicate sexuality and disability with race and class and to consider the voices of disabled males and their understanding of sexuality, sex, and sexual identities (McCarthy 1999).

Due to the common assumption that disabled people are not sexual beings, there is no consideration of disabled individuals who are gay, bisexual, lesbian, or transgendered. Because of this assumption, the general population has a difficult time comprehending the possibility that disabled people not only engage in sexual activity, but also struggle with their sexual identities (Tremain 1996). There are gaps in the literature that fail to address how they define and deal with their sexuality as well as their experiences of being marginalized

both in the areas of being sexual minorities and having disabilities (Abbott and Howarth 2005; Harley, Nowak, Gassaway, and Savage 2002; Shakespeare et al. 1996). Not fitting in and facing exclusion from the GLBT and the disability communities is a common experience, so they never feel at home in either community due to their lack of acceptance (Abbott and Howarth 2005; Harley, Nowak, Gassaway, and Savage 2002; Henry, Fuerth, and Figliozi 2010). In addition, in response to disability, there is a push from the medical community to do things as normally as possible. Since heterosexuality is the norm, the implied expectation of the disabled population is to be as normal as possible and that they need to integrate with their heterosexual able-bodied peers to the best of their abilities. But for those who are sexual minorities that expectation contributes to further confusion and social isolation (Abbott and Howarth 2005; Harley, Nowak, Gassaway, and Savage 2002). Experiencing multiple forms of oppression and discrimination not only influences disabled individuals' identity development but life opportunities and social relationships as well. The significance of the voices of those who are disabled sexual minorities must be recognized (Abbott and Howarth 2005; Harley, Nowak, Gassaway, and Savage 2002; Henry, Fuerth, and Figliozi 2010).

For those who are both disabled and sexual minorities, there is a demand for integrated services from both GLBT (gay, lesbian, bisexual and transgender) organizations and disability services. The problem is that disability and sexuality have been addressed separately. GLBT services focus on psychological services, student affairs, and rehabilitation counseling that revolve around sexual orientation; while Disability Services focus on accessibility, accommodations, and counseling that orient around disability (Harley, Nowak, Gassaway, and Savage 2002; Henry, Fuerth, and Figliozi 2010). The issue is that

the segregated approach contributes to individuals feeling fragmented, because they must deal with exclusive social worlds. They are either disabled or they are a sexual minority, but they are not seen as whole persons. The result of fragmenting personal identities is alienation and oppression of those who are disabled sexual minorities.

Within higher education, a safe and open space for those who are in multiple marginalized positions that promotes self-understanding, self-acceptance, and healthy and positive sexual identities is needed (Harley, Nowak, Gassaway, and Savage 2002). It is crucial that universities present a safe place where one can view an individual as a whole person rather than further compartmentalizing the individual. This need involves new holistic strategies, new policies, and training that promote awareness and diversity, and stops perpetuating oppression on multiple levels (Abbott and Howarth 2005; Harley, Nowak, Gassaway, and Savage 2002; Henry, Fuerth, and Figliozi 2010; McCarthy 1999). As Harley, Nowak, Gassaway, and Savage (2002) noted, education is a social institution that plays an influential role in shaping the attitudes and perceptions of self and of others, shaping and reinforcing social norms. To achieve social change involves changes throughout the social institution itself. This is not to argue against the importance of providing a safe space, but there is a need for changes within social expectations, financial aid, athletics, residential halls, campus safety, classroom space, the university's climate, academic programs, counseling, and the curriculum in order to shift towards a more diverse, progressive, and positive environment (Abbott and Howarth 2005; Harley, Nowak, Gassaway, and Savage 2002; Henry, Fuerth, and Figliozi 2010; McCarthy 1999).

There is also a need to cross-fertilize between Queer Studies and Disability Studies to avoid maintaining the notion that sexuality and disability are not only isolated identities, but

isolated fields as well. Queer theory and disability theory have their similarities and differences in experience and theory. The problem is that there are few attempts to bring them together thereby, thereby perpetuating the separatism between queer and disability studies (Sherry, 2004). Within GLBT studies, there has been progress incorporating the voices of individuals with disabilities and expanding the literature to understand what sexuality means and the diversity of sexual identities (Abbott and Howarth 2005; Harley, Nowak, Gassaway, and Savage 2002; Henry, Fuerth, and Figliozzi 2010; McCarthy 1999). This effort is the same within Disability Studies when exploring what disability means and the experiences of being disabled. Both disability and queer are social markers that cover a broad range of impairments and sexual orientations that do not adhere to heteronormativity. They embody similar experiences: an identity that is not shared with the rest of the family like ethnicity: eugenics threats, discrimination, stereotypes, social exclusion and marginalization, and the general practices of passing and coming out.

Queer Studies and Disability Studies both used feminism's belief that the personal is political and the social constructivism in their theories demonstrates the importance of subjective experiences, and how these identities are constructed and shaped by social institutions and social interactions. They both challenge the hegemonic binary ideologies such as heteronormativity and normalcy (Sherry 2004). There is a need to see how disability studies and queer studies influence and construct one and another and how they can complicate and broaden the understanding of sexuality and disability (Abbott and Howarth 2005; Sherry 2004). Intersecting Queer Studies and Disability Studies enables the opportunity to extend beyond what has been established in the current literature. Tying together sexuality and disability enables one to see commonality between two social

categories, and to see where they share overlapping experiences in privilege and oppression. Together they challenge the binary concept of sexuality and disability. Sherry (2004) noted that queer theories have done considerable analyses of coming out of the closet, which could be used as a different lens to understand those with disabilities and how they may come out of the closet rather than regarding disability exclusively as a medical condition rather than a social identity. Halting oppression involves not only cross-fertilizing ideas and theories within the fields, but weaving together Queer Studies, Disability Studies, Race, Ethnicity, and Gender Studies, Women's Studies, Ageism, Feminist Studies, Masculinity Studies, et cetera, in order to broaden and complicate each field to see how they all play a role in the whole picture (Harley, Nowak, Gassaway, and Savage 2002; Sherry 2004).

This literature review indicates a need to expand the field of Disability Studies to generate new research paradigms, theories, practices, and policies that enable empowerment, liberation, and social justice. Gabel (2005) argued the need for a theory with a flexible framework that allowed Disability Studies and disability literature to shift away from the determinist and universalist notion of disability. Disability is not a dichotomous experience, an either/or experience; there are a multitude of factors, structures, and social identities that all come together to shape the meaning and experiences of disability. The reality is that disability is part of the human experience that can impact anyone. Those with disabilities still experience sexism, racism, classism, peer pressure, and other forms of social oppression and inequalities just as others do. Disability is not a solo experience. In other words, a disabled individual is also a man or woman, a person of ethnic or racial background, a person with a specific sexual orientation, and a person of particular social standing. Individuals have multiple social identities and while one may be more prevalent in social interactions and

situations; the context plays an influential role. There is a need to see disability as part of everyday experience, a social phenomenon, and a social identity.

The problem that persists is that disability remains absent in other fields of study, such as race, class, and gender studies, feminism, and social justice. In order to move towards social change and broaden our understanding of disability, there is a need to fuse interpretation and experiences of disability in all academic fields and vice versa, and part of the everyday experience, otherwise all academic fields remain incomplete. Segregating the academic fields reinforces the notion that disability is an isolated, individualized, and segregated experience and upholds the dominant hegemony of disability as an individual isolated incident (Gabel 2005; Linton 1998; Morris, 1992). The failure to discuss disability is to perpetuate and uphold normalcy rather than challenge what has been taken for granted.

In order to do so, there is a need to shift away from the dominant polar models of disability and develop a multi-disciplinary inclusive framework where disability can be explored in such a manner that continually broadens our understanding and challenges ourselves to better understand disability (Gabel 2005; Johnstone 2001). It is important to note that it is not adequate to include disability as an afterthought with the other human characteristics of race, class, gender, and sexuality. As Davis (1995) noted:

The point is that disability is not an area that can be simply included into the issue of race, class, and gender- it is already there in complex and invisible ways. There is no race, class, or gender without hierarchical and operative theories of what is normal and what is abnormal (162).

Thus, race, class, gender, and sexuality must be included in disability research as well as disability included within race, class, gender, and sexuality research because in reality, all of the social categories are already overlapping, influencing, and reinforcing one another. In

order to see how all the social categories intermix, there is a need to connect disability with the faces of those who have experiences with disabilities and to create a space where disability research includes the voices of those with disabilities and allows them to be part of the research process rather than just study objects (Morris 1992). As Collins (2004) noted, “One way to dehumanize an individual or a group is to deny the reality of their experiences” (535). To reduce someone to a disability is to strip them of their being. That is why it is so important to stop separating disability from the other categories.

There is also a need for those who conduct research to remember to keep a moral and political focus that challenges and confronts disability in order to fulfill the commitment of social justice in promoting rights for those with disabilities. After reviewing the approaches used to critically explore disability and my attempt to present a more inclusive and intersectional approach to disability, I opted to use Collins’ (2004) concept of intersectionality and interlocking components, and Titchkosky’s (2006) concept of normalcy and background expectancies as my framework to convey the complexity and diversity of the experiences of racial minorities with disabilities. I will briefly explain the two concepts in the following chapter along with justifying why these two concepts are beneficial in understanding the participants’ experiences of being ethnic minorities with disabilities.

## CHAPTER 3: THEORETICAL AND METHODOLOGICAL APPROACH

### Introduction

I will use a methodological approach that applies Collins' (2004) intersectionality and interlocking components and Titchkosky's (2006) concepts of normalcy and background expectancies as different lenses. Such an approach provides the means of showcasing how race, disability, class, gender, and sexuality intersect, overlap, and reinforce one another within the experiences of ethnic minorities with disabilities. Combining these two authors and their concepts in one approach will enable the participants to vocalize their experiences and enable the readers to grasp how disability is not an isolated and segregated experience, and to see how race, class, gender, and sexuality must incorporate disability into their frameworks. In other words, the reader will be able to see how all the social identities reinforce and clash with one another.

### Collins' Intersectionality

Collins (2004) advocated for a more inclusive framework that shifts away from additive analysis, towards seeing how race, class, gender intersect and interlock in everyday lives and relationships. Authors such as Collins (2004), Young (2000) and Dei (1996) recognized the need for a more comprehensive framework when exploring race, class, gender, sexuality, and the concept of oppression. Collins (2004) recognized the need of a framework that examines how oppression operates on an individual level in order to understand oppression on an institutional and symbolic level. Young (2000) demonstrated the need of a framework that enabled recognition of the individual and group experiences on multiple levels in order to gain further in depth understanding of oppression, rather than reducing oppression into a dichotomous hierarchy. Through Young's five faces of

oppression: exploitation, marginalization, powerlessness, cultural imperialism and violence enables the reader to not only grasp the different forms that oppression operates on an everyday structural and personal level, but also recognize the need to cease reductionism and cease addressing different forms separately such as racism, sexism, classism, heterosexism, and ageism. Young (2000) and Dei (1996) recognize that social change cannot progress if we fight for overcoming racism while ignoring heterosexism, classism, sexism, and ageism.

Dei (1996) recognizes the need for a “new theoretical synthesis to rewire knowledge in the academy” (55), that enable individuals to recognize and understand how their multiple identities influences their experience and interactions. Dei (1996) argued for an integrative anti-racism study that focuses on a multifarious framework of social oppression rather than an additive framework. Collins (2004) recognized that the additive analysis framework is problematic due to its dichotomous either/or approach that stratifies race, class, gender, and sexuality rather than seeing how they all work together simultaneously. The issue is that the additive approach indicates one social identity is more prevalent over the other, which creates a separatism hierarchy. This means one social identity is more oppressive than the other, such as being black is more oppressive than being a woman. This forces the individual to choose between her race or gender in being most oppressive in her life, but social identities are not static. This indicated there is a need to see and understand the complexity of the human experience that is influenced by social interactions and self-conceptualization of who they are. Dei (1996) also argued the need to critically examine how the dominant hegemonic discourses influences how the multiple identities are represented within the academia.

Through the intersectionality and interlocking framework, it is possible to see how the social identities of race, class, gender, sexuality, and disability along with the social

ideologies clash, reinforce, and perpetuate one another both on a personal and societal level. At the same time, it is important to recognize that some social identities are more salient than others are in different situations, so there is a need to consider the context (Collins 2004; Dei 1996). In public settings, such as school or in a bar, our superficial physical features of race and gender are the main social identities that we convey. In private settings, such as with our families or a group of friends, other social identities including sexuality or disability may become more apparent due to the intimacy. As Collins (2004) noted, “Race, class, and gender may all structure a situation but may not be equally visible and/or important in people’s self-definitions” (532). That is not to say that there are not some situations where one identity is more prevalent than the other; they are not segregated experiences, but rather intersecting and overlapping experiences. Whereas it is important to recognize the significance of the context, there is still a need to see the relationships between all the social identities to understand how they all intersect and interlock with one another.

