UNDERSTANDING FACULTY MEMBERS LIVING WITH DISABILITIES IN HIGHER EDUCATION

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE DOCTOR OF EDUCATION

BY

LOIS WEISS

DISSERTATION ADVISOR: DR. MICHELLE GLOWACKI-DUDKA

BALL STATE UNIVERSITY
MUNCIE, INDIANA

DECEMBER 2016
UNDERSTANDING FACULTY MEMBERS LIVING WITH DISABILITIES IN HIGHER EDUCATION

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE DOCTOR OF EDUCATION

BY

LOIS WEISS

DISSERTATION ADVISOR: DR. MICHELLE GLOWACKI-DUDKA

APPROVED BY:

<table>
<thead>
<tr>
<th>Committee Chairperson</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Committee Member</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Committee Member</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Committee Member</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Committee Member</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dean of Graduate School</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ball State University

Muncie, Indiana

December 2016
ABSTRACT

TITLE: Understanding Faculty Members Living with Disabilities in Higher Education

STUDENT: Lois Weiss

DEGREE: Doctor of Education

COLLEGE: Teachers College

DATE: December 17, 2016

PAGES: 119

Despite increased disability awareness and the advancement of disability rights laws, the stigma of disabilities continues to be a problem in our country. Ableism is the outcome of negative attitudes towards disabilities perpetuating the belief that being able-bodied is preferable over being disabled (Siebers, 2008). This study examined attitudes towards disabilities in the world of academe through the stories of disabled faculty. The purpose of this study was to understand the experiences of faculty members living with a disability in higher education and how they used the transformative learning stages in their adaptation and growth. Seven faculty members were interviewed for this study selected from both a four-year public university and a two-year community college. The study was designed using an adult education framework and data was analyzed using Mezirow’s transformative learning theory. Critical disability theory and feminist disability theory were also used to help understand the data. A narrative inquiry approach was used by completing semi-structured interviews which provided space for the participants to tell their stories. Each of the participants identified moments of transformative learning throughout their educational and professional journeys. Their experiences illuminated the ongoing stigma of disabilities, even within the world of higher education.
ACKNOWLEDGEMENTS

I would not have been able to complete the doctorate program and this study without the help and support from many different people. I am eternally grateful for each one and for their encouragement. First, I would like to thank my family because without their support, this would not have been possible. To my husband, Jon, I thank you for being willing to step in and take care of the children and things around the home during the many nights I was in class. I may not have always appreciated your prodding to go work on my papers but I know that without your encouragement and support, I would not have finished those papers on time. To my children, Kyle, Sean, and Emily, I thank you for understanding the need for me to be away from home and to miss some of your activities