With race, class, gender, disability, and sexuality, there is a broad spectrum of experiences, not a singular experience for a particular social identity. Although there are common shared experiences within each of those social identity categories, it is important to avoid the mistake of generalizing one experience for all; for an example, generalizing the white middle class women’s experiences for those of all women regardless of social background (Morris 1992). Collins (2004) substantiates this point by demonstrating that when making a list of male and female characteristics, those traits change when considering the elements of race, class, and gender. Stereotypes and cultural representations tend to be dichotomous such as male and female, which is evident when listing the traits of the two categories as polar opposites, but incorporating race complicates the gender list further by

employing different descriptive words or by having different options of words to use. For instance, powerful is often a word choice for a white male; while dangerous is frequently a descriptive term for a black or Hispanic male. Intersecting multiple social identities complicates personal experiences, and given the context, one category may have saliency over the other.

Dei (1996) cautioned that there is a need of balance between subjective experiences and social change. In other words, it is important to recognize the value of subjective experiences and exploring race, class, gender, sexuality, and disability simultaneously, and to use the knowledge we gain from the subjective experiences to shift towards constructive solutions, social change, and social justice. Dei (1996) recognizes the value of understanding our own personal experiences as an important part of the process of understanding how the world shapes our knowledge. Dei (1996) stated, “Lived, personal experience is central to the formulation of any social knowledge” (63). There is a recognition that critical reflection on our own personal experiences is necessarily in order to work together for social change. To understand how we in terms of race, class, gender, sexuality, and disability engage with the world, and how the world defines us, and how we define ourselves is the first step towards understanding the common grounds that we share and differences that we embodied, in order to progress towards social justice.

Through this framework enabled the author to grasp how race, class, gender, and sexuality influence the lives of those with disabilities. Through the lens of intersectionality and interlocking perception of social categories disrupts the notion that disability is just a medical condition, thus disability is part of the everyday process. As noted with race, class, gender, and sexuality, all of those social identities influences the individuals subjective

experiences, which is the same for the disabled individual regardless of how pervasive their disability influences their lives. In other words, an individual does not cease being male, female, black, Asian, homosexual, heterosexual, and so on just because the individual has a disability. Even though disability is generally a dominant master status as race or gender is, there is still a need to explore how race, class, gender, sexuality and disability intersect and interlock in the everyday lives of those with disabilities in order to cease perpetuating the dominant hegemonic discourse of disability.

#### Titchkosky's Background Expectancies and Normalcy

Titchkosky (2006) viewed disability as a social identity and social phenomenon that is continually constructed by the discourse of normalcy that is in turn shaped by the social, historic, economic, and cultural forces that modify the definitions of disabled and nondisabled. Titchkosky (2006) argued that disability can teach us about society, and by weaving her own personal experiences with disability, she demonstrated how disability is a social product that reveals much about how normalcy operates on an everyday level. As Linton (1998) reemphasized that societal values construct normalcy, therefore there is a need to problematize disability beyond the medical and rehabilitation point of view. Davis (1995) argued that to challenge the hegemony of normalcy is not sufficient, and that we need to start with the normal body to understand the disabled body. In other words, to critically examine the construction of disability is to examine the construction of the normal body as well. To exclude the normal body is to perpetuate the legitimacy of the normal body as the unspoken norm just as whiteness was in race studies (Davis, 1995).

To critically think about disability is to realize that society is a system of norms that reinforces, maintains, and is structured by social interactions and expectations of one another,

therefore disability is a social phenomenon (Davis, 1995). The societal conception of a normal body is socially constructed; therefore, disability is a social construction as well. There is nothing ‘natural’ about the idea of a normal body (Davis, 1995). As Davis (1995) noted, “The construction of disability is based on a deconstruction of a continuum” (11). Those who view themselves as normal construct disability through the construction of the notion of normal. To reveal how disability is a social construction is to deconstruct how those who view themselves as normal establish normalcy (Davis, 1995). Contesting the idea or meaning of disability allows a space to present a different perspective of disability (Davis, 1995).

The concept of normalcy not only reveals how the body is a socially constructed product, but also is a lens that enabled the readers and scholars to see how normalcy operates on an everyday level. In the everyday process, people go through their daily routine mindlessly, thus failing to question why something is the way it is, or why something is done this way, but not another way. It is not until we encounter or witness a different routine is when we question the everyday routine. Utilizing her background expectancies provides a way to examine how race, class, gender, sexuality, and disability influence and shape one another and reinforce social expectations. Titchkosky (2006) explained that, “Background expectancies include rules, procedures, and norms that guide behavior, but to which little attention is paid and thus little thought is ever given” (13). When a person does not follow or exhibit those background expectancies, it leads to a disruption of the normal process of interaction. Everyday processes that we undergo such as getting up, showering, going to work, coming home, eating dinner, and going to bed are not critically considered but are just

seen as ordinary routines that we all experience in life. It is not until we encounter something unusual that we pause and reassess the situation.

Titchkosky (2006) offered the example of taking the stairs everyday to get into a building. It is a natural process for most people to walk up and down those stairs to enter or exit a building. One day when an individual witnessed a person in a wheelchair struggling to access the building there was a pause and a realization that taking the stairs everyday is not possible for some people and prompted the question of how do those who are different access the building. It is moments like this when the person views the stairs in a different light. The concept of normalcy and the background expectancies enable us to see how the intersection of identity and culture with disability complicates the picture, thus disability is never something that goes wrong, or the inability, but much more, therefore disability is a mean of revealing the finer print of culture and society, and race class, gender and sexuality. Before proceeding to justify the choice of methodology that I implemented, I need to express my personal reasons for pursuing this thesis topic to help the reader understand the personal significance of this thesis.

## CHAPTER 4: MY POSITIONALITY

### Introduction

To understand the reasons why I pursued the topic of exploring the experiences of racial or ethnic minorities with disabilities for my thesis, I need to explain my background. My personal biography shaped my philosophy about how disability should be approached. This thesis provided an opportunity to seek out other racial minorities with disabilities to further explore the circumstances of those who may or may not be in situations similar to mine.

### Personal Reasons for Pursuing this Research Topic

I consider myself a hard of hearing Korean adoptee who grew up in a predominantly white community and family. Growing up, I had limited circumstances that challenged me to consider my race and my disability and the relationship of those two identities with society. Most of my childhood revolved around catching up with my nondisabled peers in terms of language development, academics, and social behavioral cues, thus my disability played an early and significant role in my identity formation. My disability made me aware that I was different from both my nondisabled and my deaf peers. My hearing loss enabled me to transition between the hearing and deaf world, because I was able to grasp different social and cultural expectations. It was not until I attended school in Hawaii that I became aware of how my Asian physical appearance played a role in social interactions and expectations. In Hawaii, I encountered people who assumed because I look Asian, therefore I must be familiar with Asian history, culture and politics, and be fluent in an Asian language. I was extremely baffled as to why people would make stereotypical assumptions about me or

assume I was born and raised in Asia. Before living in Hawaii, I had no idea of what it meant to be an Asian, an Asian female, or an Asian American.

During this time, I felt increasingly fragmented in terms of who I was. Was I Korean? Was I Asian American? Was I a female? Was I deaf? Was I hard of hearing? This sense of fragmentation plagued me throughout my college education and led to my desire to answer those questions; I had to know: Who was I? I relentlessly sought out literature in Japanese Studies, Asian Studies, Korean Studies, Asian American Studies, Sociology, Psychology, History, and Cultural Studies in order to understand, but none presented the answer. I was seeking a piece of literature that reflected the personal turmoil that I was experiencing. The absence of finding someone who understood what I was going through led to a sense of bleak loneliness. I literally felt like my body was split into multiple individual identities, and I feared that I would not be able to bring myself back together as a whole being.

I sought counseling for help grasping the situation, but even then, the psychologists did not understand what was going on with me. This sense of bleakness and loneliness led to self-cutting as a coping mechanism to deal with the feeling of sinking into a darkness of desperation. It was not until my graduate studies, when I encountered a professor who saw the value of my experience and understood the urgency of being able to pull my multiple identities back together as a whole person. He encouraged me to explore my experiences through an autoethnography. The writing process was arduous to complete, but in the end, it was worthwhile. Through the process, I was able to understand how my multiple identities intersected and interlocked with one another, shaping my perception of self and my social interactions. I was able to recognize how social institutions, power, privilege, oppression,

and ideologies combined to shape my personal experiences. I was able to present a paper that detailed what I was desperately seeking throughout my undergraduate years, and I gained a sense of wholeness and a sense of inner peace. Writing an autoethnography that allowed me to explore and organize my experiences in an active textual format piqued my interest in others who had similar experiences.

Since I had the opportunity to explore my own personal experiences, I wanted to present the same opportunity for others to explore and vocalize their experiences. Being able to make the connection between self and the bigger picture is priceless, and to not be able to do that can damage the person's inner being. Mentioning my cutting, I have no desire for pity, remorse, or disgust towards what I did. My intent is to emphasize the importance of understanding how damaging it can be for those who cannot find their experiences in the literature, or who do not know others who have undergone similar plights, and for those who feel fragmented. There are real life consequences when they remained lost, lonely, isolated. That is why I accepted the opportunity to publish my paper with my professor's encouragement because through him I realized not only the value of my experiences, but what I could bring to academia. Simply put, I found my voice. With this paper and future papers, I hope to help others as my professor helped me. To see the value in your experience and to see who you are and all the social factors that shape who you are and your social interactions is to understand, which is one of the most precious gifts of all. That is what led me to pursue this thesis topic: racial minorities with disabilities.

Along with my personal experiences, I was weary of reading about disability and race from the pervasive dichotomous stance: medical model vs. social model, normal vs. abnormal, black vs. white. In my course of education, race discussions seemed to revolve

around the black and white conflict; all the other ethnic groups were an afterthought. In addition, the Korean adoptees' experience is non-existent in the discussion of race. Race and ethnicity studies have begun to branch out, enabling Asian Americans, African Americans, Hispanic/Latinos, and others to incorporate their experiences and contest the black and white dichotomy. The disability literature oriented around disabled and nondisabled. I felt no connection to the disability literature, which reflected the repetitive themes of overcoming the disability or personal tragedy. There is so much more to race and disability (and other social identities) than two extremes. As Davis (1995) noted, "Disabled people are thought of primarily in terms of their disability, just as sexual preference, gender, or ethnicity becomes the defining factor in perceiving another person" (10). To reduce disability and race (along with the other social identities) into a set of binary oppositions is to erase the wide spectrum of diversity (and voices) within those social categories, and to repeat the same arguments.

Alice Walker (quoted in Morris 1992) conveyed exactly what I felt, "In my own work I write not only what I want to read... I write all the things I should have been able to read" (162). I have grown weary of reading literature that portrays how awful the lives of those with disabilities are or how those with disabilities suffer double oppression. This is not to say that the current body of literature is not substantial, but there is a need for a space that allows disabled people to take control of their subjective experiences and a need for research that does not focus only on how oppressed and tragic the lives of disabled people are. Research is a source of personal liberation, and a means of validating one's existence. Research that does not focus on how oppressed we are or the negative representation of disability is needed, because disability is not an isolated experience or condition. There is a need to incorporate the full diverse experience of disability.

And, to make the shift requires one to use personal experiences to challenge the dominant ideologies and hegemonies. Continuing to contest your understanding of society and self involves continually expanding one's understanding through diverse lenses, and experiences. "None of us alone has a comprehensive vision of how race, class and gender operate as categories of analysis or how they might be used as categories of connection. Our personal biographies offer us partial views" (Collins 2004: 540). As Collins (2004) noted, our own personal experiences do not embody the same pieces, but we each offer a piece that contributes to the larger puzzle; so we need to be open and realize that we are all working towards social change and social justice.

On a personal note, I wish to express my gratitude to those who were willing to share their experiences with me. I feel extremely privileged in not only hearing about their personal stories, but also having the opportunity to present their voices within this thesis. Through their voices, I was able to broaden and challenge my understanding of race, class, disability, sexuality, and gender, and how they influence and clash with one another. Because of their willingness to share their experiences with me, I was also able to pursue an area of interest that has personal significance for me. Thank you.

## CHAPTER 5: METHODOLOGY

### Introduction

The focus of this chapter is to give an overview of the methodology that shaped my research. The phenomenological methodology and the social constructivist paradigm enabled the researcher to focus on allowing the participants to describe their experiences as racial and ethnic minorities with disabilities. The value of this method is that it allows the participants to describe their experiences, a methodology that is almost non-existent in the academic literature, and to challenge dominant ideologies of disability, race, class, gender, and sexuality. Through the process of understanding and describing the participants' experiences, the researcher was able to challenge the notion that disability is not an isolated social phenomenon, and that disability, as with the other social categories, intersect and interlock with one another.

### Methodology

The purpose of this research is to advance the literature and field of study on disability through the experiences of other racial and ethnic minorities with disabilities beyond my personal autobiography. This project is an extension of an autoethnographic paper in which I wrote about my personal experiences of negotiating race, class, gender, sexuality, and disability in everyday life. As stated previously, there is a gap in the literature where there has been little or no examination of disability within an intersectional framework of race, class, gender, sexuality, and disability; therefore, the focus of this paper is strictly exploratory. For this thesis, the research questions are: What are the experiences of ethnic minorities with disabilities? How do race and disability intersect and influence each other in everyday contexts? Are there differences between the experiences of those who have

disabilities that are more apparent and those with “hidden” disabilities or more apparent racial/ethnic differences? A purposive sampling technique was used in order to seek out participants who fit the criteria of the research questions. The criteria included individuals with a non-dominant ethnic or racial background, and a diagnosed disability. Purposive sampling is considered appropriate when the goal is to select unique cases that may be extremely informative about unique situations or phenomena. This sampling method allowed me to select individuals based on the specific research questions. Purposive sampling is also ideal since it enables the researcher to pursue several different means of identifying ethnic minorities with disabilities for this study.

I contacted the disability services at twenty to thirty midwestern universities inquiring whether they would be willing to submit a letter of intent on my behalf to potential participants. Some of the schools I contacted did not have any potential participants, and those who did forwarded the letter to potential participants who seemed to fit my criteria. I focused on finding participants at universities to maintain consistency of participant age range, and because college is a time when students leave home and gain exposure to new environments that promote exploration of their identities. For additional potential participants, I sought out other individuals or faculty members involved with the disability community or who work in disability studies.

For this study, only five participants contacted me and were willing to take the time to share their experiences as racial or ethnic minorities with disabilities. Two others contacted me, but after responding to their emails, there was no response. The participants consisted of three females and two males. The five participants were attending three different midwestern universities during the times the interviews took place. Three participants went to the same

midwestern university, while the other two went to two different midwestern universities. Only one of the participants grew up in the Midwest, while the remaining four participants grew up in other states. In addition, four out of the five were bilingual. All of them aspired to obtain higher education degrees: Masters and PhDs. In terms of disabilities, they all had a disability within the same category with some minor variations; for instance, one participant has an obvious speech difficulty, but that was related to the disability itself. Overall, their disabilities were not physically apparent. They were tested at different times, but three of them were diagnosed while attending the universities. One of the participants was diagnosed several years ago, but not at the university. One participant was diagnosed with one form of disability in middle school and the other disability while attending college. They all received similar accommodations through disability services. The participants are coded as: Participant One (I1), Participant Two (I2), Participant Three (I3), Participant (I4), and Participant Five (I5) to maintain their confidentiality.

In reference to their disabilities, I indicated only that the participants' disabilities were generally invisible or disguised by their race or gender. Because the participants were part of a unique population and the Midwest is predominantly white, I did not disclose specifically what the participants' disabilities were in order to maintain the confidentiality of those who participated in this research project. Through the interview process, three participants made it clear that they were not interested in having their disabilities revealed, and two participants were either ambivalent or were okay with revealing their disabilities. Even then, I did not want to violate any confidentiality issue on behalf of the three participants who did not wish to disclose, so I did not reveal exactly what disability each participant has.

For this thesis, examples of visible disabilities include a blind person wearing dark sunglasses and carrying a white cane, an individual in a wheelchair, or someone with obvious indicators such as a prosthetic device or hearing aids. Invisible disabilities refer to those not readily seen when looking at the person, but affect the person on a daily basis such as diabetes, epilepsy, dementia, or tinnitus. Disability is not a static state; in the participants' experiences, their disabilities are not physically apparent such as a prosthetic arm or a cochlear implant, but their behavioral and verbal cues reveal characteristics of their disabilities. At the same time, when overlapping, race, class, gender, sexuality, and disability characteristics, the social categories reinforce each other or render the disability characteristics invisible. These characteristics will be examined further in the discussion chapter.

For this study, I utilized semi-structured in-depth interviews with each participant. I used an interview schedule to ensure consistency of the questions asked and to help keep the interview focused on the research question. The interviews began with an introduction of my personal experiences to encourage the participants to start talking about their backgrounds and branched out from there. In the process of discussing their backgrounds and by semi-structuring the dialogue, the participants were able to focus on their experiences of being minorities with disabilities. Generally, it was easier for the participants to start talking about their disabilities and then talk about their other social identities before discussing how all of their social identities influence who they are and their everyday experiences. A copy of my interview schedule is in the appendix.

All of the interviews lasted from an hour and a half to three hours. Three of the interviews were conducted as face-to-face interviews, and the remaining two interviews were

conducted over the telephone on speaker mode; I was able to record all the interviews on a recording device. The last two were done by telephone because I was moving back home, and the interviewees were not in the Midwest at the time that the interviewer was. Two people transcribed the interviews on my behalf. During the coding process, I listened to the audio recordings and read the transcripts to document any important pauses, intonations, or emotional expressions that may be relevant to the data analysis. Measures of trustworthiness (i.e., recording the interviews, usage of the same interview schedule for all participants, careful maintenance of a log in the field, and contacting participants for further information) were implemented in the process of data coding. After the transcription process was completed, the coding process involved highlighting significant statements, and repetitive themes that showed up in all of the interviews. I applied the theoretical framework of Collins' (2004) intersectionality and interlocking components and Titchkosky's (2006) concept of normalcy and background expectancies to the participants' experiences to highlight and flesh out significant points of the participants' experiences.

Overall, for this research project I used the social constructivist paradigm and the phenomenological methodology. Social constructivist paradigm is a worldview where "individuals seek understanding of the world in which they live and work" (Creswell 2007: 20). This paradigm recognizes that individuals and society engage with the construction of social reality, thus it is a continual process of constructing meaning and knowledge through the social interactions. In the process of trying to understand their experiences, individuals construct subjective meaning to explain their experiences. The interpretations of the subjective meaning are influenced by the historical and cultural norms during an interactional process. To use this paradigm is to seek and embrace the diversity of experiences and

meanings (Creswell 2007).

Phenomenological methodology emphasizes understanding and describing the phenomenon from the subjective meaning given it by the individual, in contrast to the quantitative and scientific focus on material things, which ignores the subjective meaning. This is not to devalue quantitative contributions, but simply the phenomenological methodology is ideal for this particular research question. This methodology stresses that if we wish to understand society, our experiences, and everyday process, we have to start with ourselves, which involves recognizing our role in the process. For this methodology, subjective meaning is perceived as the main source of knowledge, thus intention and sensations influence the participants' perceptions enabling them to understand what is going on around them. As Moustakas (1994) explained, subjective meaning develops from engaging with the object in nature, thus the meaning and object are intertwined. This perspective indicates that to understand the objects before us, we need to return to ourselves and reflect upon how our perceptions play a role in our experiences with the objects. Through self-reflection, we are able to engage with how meaning is constructed and combined with ideologies, culture, history, and personal biography to obtain a more complete understanding of our experiences. Husserl used the term 'act' as a label for the experiences of meaning. Act indicates that in the process of understanding the meaning there is an act of experiencing the object, thus knowledge is rooted in perception, thoughts, and intuition. To understand the knowledge itself, there is a need to reexamine and reflect upon those meanings in order to elicit insights about the phenomenon. It is important to recognize that the object does not have to actually be physically present: it could be part of mental conceptualizations (Moustakas 1994).

This methodology and paradigm are both well suited to the research question and allowed the researcher to focus on the subjective experiences of a unique population. This approach also enabled the researcher to address a marginalized population that is not included in current academic literature and to challenge the accepted concepts and ideologies of disability, race, class, gender, and sexuality. Understanding and describing participants' experiences enables the researcher to delineate a diversity of perspectives and recognize the commonality of their experiences as well. This methodological approach allows the participants to share their subjective meanings and weaves historical and cultural norms into those subjective meanings. The focus of this thesis was to present a space where the participants had the opportunity to explore their experiences as ethnic minorities with disabilities and to challenge the homogenous and singular conceptualization of disability, while revealing their shared experiences of being ethnic minorities with disabilities. In other words, phenomenological methodology is a means of broadening our understanding of the human experience through the lenses of the participants rather than from the researcher's stance.

The participants' experiences support the need for the researchers to study the intersection of disability, race, class, gender, and sexuality to broaden our current understanding of each of those social identities and also to recognize the significance of overlapping these social categories in order to grasp a deeper understanding of how disability is a social identity, a social phenomenon, and part of the every day process. To understand this phenomenon we need to start with ourselves by examining how our experiences shape who we are and how who we are shaped by our experiences (Moustakas 1994). Through the experiences of ethnic minorities with disabilities we can find a basis for shifting towards a

more inclusive approach to disability, race, class, gender, and sexuality that no longer segregates each of these identities and fields and recognizes how they intersect and interlock with one another. In addition, discussing their personal experiences empowers those with disabilities by providing a space where they can share their stories, perspectives, and experiences, and recognize the value their experiences offer to academic literature.

In terms of limitations of this study, I recognize that the purposive sampling and the unique population interferes with the ability to generalize and that the researcher's personal motivation for pursuing this topic may influence the study itself. Purposive sampling precludes randomly selecting participants, but rather specifically chooses them based on the researcher's criteria. For this study, the criteria were for the individual to have a disability and an ethnic or racial minority background. I recognize the inability to generalize my findings because of the purposive sampling, but that may be achievable later when further research is conducted on the experiences of racial and ethnic minorities with disabilities. It is also important to recognize that with a qualitative study and methodology is dependent on the specific research question and for this study, the focus was gaining in depth and diverse understanding of racial and ethnic minorities with disabilities.

In addition, phenomenological methodology recognizes that the first person report of life experiences increases the validity of the research, because perception is what leads to the truth, and that involves describing what one is seeing, feeling, and recognizing the relationship between self and the phenomenon (Moustakas 1994). Further, there is a need to challenge the dominant hegemonies and ideologies that are present in the literature and fill the gaps in the literature by introducing new perspectives and experiences. How else are we going to continually challenge our individual understanding and expand the literature if we

do not incorporate new perspectives and experiences? How will we implement social justice and social change if we silence or marginalize the voices of those ethnic or racial minorities with disabilities?

There is also a need to recognize my role in this research process. It is important to mention that due to my own autobiography, I have a personal interest invested in this thesis, which motivated me to take on this project. The challenge with the phenomenology methodology is for researchers to try to eliminate prejudice or presupposition. In other words, it involves looking at the data free of prejudice, presupposition, and assumptions to describe phenomena the way they are in order to obtain the essence of the meaning. This involves self-reflection and awareness of the researcher's part in this process by bracketing their personal feelings, conceptions, and motivations. I acknowledge that this thesis is an extension of an autoethnography that I wrote about my own personal experiences as a racial minority with a disability. To accept that I do have personal motivation and investment in this project is to recognize that my own background and interests shape my interpretation of the responses to my research question and that I am driven to understand and to fill a gap in the literature.

In the process of interviewing and analyzing, I had to make a conscious effort to not assume that the participants' experiences embodied mine, but rather focus on them describing their experiences from their own point of view. Another focus of my research is to incorporate the diversity of disability and place a face on disability. I am not seeking self-validation through others who may embody experiences similar to mine, but I am seeking to challenge the homogenous singular conceptualization of disability by recognizing the diversity of disability when considering race, class, gender, and sexuality. Throughout the

interview process, I came to realize that disability is not as dominant a master status as the literature indicates, and that weaving in race, class, and gender with disability presents a bigger and more complex picture of disability.

### Summary Listening of the Participants

#### Participant 1:

I1 grew up in the Midwest and was attending a midwestern university seeking a degree in mathematics at the time this interview took place. She emphasized that being blond and a Caucasian female influenced her life significantly. She perceived her disability as a medical condition rather than part of her identity.

#### Participant 2:

I2 grew up outside of the United States, but was obtaining his degree in construction engineering at a midwestern university at the time this interview took place. He is bilingual and has an accent. He was older than the other participants, which may have influenced his perception of his disability. For the most part, he was okay with his disability because he viewed his disability as part of the aging process. He also emphasized that his race and foreign status play the greatest role in his everyday experiences.

#### Participant 3:

I3 grew up in the south central area of the United States in a mixed Caucasian and Hispanic community. She labels herself as biracial. She was attending a midwestern university obtaining a degree in science at the time the interview took place. I3 was the only participant that seemed to have a clear perception of how all of her identities of race, class, gender, sexuality, and disability influenced her life. She embraced all of her identities as well and emphasized her desire to be a role model for the future generations by accepting who she is and challenging stereotypical notions.

## Participant 4:

I4 was not born in the United States, but she grew up on the West coast in a large Hispanic community. She is bilingual and has a slight accent. She was attending a midwestern university to obtain a degree in mathematics at the time the interview took place. I4 noted that being a woman of color are the attributes that have the greatest influence in her life. She emphasized that she feels singled out due to being a woman of color in a male dominated mathematics field at a midwestern university with limited diversity. In terms of her disability, she spent considerable time discussing whether she really had a disability or not, but in the end she conveyed that she felt that her disability traits make up a part of who she is, along with her gender and racial identities.

## Participant 15:

I5 grew up on the East coast in an extremely diverse community. He was attending a midwestern university to obtain a degree in economics and psychology at the time of the interview. He has a slight speech accent because of his disability. Overall, he perceived his race and gender as the biggest influence in his life. He expressed early confusion and frustration with his disability, but currently he is okay with his disability, and sees it as a part of his identity.

## CHAPTER 6: RESULTS

### Introduction

During the interviews, three consistent themes appeared in the participants' discussion of their experiences of being racial or ethnic minorities with disabilities: discussion of being diagnosed with a disability, discussion of their other social identities of race and gender, and discussion of how all the social categories influence their experiences. To enable readers to follow the participants' thoughts, I broke the data into the experiences of I1, I2, I3, I4, and I5. This will allow the reader to grasp each participant's experience in a more holistic manner and provided a space where each participant could vocalize his or her experiences. In each participant's conversation, I focused on three themes: focusing on disability and the conflicting and shared thoughts of how they perceive their disabilities, to considering how their other social identities come into the picture disrupting the notion that disability is the master dominating status. The third theme focuses on bringing disability and the other social categories together to see how all the social identities make up and influence the individual's experiences. My intent is not to write a tragic or a happily ever after story line, but rather to showcase how all the social identities are part of the everyday life.

Focusing on disability highlights how all the participants shared similar themes in the discussion of their experiences with disability and how they defined their disabilities. Throughout the interview process, the participants went back and forth between accepting their disabilities to shifting towards the frustration of being labeled or treated differently, to relief in understanding what was wrong with them, to the frustration of being different. Focusing on disability strips away the person's age, gender, sexuality, race, ethnicity, and class identities along with their cultures and histories; in other words, it erases the faces of

those with disabilities. As the participants share their experiences with disability, their social identities remain abstract or partially fractured. Shifting the focus to their other social identities of race, class, gender, and sexuality, it became evident that disability is not always the dominant factor in an individual's life, as it is portrayed in academic and personal accounts. Those diagnosed with disabilities or see themselves as disabled do not always consider their disability as the factor that has the greatest influence on their life experiences. The greater influences were variable depending on the context and the combination of social identities in play.

The third theme of weaving together disability, race, class, gender, and sexuality demonstrates that considering multiple social categories provides a more complete picture of the participants' experiences and how they perceive themselves. This section challenges the notion of how disability is conceptualized as an isolated medical condition. In the next chapter, I expand on this theme by weaving in the participants' experiences with the theoretical framework to see how disability is a social identity, social phenomenon, and part of the everyday process intersecting and interlocking with race, class, gender, and sexuality.

#### Participant 11

##### Focusing on Disability

I1 expressed strong negative feelings towards disability due to the negative association between disability and lack of intelligence. She expressed relief in understanding and knowing what was wrong with her, but at the same time, she wondered if that meant she was stupid or disabled. I1 noted that she struggled to separate the difference between intelligence and disability. She is aware and understands the stigma of disability. She recognizes that others view disability as being unintelligent. She goes on to emphasize that

having a disability does not mean one is less intelligent nor are the two related; this belief is just a stereotype. She reinforces that disability should not mean dumb, but what it should mean is that one learns differently, not that the person is less intelligent. While trying to understand her disability, she expressed frustration in trying not to call herself stupid, because she cannot process like everyone else. I1 was frustrated by those who are smart but lazy, because she has to work harder to succeed at the same level as her able-bodied peers. I1 also noted that she appreciates accommodations since they help reduce stress and enable her to succeed academically; she also wished she had known earlier “what was wrong” with her. She noted that her disability does not affect her social life. I1 also stated that she did not like others knowing about her disability.

#### Focusing on the Other Social Identities

I1 felt her blond hair color and being female in a male dominated field are the main traits that influence her everyday interactions. She stated that she encounters greater reactions and negative stereotypes with the blond hair and is therefore treated as dumb or stupid because of the visibility of her gender and blond hair color. She expressed stronger feelings towards the blond female stereotypes than the disability stereotypes. She also expressed that she feels the need to compensate by indicating that she has a high IQ or that she graduated with a 3.6 GPA to help reinforce that she is, in fact, intelligent. She also noted that is part of the reason she is a driven perfectionist and why she works harder to succeed academically. She said that her friends see her as a driven perfectionist as well.

#### Weaving Together the Social Identities

I1 indicated that having blond hair and being female are the main influences in her everyday experiences; she does not view disability as a heavy influence in her life compared

to someone with an obvious disability. She stated that she does not view herself as disabled, but she knows she has a disability. However, she does not feel that it is part of her identity. She reinforces that disability has a limited impact on her life; therefore she does not see herself as a disabled female. She does not accept that having a disability makes her disabled. She notes that the only influence her disability has on her life is that she needs to work harder to succeed academically, because she has difficulty reading and takes longer to process and comprehend the materials. She feels that when she reads something she has to come back to the material to let her brain boot up in order to comprehend. She noted that she uses more areas of her brain to understand her reading materials. She said that her disability does not push her, but considering that her dad has a master's degree and that she is a driven perfectionist, she wants to do well in school too. If she fails, she does not blame her disability, but rather that she did not try hard enough. She noted that might be partly because while growing up she was expected to achieve like everyone else regardless of the challenges she encountered to succeed academically prior to being officially diagnosed in college.

She reinforced that her disability plays little part in her life because of the invisibility of her disability, while her hair color and gender are readily apparent. She expressed that when she has revealed her disability, people talked down to her and generally treated her as if she were mentally disabled. She stated, "If...like if that's first thing that they know, then they tend to act like I'm stupid" when people find out about her disability before knowing who she is. She feels the need to compensate by indicating that she has a high IQ or a 3.6 GPA to help reinforce that she is intelligent. However, when she reveals her disability to those who know her quite well, they are generally shocked because they have difficulty separating disability from lack of intelligence. She noted that her friends are amazed at how

intelligent she seems even though she has a disability, thus disrupting the stereotype that disability equals being dumb. She noted that her friends see her as a driven perfectionist rather than disabled and view her perfectionism and desire to succeed academically as part of her personality.

### Participant I2

#### Focusing on Disability

I2 expressed frustration and confusion about being diagnosed and having to obtain accommodations, but as with the other participants, he noted the accommodations of having extra time for his exams and homework help him succeed academically and reduce his stress; but he would rather not need those accommodations. The one thing that is different about I2 is that he felt that getting older helps him better tolerate receiving accommodations and accept his disability. Because he perceives his disability as part of the aging process, I2 did not express frustration so much as understanding that with the disability he will always have to try harder.

#### Focusing on Other Social Identities

I2 felt that his race and foreign status wields a greater influence on his experience attending a midwestern university. I2 spent a considerable amount of the conversation discussing the situation he was encountering in the department where he felt that he experienced discrimination because of his social identities as a racial minority and a foreigner. He argued that it was evident among his peers and from the grading of his homework and exams. Throughout the conversation, he consistently reinforced that it was a minority issue rather than a disability, gender, or an ageism issue. Throughout the conversation, he focused on acceptance as a racial minority. Within his department, he

observed a difference in how the professors and his classmates treated him. He feels that some professors do not like foreigners, and that was reflected in the grades he received or the way they talked to him. He said that he received lower scores on his homework assignments for the same answers as his peers (comparing home work answers), and he has had his professors look over his homework assignments. He noted that the professors raised his scores in eighteen out of twenty homework assignments after rechecking them. He noticed that his peers did not seem to have similar experiences. He feels it is clear discrimination.

I2 is struggling to understand but does not quite grasp the situation due to his limited understanding of racial issues and race history in America. He feels there is always someone who will try to push him down and argued the need for tolerance within his department. He noticed that people do not want to talk to individuals who appear different, but he is not certain that this is discrimination due to his age or being from a different country. He also noted that he was not sure that the disability influences his classmates' and professors' responses to him, but he does feel that he is encountering exclusion from the students due mainly to his minority status rather than his disability or gender identity. He did note that he is one of the oldest students, and when I asked whether he considered his age a factor, he said, "I don't know, I don't think so. It is minority." He observed in class that the Asians from overseas were treated better, because the professors respond positively to Asian students' questions. He says he feels there is a degree of "I'm superior and you are not" tone in the classroom environment. He feels that there is a hierarchy in the classroom ranking Americans, Asians, and Africans and that the American blacks were treated better than him and the Africans who were born and raised in Africa. He talked with the other minorities and they encounter similar reactions from the professors and peers; he is struggling to understand.

He feels strongly that it is a minority issue and that the Midwest is not open to foreigners and minorities. In his situation, he saw that being a foreign racial minority is the biggest influence in his life and in his academic pursuits.

### Weaving Together the Social Identities

Similar to I1, I2 felt his disability did not have a great influence on his experiences. The main difference between the two is that he felt that getting older helps him better tolerate receiving accommodations and accepting that he does have a disability, but it is not part of who he is. He accepted that as you get older your mind takes longer to process, so he sees disability as part of natural process of aging. This perception may be due to the fact that he is older than most students, and that he was not diagnosed with this disability until much later in life; thus his disability did not impact him throughout his life as it did the others. He recognized and accepted that he will have to try harder due to his disability. In addition, he felt that disability was not an issue since it was not viewed as an issue in his country, and that all people were accepting of differences there. He also reinforced that having a disability did not make him any less masculine, but that it was part of the aging process. I2 seemed more focused on the minority foreigner issue, because it is more prevalent in his life right now and tied in with his career goals.

### Participant I3

#### Focusing on Disability

I3 was the most optimistic about her situation. As I1, she wished she was diagnosed earlier in her life, so she could have understood in her childhood “what was wrong with her.” She felt that the diagnosis changed how she perceived herself. She no longer perceived herself as lazy or dumb, because she had an actual medical reason that justified why she is

different from others. Knowing the medical condition, and understanding how the disability influences her abilities socially and academically, allows her to learn how to control her disability and work around it in order to succeed academically.

She stated that she is not going to let her disability stop her. She recognizes “it is always going to be a part of me.” She did express mixed feelings about having to take medication, but is aware that taking medication enables her to achieve like everyone else, and she is able to work to her full potential. However, she did state that she feels frustration in that she cannot achieve the same as everyone else. At the same time, she expressed appreciation that her disability influences how she learns and comprehends the academic literature because she is able to utilize different means of teaching and learning based on her own personal experiences when helping someone else understand the academic materials.

As with I1, I3 expressed frustration with having to work harder in order to succeed academically. She felt she cannot experience college like everyone else because she has to devote so many hours to doing her homework and studying for exams in order to do well and achieve like everyone else; at the same time she expressed pride in her work ethic. I3 noted that she was aware of the social norms and rules but felt that there is an increasing acceptance of her particular disability, which is evident from the phrases people use. She felt she did not really have a negative experience because her disability is more accepted or at least more publically discussed in the media. She feels that her disability is similar to being biracial in terms of how both have become more acceptable to the general population over time. Acceptance of biracial people has gradually increased in America, and today the general population does not blink an eye at seeing biracial individuals. I3 sees how her

disability shapes her experiences and understanding that allows her to appreciate the assets of being different.

### Focusing on the Other Social Identities

I3 emphasized the struggle of having to prove herself as a female, a woman of color, and a woman in the sciences. In this male dominated field of science, she encounters challenges of advancing in the face of the stereotype that females are not good in the sciences. She acknowledged that her socioeconomic background and being biracial might play a role in her experiences. She expressed that being biracial does not affect her as much as someone who has stronger ethnic physical characteristics. She has a lighter skin color, lighter hair color, and slim physical features. She also mentioned her parent's upbringing influenced her ability to adapt in both the upper class white world and the world of working class ethnic minorities and enables her to adjust in a midwestern University.

I3 is aware of the negative stereotypes of Hispanic students and that minorities have to work harder in a white dominant institution. Due to those negative stereotypes, she understands that she will always have to work harder to overcome those stereotypes. This is the same for the stereotypes that girls are not good in science or math. She is also aware that looking racially different influences her ability to fit into both worlds. She noted that she did undergo the common experience of feeling as if she was not white enough nor Hispanic enough to fit into either group. She was either not skinny or blond or she did not share the common characteristics of speaking Spanish or wearing Hispanic dress styles. She dresses more like white people in clothing like sweaters over tight t-shirts and wears fake pearl earrings rather than gold hoops. She did not hang out where most other Hispanic peers hung out, because most of her time off was filled with academically related activities. She

struggles with her social identities in terms of understanding that she has multiple challenges to overcome.

Even though I3 realizes it will be harder to be a biracial female in the field of science, she still makes an effort to look Hispanic to set an example. She dyes her hair a darker color and tries to spend time outside to darken her skin. She stated, “I like looking Hispanic because it makes me different. It’s my identity.” She was the only participant who emphasized that in spite of everything she is dealing with that she felt strongly about wanting to be a role model to others. She wants to show that anything is possible and to prove she can do anything she wants to do to those who did not believe in her.

#### Weaving Together the Social Identities

I3 was one of the few participants who viewed herself as disabled, a racial minority, and a female. She emphasized the struggle of having to prove herself as a female, a woman of color, disabled, and as a woman of color in a white male dominated science field. She wanted to prove that she could overcome all the hurdles of being Hispanic, female, and disabled with a future PhD goal even though she realized that it will only get harder, especially in an academic doctoral program. She emphasized that all of her identities shape who she is today.

Being biracial and disabled seemed to be the primary influences in her ability to interact in different worlds. Growing up, I3 struggled with her biracialism in terms of not being able to fit completely in either world, but at the same time, her experiences enabled her to adapt to different environments including the present midwestern university setting. It seems that she has an easier time dealing with her biracial background, because in today’s society biracialism is viewed as “cool.” In addition, with her disability she gained exposure

to the diversity of disabilities early in the high school she attended, which had a considerable population of students with disabilities.

She noted also that her disability and biracialism enabled her to see things differently and enables her to employ different techniques to help others understand their course materials. She is aware of how her racially different appearance influences her ability to fit into both worlds. Her skin tone is on the lighter side along with her more slender features, so her physical appearance does not strongly indicate Hispanic. She noted while growing up that she struggled with the feeling of not being Hispanic enough or being white enough, but presently she appreciates those experiences since they allow her to be able to interact in different settings and with different people. She recognizes that she has to work harder due to the negative stereotypes of Hispanics, being a woman of color in a dominant white institution, and due to her disability. Even though I3 realizes it will be harder to be a biracial female in the field of science, she actually makes a conscious effort to tan and dye her hair a darker shade to appear more Hispanic and to challenge the Hispanic stereotypes.

She expressed frustration in not having the time to experience college like everyone else: to socialize and party. She has difficulty processing what she reads; consequently, it takes longer for her to read, complete her homework assignments, and her exams. I3 noted that her disability does influence her social interactions in terms of how she tends to switch topics and has a harder time staying on track or on one subject. For instance, when she is studying with her boyfriend, she tends to get sidetracked and changes from topic to topic while trying to focus on the homework assignment. She also mentioned as an example that when her father was trying to get her to complete her homework assignments, she would

need to sharpen a pencil and in the process of going over to sharpen her pencil, she would get distracted easily by different things on the way to sharpening the pencil.

I3 was different from the other participants in seeing her disability as part of who she is. She stated that she had a hard time separating her disability from herself, thus it is part of her personality, and if she did not have it, she would not be the same person. Goofy, silly, optimistic, difficulty sitting still or focusing on one subject are some of the traits that she sees as part of who she is rather than medical conditions. She understands why she is the way she is. Since the time of her diagnosis, she had come to see those traits as part of who she is. She noted that she likes being different because it is who she is. Nevertheless, she does express frustration in being unable to achieve the same way as everyone else, and in the end she realized what is more important, which is to be able to achieve her full potential. She also noted that she tends to overcompensate to demonstrate her abilities and intelligence and to overcome multiple challenges. She strives to be a role model because she understands there are very few that are in the same situation as she is. She sees herself as who she is and sees the challenge but wants to show that nothing is impossible. She concluded, “So, yes the road is going to be long and bumpy, but the end is worth it, I feel.”

#### Participant I4

##### Focusing on Disability

I4 felt that at times she was not certain she has a disability. At the same time, she was ambivalent about caring or not about knowing whether she has a disability and other times she cared about knowing she had the disability in terms of “I think that disability makes me want to do better things.” I4 was not the only one who expressed this notion, since I1 and I5 also expressed confusion about whether they really had disabilities due to the invisibility of

their disabilities. I4 noted that it was no one's business to know about her disability. She is not comfortable telling people about her disability and appreciates being able to be flexible in sharing her disability or not. She noted that she is aware of the difference of her experience, because her disability is not so readily apparent. She (along with the other participants) noted that she had flexibility in choosing when or whether to disclose her disability; she did not have to constantly watch her body language and verbal cues while socially interacting with people because most of her disability characteristics seemed to be part of her personality. She expressed appreciation in being able to conceal her disability and being able to disclose her disability on her own terms.

She also noted that the accommodations help, and that is what counts even though she is not certain that she has a disability. I4 stated, "Sometime I don't think I have it, but most people do think I have it." I4 is aware that disability is not well accepted and that there is a negative response to disability because ability is privileged and taken for granted. She noted that science determines what is normal and categorizes what is not normal in America. She felt her homeland culture views disability differently since it should not matter how long it takes to achieve your goals as long as you can perform. She observed that American culture has a "let's fix you" approach. She felt her homeland culture denies disability or does not separate people into disabled and non-disabled categories, but expects those with disabilities to achieve whatever they can and strive to achieve regardless of what approach or methods are used. She did note that disability appears to be a negative condition in both her homeland and American cultures. Overall, I4 feels that her disability does not influence her experiences, and she does not tell people except for her mom that she has a disability.

Focusing on the Other Social Identities

I4 strongly felt that being a woman of color has heavily influenced her experiences. She is more aware of her race and gender as a minority woman of color in the mathematics field. She is reminded of her status by the sexist comments she receives from her male classmates. She explained that there are many group homework assignments, and that is when she encounters sexist comments or sexual innuendos. She noted they make jokes saying that she sucks at math because she is dumb, or they make up songs that undermine her intelligence. She noted that she gets annoyed when a guy starts hitting on her, or when there is an expectation that if they do most of the work, she is supposed to be extra nice to them. She noted that in response to those sexist comments, she would just play dumb or pretend she does not understand because she realizes that the group work cuts her work time in half. She expressed frustration from being constantly teased or put down, but at the same time, she plays the stereotypical roles to cut down the time she would have spent on her homework assignments.

I4 feels she encounters double discrimination as a female and a minority; she identifies herself as brown, female, Mexican, and a Chicana. She noted it is frustrating because as a Latina, brown, and a girl she stands out, so she cannot really blend in at her school that is a predominately white institution or in a male dominated field. In the Hispanic community at home, she noted that being loud and outgoing is the social norm, but in the Midwest she stands out as the one who is different or odd. She feels she stands out even more because she is pursuing a mathematics degree, which stereotypically is not a typical field for Hispanics and females. A stereotypical pursuit would be for her to pursue a Spanish degree. I4 did recognize at times that she is frustrated with having to work harder because she is a woman of color. At the same time, she talked about how she is okay with being an

ethnic minority female in a math field because she feels you cannot let people get to you, and you just have to push forward.

### Weaving Together the Social Identities

I4 recognized how dominant her race and gender identities are in her everyday experiences. In regards to her disability, at first she was rather ambiguous about whether she had a disability or not, but she made it clear that if she did have one she was not interested in having anyone know about it, since she did not see the relevance of others knowing about it. She noted that she appreciated not having to be hyper-vigilant with her behavioral and verbal cues, so most people read her disability characteristics as part of her personality. As with I3, she views being scatterbrained, forgetful, cheery, hyperactive, happy, talkative, as traits that shape who she is today rather than a medical condition. That is just how she is. She does see disability as part of her experience but not necessarily a form of oppression in her life. As she noted that while her general personality is cheery and hyperactive, she questioned whether she is really a happy person personality-wise or if that characteristic is part of her disability. She does not view herself as a disabled individual.

I4 noted that she is generally accepting of who she is due to strong friendships and that her friends accept her for who she is. She noted that she has difficulty listening or staying on the same subject, or she will zone out, along with always forgetting things like losing her cell phone or her keys, but there is general acceptance from her friends who see it as who she is. Her friends tease her about losing stuff as it is an everyday and acceptable occurrence. She noted that one of her friends who found out about her disability suggested that her disability is the reason why she is so smart and excels in math. She noted, "So, I feel like being a math major also validates my disability or something. It makes it okay." She

indicated that her friend felt that her disability was the reason why she was able to do well in math, thus her disability is viewed as an asset rather than a disabling attribute. Interestingly enough, she noted that her disability makes her want to try harder to meet the higher expectations that are set at the university she is currently attending. Overall, her motto is to not let people get to her, and to just push forward with life and towards her goals. She tries hard to not stress about it and focuses on being happy.

### Participant I5

#### Focusing on Disability

Prior to his diagnosis, I5 noted that he felt uncomfortable, ashamed, and angry because he could not understand why he was treated differently. Why did he have to go to a different room to take a test or have more time to take a test? When he was first diagnosed, he expressed that he did not feel like he had the disability and then felt that he was labeled. He felt that with the label people perceived him as dumb or stupid. He feels that people perceive him as unintelligent because of his difficulty expressing himself orally and in written language, which frustrated him. At the same time, he was relieved to understand what was wrong with him. He feels that it is human nature to make the assumption that something is wrong if a person appears or acts differently. He feels like he is being treated differently because of how long it takes for him to express himself. He was frustrated by how long it takes for him to comprehend, but he appreciates the accommodations provided because of the reduced stress and academic success he experiences along with understanding “what’s wrong with him.”

Presently in college, he feels differently in terms of being labeled dumb or stupid and knows that the feelings he experienced were stupid; he learned to get over it, so when he

encounters people who do not understand his situation, he just shrugs it off. I5 also had no desire to share his disability. I5 went back and forth between caring and not caring that he had been diagnosed because he felt that someone put a tag on his identity; at the same time he expressed both comfort in understanding “what was wrong with him” and frustration from being diagnosed. I5 differed from I1, because he sees his disability as part of who he is.

#### Focusing on the Other Social Identities

I5 felt that gender and race impact his everyday experiences and how he perceives himself as a Hispanic American. He viewed his race as the defining factor in his life. He noted that he has not really encountered much difficulty in terms of race and gender. Overall, he had a positive education experience with teachers and peers who were helpful and enabled him to succeed academically. He did note that people will always make assumptions about who you are based on your physical appearance and body language, and there is nothing he can do about that, so he opts to shrug it off.

#### Weaving Together the Social Identities

Generally, I5 felt that gender, race, and disability affected the person he identifies himself as, but he noted that he feels his race is the defining social category in his experience. For him, his oral communication gives away his disability, but at the same time, he said that not many people mentioned or acknowledged that he was having difficulty communicating. When asked if perhaps this was related to his racial minority appearance with the expectation that perchance people assumed he was not fluent in English or due to the stereotype that males have difficulty verbalizing their thoughts; he thought it possible, but had not given it much thought. Presently, he feels that his race is the defining factor in his life.

Generally, his attitude is similar to that of I4 in terms of shrugging it off if people look down on or make assumptions about him. I5 does not see his disability as a big part of his life, but more of who he is like most of the other interviewees; he sees it as who he is, realizing that he cannot change that aspect of himself. He knows that with his disability it takes him longer to process information and he encounters difficulty locating the word that he is trying to express. He recognized that people probably assumed because of his difficulty communicating orally and in writing and his slow reading comprehension that it was due to his gender and racial appearance as a Hispanic male. There is a general assumption that English is the second language for most Hispanics or any foreigners.

## CHAPTER 7: DISCUSSION AND CONCLUSION

### Introduction

The participants' experiences highlighted the diversity of experiences for those with disabilities that are complicated by race, class, gender, and sexuality. By discussing their experiences, they disrupted the dichotomous and medical conceptualizations of disability that are so prevalent in today's society. In the course of their discussions, they reveal how race, class, gender, disability, and sexuality intersect and interlock with one another. There is no single dominating master status or homogenous experience, but there were some common experiences. Disability is a social phenomenon that evolves from social relations within a complex web of society. As with race, class, gender, and sexuality, disability is not an isolated social category; all of these social categories are continually reconstructed and reinforced through social interactions between individuals and society (Michalko 2002).

There is a need to shift the meaning of disability towards social identity and a social phenomenon and to regard disability as part of the everyday process rather than an isolated segregated homogenous experience in order to complicate disability itself. The essence of the data discussion is to focus on how disability is a social identity, a social phenomenon, and part of the everyday process by weaving the participants' experiences with the theoretical framework to convey the complexity of disability. The data discussion is broken into three sections including understanding how disability is a social identity or part of the individual, a reflection of society, and part of the everyday interactional process. It is important to note that all three social identity, social phenomenon, and everyday process overlap and intersect just as race, class, gender, and disability do; consequently, they are not segregated or static experiences.

### Disability as a Social Identity

When considering identity, identity is a label that defines or is bestowed upon us. In the process of social interaction, our behavioral cues, the language we use, our style of speaking, and how we dress and present ourselves reflect an image of who we are. Some identities are not readily conceived as natural or ritualized. To celebrate our ethnic heritage such as Asian American, African American, Irish American, or to celebrate our womanhood or masculinity, or to celebrate our homosexuality, bisexuality, or heterosexuality are deemed as natural and are some of the identities seen today. Disability is not perceived in such a manner. Rather than an identity, disability is something out of the ordinary, unexpected, or a medical condition that happens to an individual. It is seen as “an attachment” rather than part of the person (Michalko 2002; Titchkosky 2006). The participants’ experiences challenged that notion that disability was an attachment, a medical condition, or an isolated segregated phenomenon. I3, I4, and I5 indicated in similar statements that their disabilities are part of who they are:

I3: “It [disability] probably does [affect my social life], and I have just learned to... I don’t want to cope with it [disability], but it’s hard for me to separate my disability from myself... like it’s become part of like my personality and stuff, like... I don’t know how to explain it. Because if you go online and look at kind of the characteristics, you know, like being clumsy or just certain things about how you interact with people, you know, that’s just who I am.”

I4: “...disability is one of the things that make me who I am. Like if I didn’t have it, I wouldn’t be the same person.” [I4 was the most ambiguous about whether she had a disability or not, but once she stepped away from being labeled, or having a disability, she was able to state that she saw her disability characteristics as part of who she is.]

I5: “Like I said before, it is who I am [when referencing to his disability]. You can’t change that. Well, like you know, you can’t change your personality so you can’t change your personality or how you talk or think. It is how you’re born; that is the

way you are.” [I5 saw his disability as his personality in terms of that is what you are because you were born that way.]

Their disabilities affect more of their everyday interactions and shape their social interactions and self-perceptions. They recognized they would be different persons without that disability component in their lives. This is not to indicate that all those with disabilities define or embrace disability similarly; some embrace the disabled identity vs. seeing themselves as a person with a disability. Not all of the participants readily saw their disabilities as part of who they were. I1 made it clear that she viewed herself as someone with a disability that was a medical condition that she had to learn how to work and live with, but other than that, her disability had a limited presence in her life. I2 saw his disability more as part of the aging process, which ties in with the general association of disability with aging. As with I1, I2 noted that his disability had minimal presence in his life. I3, I4, and I5 saw how their disability characteristics influence and shape who they are, and they embrace those disability traits as part of who they are. This may be because they were diagnosed later in life, so they grew up not knowing what was wrong with them. They grew up dealing with their traits and accepting that is how they are -clumsy, hyperactive, loud, scatterbrained, easily distracted, and so on. After being diagnosed, they gained awareness of why they were different, and as they aged, they grew to appreciate those traits that made them who they are.

Before the diagnosis, all of the participants wondered: why am I not like everyone else? This is an instance of the failure of background expectancies. In general life processes we all go through the motions of childhood, going through school, wanting to be like everyone else, having friends, having relationships, and so on. When there are disruptions in this process, people stop and ponder what is wrong with them, and why they are not like

everyone else. For the participants, their disruptions happened when they were unable to succeed academically or to interact as their able-bodied peers. Most of the participants were diagnosed while attending college, so they spent most of their K-12 years struggling to understand why they were different. After the diagnosis, disability services presented accommodations that helped fix or mask the disability and render it invisible so it was no longer a disruption within the academic institutions.

Once the disability is “fixed” it continues to exist under the radar in an individual’s life, or in other words, the disability is no longer a disruption. Thus, disability is not viewed as a social identity. This is not to say that everyone who has a disability embraces a disability identity, and that is partly due to disability as a now factor. Disability is perceived as a ‘now’ factor when a person’s disability goes through society and life invisibly until there is a disruption or until the background expectancies fail (Michalko 2002; Titchkosky 2006). Those participants who were unable to mask their disabilities completely due to their presence in daily activities viewed their disabilities as part of who they were. I3, I4, and I5 acknowledged that they would be completely different people if they were never diagnosed with their disabilities. The other participants, whose disabilities are invisible or masked by accommodations and no obvious traits persist, are able to say that disability does not play a significant role in their lives. This statement reflects the diversity of how individuals interpret their disability. Embracing who they are or seeing disability as part of themselves disrupts the notion that disability is an isolated medical condition or that disability is an isolated segregated condition that can easily be plucked out of the bigger picture because after it is fixed it is no longer part of the everyday process.

### Disability as a Social Phenomenon

Disability is also a social phenomenon that is experienced and constructed by everyone (Titchkosky 2006). Disability is not simply a condition that you can “turn off,” but rather the meaning of disability is continually constructed and reconstructed through social interactions that reinforce stereotypes, meanings, definitions, and representations of disability. Critically examining disability and how disability is treated by society and culture reveals much about the culture and society itself (Striker 1999; Titchkosky 2006). As a social phenomenon, disability shapes an individual’s self-development and identity construction, which includes the physical, social, environmental, and cultural representations of the body; the collective representations of normalcy all contribute to an individual’s identity (Michalko 2002; Titchkosky 2006).

The participants’ discussion of disability reflected their conflicts and confusion about being different and they struggled to express their frustration with normalcy. In the process of trying to separate disability and lack of intelligence, they were struggling to grasp the social normalcy behind disability and to resist the stereotypical representation of disability as dumb. Growing up, they recognized that they were different from their peers, but they did not understand why until after being diagnosed. After being diagnosed with a particular disability and understanding how they were different, they still struggled with separating disability and lack of intelligence. Even though they understand there is a societal norm that privileges and ranks ableism over disability, they still struggled with separating how they perceived themselves and how to resist the dominant ableism norm of society. This is evident in the participants’ conversations:

I1: “Am I not understanding this material because I am stupid and I have a disability? And because you associate it...because it’s like the disability and stupid go hand in hand, like what society tells you.”

I5: “Sometime, I feel, like a little stupid because it takes me a while to express what I am saying. That is frustrating; I take longer to express my ideas than others.”

I3: “I know it’s not... it’s not because I am lazy that I can’t do it or it’s not because I’m stupid that I read slower than everyone else. It’s because, you know, there is something, you know, that is inside me that, you know, I can learn to... I can learn to get a handle on it [disability].”

Even with I4 who was the most ambiguous about whether she had a disability or not, she still made it clear that it was no one’s business to know about her disability. I2 did not seem to have strong feelings towards his disability except that he recognizes that becoming disabled is part of the ageing process, and that he will have to work harder to succeed academically.

Even though most of them expressed general acceptance of their disability, they still struggled with whether they were dumb because of their disability or they were dumb regardless of the disability. They struggled with having to work harder in order to achieve at the same level as their nondisabled peers. This “disruption” influenced how they accepted the disabilities in their lives. The process of either accepting their disability as part of their identities or seeing their disability as something apart from themselves, reflects how society interprets, treats, and defines disability. In other words, disability is a reflection of society’s values and norms. To mime is to reflect upon the meaning of disability and/or reinforce social norms in order to be a part of society by passing (Michalko 2002). Passing is a vivid depiction of a clear understanding of the situation and how the situation itself is accomplished, thus a vivid depiction of ordinary life.

The participants' efforts to minimize the effects of their disabilities and the desire to keep their disabilities to themselves reflect their understanding of the social norms pertaining to normalcy and abnormality. Through their choices and actions, they perpetuate society's values and norms regarding disability. They are conforming by subconsciously and consciously upholding that disability is undesirable by understanding and implementing the belief that if one has a disability, one must make changes to be more normal because that is what is desirable. In this process of passing, the participants' experiences describe a complex picture of the disabled experience that involves understanding social norms, expectations, power, hegemony, and ideologies. Achieving normalcy involves extensive work and attention to detail. To be marginalized and try to pass is a process of recognizing normal expectations and the effort involved to meet those expectations. To know the social norm is not enough, the individual must know and understand the whys of all the details. For instance, whenever one hears an extremely loud sound such as a fire alarm, nails on the chalkboard, and explosions, people tend to cover their ears and wince while trying to remove themselves from the source of sound. Something so simple as covering your ears and wincing may be how people normally react, but someone who does not hear those loud sounds has to figure out through observation what "normal" people do and why in those ordinary events.

The point is that disability is not something that is experienced by the disabled alone, but disability is experienced and constructed by everyone. The process of observing and receiving feedback helps shape our knowledge of social norms and background expectancies. Through trial and error, the participants have come to understand what is socially desirable, socially acceptable, and socially ideal. In the interactional process, when the participants

receive negative feedback from nondisabled peers, such as being treated as dumb after learning of a disability, the participants processed the negative association of disability and the lack of intelligence and subconsciously understood that disability is not a desirable trait. This interactional process helps not only shape their understanding of societal norms and ideologies through interaction, but also demonstrates how both sides are interdependent in the construction of those social norms and ideologies. Disability is not shaped by itself, nor is disability shaped solely by the nondisabled, but rather disability is a continual construction of each shaping what the other one means. In other words, disability as a social phenomenon is a reflection of society's values (Davis 1995; Lipton 1998; Michalko 2002; Titchkosky 2006).

#### Seeing Disability as Part of the Everyday Process

In addition, there is a need to see disability as part of the everyday process rather than an isolated incident or condition that affects only the individual. As noted previously, disability is a social phenomenon that is continually constructed by all parties, thus constructing what it means to be disabled or how one embraces disability as part of oneself. Complicating disability with race, class, gender, and sexuality demonstrates a way of seeing how disability is part of the everyday process. As with race, class, gender, and sexuality, these social categories are continually shaped and constructed by societal interactions, which in turn also influences those very social interactions. As noted previously, it is not a simple task to see how disability, race, class, gender, and sexuality overlap, influence, reinforce, and shape one another. As Davis (1995) noted, "Disabled people are thought of primarily in terms of their disability, just as sexual preference, gender, or ethnicity becomes the defining factor in perceiving another person" (10). This assumption indicates a need to further our

understanding of disability, race, class, gender, and sexuality as social categories that intersect and interlock with each other instead of viewing the social categories within an additive hierarchical framework.

First, each social category has a set of social norms and stereotypical assumptions. For instance, considering gender roles, it is socially acceptable for males to be: masculine, strong, independent, confident, aggressive, competitive, unemotional, and the breadwinner. Females may be: feminine, weak, dependent, talkative, emotional, passive, and nurturing. Considering race, each race and ethnic group has constructed meanings and characteristics that are assumed about the individual. For instance, Hispanics tend to be portrayed as: loud, obnoxious, talkative, lazy, maids, bus boys, landscapers, sultry, curvy, sexy, illegal immigrants, and as having accents and large families. When intersecting race and gender, this presents a narrow list of stereotypic assumptions about each race and gender pair. For instance, Hispanic females tend to be associated with being low class maids or voluptuous sexy loud women, and Hispanic males are often seen as asexual gardeners or drug lords or in powerful bad boy roles.

Intersecting and interlocking social categories enable us to understand both how we perceive ourselves and how others perceive us. Incorporating disability into the picture involves understanding how disability plays a role in reinforcing race, gender, class, sexuality and social expectations along with seeing how race, class, gender, and sexuality contribute to rendering disability invisible. For instance, Titchkosky (2006) noted how her gender masked her disability and how her disability reinforced the stereotypical expectations of her physical appearance. She has a Caucasian appearance and blond hair, so when she is having difficulty telling time or processing her thoughts, which come out as scrambled or

misspoken phrases, she is seen as someone who is lazy, forgetful, confused, or quirky, original, eccentric, or easily distracted. Her physical appearance resonates with her behavioral patterns due to the blond female stereotypes of being scatterbrained, dumb, quirky, or forgetful, so her disability traits and her gender reinforce one another, perpetuating the stereotypical assumptions about what it means to be a blond white individual rather than indicating there is something wrong with her. At the same time, her disability is rendered invisible due to her physical appearance and the societal expectations surrounding her physical appearance.

Participants I4 and I3 shared similar experiences in terms of their disability characteristics and backgrounds. They both embodied the disability characteristics of hyperactivity, difficulty focusing, fast talking and interrupting, changing the subject, and having poor memories/forgetfulness. They have similar racial backgrounds and both are woman of color in white male-dominated fields. As noted previously, there are social stereotypes of what it means to be a Hispanic female including loud, flamboyant, curvy, accented speech, unintelligent, lazy, and slow traits. I4 described herself as loud, outgoing, cheery, hyperactive, happy, and scatterbrained, which was the social norm for females in the Hispanic community where she grew up. Her disability may contribute to her being hyperactive, loud, and scatterbrained. She noted that because of her disability, she tends to have difficulty participating in conversations and gets side-tracked with other topics. In addition, her hyperactivity contributes to her difficulty focusing on one topic. She also noted that she is forgetful and tends to lose and forget where she put things. The racial and ethnic expectations of Hispanic females enable her to be hyperactive, scatterbrained, outgoing, loud, cheery, and happy without indicating that something is wrong with her; in other words the

racial and ethnic stereotypes help mask the disability. In turn, the disability not only contributes to but also reinforces the racial and ethnic stereotypes of what it means to be a Hispanic female.

This pattern is similar for I3 who views herself as scatterbrained, goofy, silly, hyper, and a fast talker who interrupts, which are traits due partly to the characteristics of her disability. It was interesting when I3 mentioned how her mom focused on raising her like a lady. When she was younger, she said she was hyper; she ran around a lot, repeatedly left her seat, jiggled her foot, talked loud and fast, used wild hand gestures, and shouted a lot. Her mom corrected her by noting that, “That’s not what a young lady does. A young lady sits quietly and doesn’t jiggle her foot, keeps her hands still and talks slowly.” I3 stated that:

“She was able to mask that [her disability], even though she didn’t realize she was masking it [disability]. She thought she was helping me become a young woman. Whereas, if I was a boy, she would be like, ‘Oh, there is something wrong with this kid. He is a little hyper. Why is he moving around so much?’ She might have figured it out earlier. But because I was a girl, she tried to fix it.”

Through her mom’s efforts of reinforcing gender expectations of a lady, she helped I3 mask her disability. At the same time, her disability characteristics reinforced the racial and gender assumptions of a Hispanic female. Their disability traits of hyperactivity, changing subjects frequently, and having difficulty focusing correlate with and reinforce the expectation of Hispanic women being loud, talkative, and outgoing, while their race and gender mask the traits that indicate they have a disability.

I5 has a more obvious disability of speech difficulty. He expressed that he has difficulty communicating verbally and in writing, because he is not able to locate the words to communicate what he wants to say, has difficulty processing and is easily distracted. He noted that he has not encountered many negative reactions to his speech difficulty. When

asked if perhaps his race and gender play a role in people being more tolerant of his communication issues, he thought it might be possible. The stereotypical male representations tend to be that they are persons of few words and express their emotions by doing something rather than talking about their emotions. As for someone with a Hispanic background, there is an assumption that English is their second language. With anyone who has an accent it is assumed that they are foreign or an immigrant, are not a native English speaker and not born in the United States. In the case of the Hispanics, there is a strong expectation that Hispanics are immigrants. Therefore, I5's race and gender mask his disability making it not readily apparent, and at the same time, his disability reinforces the Hispanic male gender role. Recognizing the overlap of disability, race, class, gender, and sexuality enables us to see disability as part of the everyday process in shaping or reinforcing assumptions about one's race, class, gender, or sexuality status.

It is also important to note that the participants had a degree of awareness of the social identities, expectations, and norms. The participants were aware and understood how they were perceived through stereotypical and societal norms in terms of their social identities. What was interesting was how the participants manipulated the social identity stereotypes to challenge or reinforce the social norms of particular social categories. Recognizing desirable and undesirable social characteristics depending on race, class, gender, and sexual identities enables one to create a map to navigate social interactions and manipulate social interactions as well.

Participant I3 embraced all of her identities of being a woman of color, a racial minority, biracial, and having a disability. She noticed that all of her identities in a white male dominated science field meant she had many hurdles to overcome. She emphasized

being a role model for the next generation; consequently she actually highlighted her racial minority status by tanning or darkening her skin and dying her hair a darker shade of brown. She does this because she is trying to challenge the stereotypes of Hispanics as lazy, dumb, and slow and that girls do not belong in sciences and math. Through her efforts, she wants to reinforce the notion that Hispanic girls, rather than girls in general, can be good at science, and that Hispanics are not always lazy, dumb, or slow.

Participant I1 emphasized that her disability has little impact on who she is and in her life. She noted that the blond female stereotypes are more disabling for her than her disability. Interestingly enough, she does not see how the blond female and disability assumptions embody the overlapping characteristics of being perceived as dumb, stupid, and unintelligent. What was interesting was that she emphasized that when people realize that she has a disability, they generally talk down to her as if she is stupid. When her disability is revealed she feels the need to say something like “I have an IQ of a genius” or “I graduated with a 3.6 GPA” in order to counter the notion that her disability means she is dumb. Through her efforts to showcase her intelligence she is contesting the stereotypical assumption about disability and the lack of intelligence.

I4 used similar tactics, but under a different guise. She noted that she encounters difficulty with the males in her study group who treat her as dumb because of her gender or racial minority status. What was interesting was that she played up the gender and race stereotypical assumptions of females being bad at math, that females need to appease males for doing their work for them, or that a Hispanic girl is bad at math and needs male assistance to succeed academically. She expressed frustration that she is treated this way due to being a

woman of color in mathematics, but at the same time she opts to act on and reinforce those stereotypical assumptions to decrease her work load.

The recognition of the characteristics of race, class, gender, sexuality, and disability enables individuals to navigate social interactions by understanding how they are perceived and how their social identities influence the interactional process. At the same time, understanding the stereotypical assumptions made about them enables them to conform to the expectations, but also challenge those stereotypical assumptions. I3 and I1 demonstrated how they countered racial and gender stereotypes; while I4 used those gender roles to her advantage. In addition, seeing how disability intersects and interlocks with race, class, gender, and sexuality enables one to see how social identities overlap and reinforce each other, also that disability may be rendered invisible by the other social categories rather than being made invisible by medical treatment or disability services. Thus, disability is regarded as part of the everyday social process. Most of the participants felt their disabilities did not influence their daily interactions as much as for those with more visible disabilities, but their disabilities were still present in their daily social interactions. Again, four out of the five participants noted that their disabilities do not play a significant role in their lives, but none of them really examined how their disabilities are masked by their other social identities. It is important to consider their ages. Most of them were at the age when they were only beginning to understand who they are and starting to wrestle with their identities. Many of them expressed confusion or hesitation in understanding how all of their social identities influence their experiences, but they all indicated that in different contexts, different identities prevail.

Bringing the social categories together reveals that disability is not a simple matter of overcoming the situation or a “poor me” circumstance; rather recognizing how it plays out in everyday situations is far more complex and diverse than the simple dichotomous representations of disability or the personal tragedy concept of disability. Examining how other social identities influence how disability may be perceived or rendered invisible invites the need for further consideration of how race, class, gender, and sexuality influence the experiences of the disabled and how disability reinforces race, class, gender, and sexuality expectations. The participants’ personal accounts reveal how disability is a social identity, a social phenomenon, and part of the everyday process shaping race, class, gender, and sexuality (Michalko 2002; Titchkosky 2006). In addition, to see race, class, gender, sexuality, and disability overlapping, intersecting, and interlocking with one another recognizes the need to consider research that accounts for the whole being rather than fragmenting an individual into separate and isolated social categories. Perhaps doing so can contribute to the individuals’ gaining a more holistic understanding of who they are. Utilizing a more holistic approach to disability presents the opportunity to display the diversity of experiences within the disability experience and to disrupt the notion that disability is an isolated case scenario.

### Conclusion

The fields of race, class, gender, disability, and sexuality have been well established in the present academic literature. To challenge our understanding of those fields and of ourselves, there is a need to expose ourselves through continual application and intersection of different lenses and frameworks to gain alternative insights and interpretations. This goal involves bringing together the well-developed fields of race, class, gender, disability, and

sexuality to complicate each other and to discover their common attributes. We do not need to repeat the same arguments, but to find new ways of examining these areas (Titchkosky 2006). The issue that remains is the persistent segregation of the fields of race, class, gender, disability, and sexuality. In terms of disability, we need to view disability as a sociopolitical phenomenon, a space where we can explore alternative insights and interpretations, and implement different lenses in order to expand our understanding of disability. To develop effective politics, one has to accept that the “position one occupies is to some extent capable of being shared by others in parallel circumstances” (Davis 1995: xix). It is important to recognize the value of cross applying fields to gain greater insight or new insights; therefore, subjects should not be segregated. As Linton (1998) noted:

Other fields have described the consequences of the splits between public and private, personal and political, mind and body, or biological and social. Disability Studies demonstrates how such compartmentalization often serves some groups better than others but ultimately serves no one well (186).

This viewpoint demonstrates the need to utilize a multi-disciplinary approach and enables Disability Studies to present a more inclusive framework where disability can be explored through multiple lenses: race, class, gender, sexuality, politics, sub-cultures, feminism, arts, culture, and etc. To create another model in response to the model that is disagreed upon such as the medical model is problematic and does not allow flexibility in exploring disability in an open-ended manner. It could restrict the study of disability to a limited dichotomous lens: either disability as a medical and personal issue or disability as a social issue or social oppression (Johnstone 2001; Michalko 2002). Simply, there is a need to shift societal and academic thinking to see how disability plays a role in the everyday social process. As long as disability remains isolated and marginalized in society and the

medical and education communities, that is how disability will continue to be treated and conceptualized. There have been multiple attempts at intersecting disability with race, class, gender, and sexuality or to expand disability beyond the medical conceptualization, but the problem is that the field of disability remains concentrated in special education, rehabilitation, psychology, and physical therapy. The marginalization of Disability Studies perpetuates the societal values and norms towards disability. As Michalko (2002) stated, “Disability is mimetic” (168).

Higher education and society must step back and critically reexamine how they approach disability and recognize how disability is part of the everyday process. Higher education wields considerable influence in shaping social norms, ideologies, and conceptualizations that shape the everyday processes. Within higher education, it is not sufficient to explore how disability is a social identity, a social phenomenon, a social oppression, or a medical condition. Disability is ever-present just as race, class, gender, and sexuality are in everyday interactions that mold and perpetuate social norms, discourses, and ideologies. By seeing and talking about disability as it is part of the everyday life, can we cease seeing disability as an isolated incident or a taboo subject. Disability research is a fight to see from different perspectives how those cracks or interruptions of everyday mundane processes are not so ordinary after all but may provide insight into society itself (Michalko 2002; Titchkosky, 2006). The way disability continues to be treated as a segregated subject that is associated with medical fields demonstrates that higher education reflects and reinforces the social norms and cultural values towards disability (Linton, 1998). Within higher education, there is a need for change in the theoretical, curriculum, and practical approaches towards disabilities (Margolis and Romeo 2000).

There is a need for theory and practice to overlap and reinforce one another. In other words, it is not sufficient for academicians to continually explore disability on a theoretical level through multiple lenses, and then fail to make strides in how disability is engaged with on an applicable level. For instance, there is a need to reconsider how the university services are segregated based on specific identities such as: multicultural affairs office, disability services, GLBT organization, African American club, Korean American club, women's society, and so on. The absence of a holistic service that considers the whole individual with their multiple identities perpetuates the notion that race, class, gender, sexuality, and disability are segregated isolated experiences. Dei (1996) argues that "there must be congruence between theory and practice that leads to a more inclusive foundation of knowledge and multiplicative analysis" (76). Simply, there is a need for changes both in theoretical and applied approaches in order to move towards social justice and social change.

Examining the participants' experiences of being racial or ethnic minorities with disabilities, intersecting and interlocking disability with race, class, gender, and sexuality allows individuals to see how disability is an integral part of their everyday experiences, which is evident in the language, the representations, and the models we use. A more inclusive framework that ceases separating race, class, gender, sexuality, and disability promotes a more holistic framework that enables a person with a disability to be perceived as a woman, a male, a Caucasian, an Indian, an Asian, a lesbian, a transgendered individual, and so on. Disability and identification are multilayered and filled with complex images in the social representations of disability. Part of the problem is the absence of those with disabilities in the academic research, which greatly influences how people with disabilities are presented in academia. The research on disabilities generally portrays people with

disabilities as objects of research (Linton, 1998; Morris, 1992). This approach must be explored and addressed, and people with disabilities from all backgrounds must be included when considering disability, social justice, social oppression, and social change (Michalko 2002).

It is essential to recognize the limitations of this study. In the methodology chapter, the researcher recognized that the small sample size and purposive sampling technique hindered her ability to generalize the findings to the general population. This may have been the result of seeking out participants located within a predominantly Caucasian population in midwestern universities. It would be beneficial to consider seeking out participants in larger more diverse cities in future studies. Seeking out college participants may have prevented finding a larger number of participants as well. Only a small percentage of individuals with disabilities attend college, and there may have been a better chance of finding more participants if the researcher had not solicited participants solely through university disability services. Doing so, however, allowed the researcher to maintain a degree of consistency among the participants, since they were all attending college during the interview process. As noted previously, it is important to note for this particular research project the focus was on exploring the diversity of the disability experiences, thus why this particular methodology, framework, and paradigm was implemented.

All but one participant were in the normal college age range of 18-24 years. Their ages may have influenced the study, because the participants were “inexperienced” or “young.” They may have not had many opportunities away from home and from school to encounter experiences that caused them to question who they are and consider how their social identities influence their daily lives. Conducting a similar study with the objective of

exploring the experiences of older participants may be beneficial. It seemed that all the participants were developing an awareness of how their social identities influence their perspectives and experiences, but throughout the interview process, it was apparent they were struggling to express how their social identities intersect and overlap. At the same time, the researcher thought seeking out participants at the college level would be ideal since that is the time when students move away from home and begin to structure their personal identities.

The chief limitation to consider was the visibility of the disability. All the participants had what are considered invisible disabilities. Their disabilities were not readily apparent and consequently were not the dominant presence in their lives. For those who have more physically apparent disabilities, such as carrying a white cane, using a seeing-eye dog, or wearing hearing aids or prosthetics, it is important to recognize that their disabilities exert greater influence in the way they perceive themselves and how they perceive others through social interactions. Ideally the researcher preferred a mix of visible and invisible disabilities in order to gain a broader sample of diversity among disability, race, class, gender, and sexuality. In this project, all the participants possessed invisible disabilities. Possibly those with more obvious disabilities may have pondered earlier how their intersecting and overlapping social identities had influenced their lives, which may have elicited more powerful data that could strengthen the present data, and contribute to generalizing the findings. This factor must be considered in the next study.

In the end, the focus of this thesis was to not only explore the experiences of ethnic minorities with disabilities, but to also offer a methodological consideration of the direction that Disability Studies need to incorporate: intersectionality. In addition, the

phenomenological methodology provided a space that enabled the participants' experiences to challenge the status quo of the representations of disability in both academia and society and fill in a gap in the literature. Through the participants' voices and my own, this research is an attempt to challenge the notion of disability as an isolated apolitical, asocial, and acultural phenomenon by demonstrating how disability is part of the everyday process. Hopefully, this study will begin to challenge and broaden disability scholars and other scholars' understanding of disability, race, class, gender, and sexuality, and will encourage them to reexamine their own concepts and approaches towards disability.

## APPENDIX: ADDITIONAL MATERIALS

## Letter of Introduction

# Iowa State University

OF SCIENCE AND TECHNOLOGY

To whom it may concern:

My name is Holly Pearson and I am currently enrolled as a sociology graduate student at Iowa State University. To complete my degree requirements, I am expected to write a thesis. My thesis will focus on understanding the experiences of racial/ethnic minorities with disabilities. The main reason I am pursuing this study is due to my own experience of being a minority with a disability. Over the course of my studies, I have come to realize that consideration of the experiences of people with disabilities is absent or limited in academic literature. With my thesis, I aim to change that and hope to increase recognition of the importance for those with disabilities to have a voice within the academic literature.

You have been given the opportunity to share your experience as a minority with a disability. Your response is important to this thesis, because the value of your experiences will be a beneficial supplement to the thesis process and to increasing the presence of those with disabilities in the academic literature.

The interview process should take about an hour to several hours depending on the interviewee. The focus is to provide you with the time to share and discuss your experiences. The location and time of the interview will be determined at a later time, and the time and location will be arranged at your convenience if you decide to participate in this project.

To ensure your confidentiality, the transcripts and interview recordings will not include any personal identification and will be kept under lock and key. Only my committee and I will have access to these records. You will be assigned a different name or number as a form of identification, and all forms of identification will be promptly destroyed once the project is completed.

Feel free to contact me if you have any questions. If you are interested in participating in this project, please contact me preferably at my email address: [hpearson@iastate.edu](mailto:hpearson@iastate.edu), or if it is easier for you, feel free to call me at 907 978 9936. If I do not answer, please leave your name, contact information and note indicating that you are interested in participating in this project. If you do choose to participate, I will be extremely grateful and deeply indebted to you.

Sincerely,

Holly Pearson

412 East Hall  
Iowa State University  
Ames, IA 50011  
(907) 978 9936  
[hpearson@iastate.edu](mailto:hpearson@iastate.edu)

## Informed Consent Letter

## INFORMED CONSENT DOCUMENT

Title of Study: Experiences of Racial and Ethnic Minorities with Disabilities

Investigator: Holly Pearson

This is a research project for my thesis. Please take your time in deciding if you would like to participate. Please feel free to ask questions at anytime.

## INTRODUCTION

The purpose of this study is to learn more about minorities with disabilities. You are being invited to participate in this study because I am interested in hearing about your experiences as a minority with a disability.

## DESCRIPTION OF PROCEDURES

If you agree to participate in this study, your participation will last for one to several hours in an interview process. If you agree to participate in this study, a time and location will be determined at your convenience. A follow-up email or telephone call (whichever is best for you) may be needed to clarify something that was discussed during the interview or to ask a few more questions. During the interview process, a tape recorder will be used to help the interviewer remember what you shared during the interview process. During the interview process, you may skip any questions that you do not wish to answer or that make you feel uncomfortable.

## RISKS

While participating in this study, you may experience risks including emotional issues of discussing or sharing something personal or memories of a negative experience. If this occurs, it is okay for you to indicate that you wish to stop the interview, or change the subject. Regarding privacy concerns, the setting/location of the interview will be determined to maintain your privacy.

## BENEFITS

If you decide to participate in this study there may not be a direct benefit to you, except perhaps on a personal level by sharing your experiences. It is hoped that the information gained in this study will benefit society by providing a body of literature that allows minorities with disabilities to voice their own experiences. In the current academic literature, there is limited to non-existent literature that discusses the experiences of those with disability, especially those of minorities with disabilities. With the information gained, the focus of this project is to change that gap in the literature by presenting a piece that embodies

the voices of minorities with disabilities. For myself, I hope to expand on this information further in other research projects that will contribute to awareness of the diversity of experiences of those with disabilities.

#### COSTS AND COMPENSATION

You will not have any expenses from participating in this study. You will not be compensated for participating in this study.

#### PARTICIPANT RIGHTS

Your participation in this study is voluntary and you may refuse to participate or leave the study at any time. There will be no penalties or negative consequences for refusing to participate or leaving the study early.

#### CONFIDENTIALITY

Records identifying participants will be kept confidential to the extent permitted by the applicable laws and regulations and will not be made publically available. However, federal government regulatory agencies, auditing department of Iowa State University, and the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis. These records may contain private information.

To ensure confidentiality to the extent permitted by law, the following measures will be taken such as all interviewees will be assigned a unique code and letter that will be used on forms instead of their names. I will have a list that will contain the name and matching code and letter that will be stashed with the transcripts and recording tapes (that will also not have any form of personal identification such as names, addresses or distinguishing characteristics) will be under lock and key when not in use, or located within a password locked computer. Only my committee and I will have access to the data. Once the project is completed, the list of names and matching code and letter (along with any other documents with identifications) will be promptly destroyed. The latest date for the destruction of identifications will take place in May 2011. If the results are published, your identity will remain confidential.

For both writing the thesis and for potential publication, I plan to use terms such as "Midwestern University" or a university in the Midwest when referring to Iowa State University. In other words, I never will identify which university in both the thesis and potential publication. In addition, I plan to use general categories such as physical or sensory disabilities in reference of your experiences, but I will not incorporate your names, detailed physical descriptions, or specific disability categories such as deaf or blind within both the thesis and potential publication to protect your confidentiality.

#### PUBLICATION

There is a potential that this research project may be published in a journal. If you have any concerns about this, please discuss your concerns and questions with me, and to be aware that I plan to protect all my participants' confidentiality.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during the study. For further information about the study contact Holly Pearson at 907 978 9936 or hpearson@iastate.edu, or my supervising major professor Dr. Betty Dobratz at 515 294-2033.

If you have any questions about the rights of research subjects, please contact the IRB Administrator, (515) 294-4566, IRB@iastate.edu or Director (515) 294-3115, Office for Responsible Research, Iowa State University, Ames, Iowa 50011.

PARTICIPANT SIGNATURE

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. You will receive a copy of the written informed consent prior to your participation in the study.

Participant's Name  
(Printed) \_\_\_\_\_

\_\_\_\_\_  
(Participant's Signature)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Witness)

\_\_\_\_\_  
(Date)

INVESTIGATOR STATEMENT

I certify that the participant has been given adequate time to read and learn about the study and all of their questions have been answered. It is my opinion that the participant understands the purpose, risks, benefits and the procedures that will be followed in this study and has voluntarily agreed to participate.

\_\_\_\_\_  
(Signature of Person Obtaining  
Informed Consent)

\_\_\_\_\_  
(Date)

## Interview Schedule

### Background

Name, age, gender, ethnic identity

Family background

Where interviewee grew up and the background of hometown

Current occupation or job

(Focus is: to gain a sense of the subject's social, class and economic background, or in other words, paint a picture for the interviewer. Plus it's an impersonal way of starting the interview and building rapport)

### Starting the Dialogue

Do you identify as a person of color or with a disability? Could you talk about how race, ethnicity, and disability shape your identity?

(Focus is: to allow the interviewee/participant to identify themselves and prevent the interviewer/researcher from making assumptions about how they identify. Plus, it's a more general and less personal question to start the dialogue)

Who do you generally associate with? And what are their backgrounds?

How do others act toward you? How do you feel about their actions? How do you handle those situations?

(Focus is: Seeing who they spend time with and if they mix with family, friends, other ethnic groups, other groups of people with disabilities or focus solely on seeking out friendships of people with similar identities and experiences)

Describe your disability or how do you define your disability

(Focus is: gaining a sense of the type of disability, how they perceive their disability, or if they even view it as a disability, and a time line of when the disability developed)

Describe a situation or experience when your disability was more noticeable.

How did others act toward you? How did you feel about their actions? How did you handle the situation?

(Focus is: Setting a context, where one can begin to discuss the experiences when their disability was more prevalent, the interactions between themselves and others, and how they handled the situation. This enables the interviewer to see if the way they handled the situation could be an indication of attempting to establish a degree of normalcy without having to "lead" the conversation with direct questions, or in other words provide an opening for them to lead the discussion)

Describe your ethnic identity, or how do you define your ethnic identity

(Focus is: to specifically target and understand how the interviewee perceives their own ethnic identity and prevent the interviewer/researcher from making assumptions about how they identify themselves. Also, begin to explore situations where their ethnic identity was more prevalent).

Describe a situation or experience when your ethnic identity was more noticeable.  
How did others act toward you? How did you feel about their actions? How did you handle the situation?

(Focus is: Setting a context, where one can begin to discuss their experiences of when their ethnicity was more prevalent, the interaction between themselves and others, how they handled the situation and assess whether the means of handling the situation could be an indication of trying to establish a degree of normalcy without “leading” the conversation with direct questions; or in other words provide a space for them to lead the discussion)

If applicable, describe a situation or experience when your gender was more noticeable.  
How did others act toward you? How did you feel about their actions? How did you handle the situation?

(Focus is: Setting a context, where one can begin to discuss their experiences of when their gender was more prevalent, the interaction between themselves and others, and how they handled the situation enabling the interviewer to see if perhaps the means of handling the situation could be an indication of their attempt to establish a degree of normalcy without “leading” the conversation with direct questions, or in other words provide a space for them to lead the discussion)

Describe a situation or experience where your disability and ethnic identity, and/or gender were more noticeable.

How did others act toward you? How did you feel about their actions? How did you handle the situation?

(Focus is: Finding a context where one can begin to discuss their experiences of when their multiple identities were engaged, the interactions between themselves and others, and how they handled the situation enabling the interviewer to see if perhaps the means of handling the situation could indicate an attempt to establish a degree of normalcy without having to “lead” the conversation with direct questions, or in other words provide a space for them to lead the discussion)

### Concluding Questions

Based on your experiences, what advice or suggestion would you give to someone who is also a person with disability, a minority, or both?

Is there anything that you would like to say that you might not have thought of during the discussion?

Is there anything else that you think I should know that is important in helping me understand your experiences or the general experiences of minorities with disabilities?

Are there any questions that you may have for me or would like to ask me?

Intent Questions to Focus On  
(For my own personal notes, and guidance reminders)

What is it like being a minority with a disability? (Experience of having double, triple, or simultaneous identities)

How do you negotiate (and feel about negotiating) your multiple identities in everyday experiences? (Focus on the interactional process through negotiation of multiple identities)

In everyday interaction, what are some of the common or generalized experiences you encounter while interacting with other people?

Using race or disability, or gender characteristics, how do you use them as a means of establishing normalcy, depending on the context?

How does your disability or race play out or figure in the other group settings? In other words, how is your disability regarded when associating with your identified ethnic group? And how is your race regarded in your disability identification?

Final question or ultimate focus:

Ultimately, what do I want from this research? What are the outcomes, what do I wish to achieve?

To problematize the experiences of minorities with disabilities (and problematize disability itself where most of the literature is focused on the social construction of disability). Provide an orientation where the fields of race and disability can begin to conjoin.

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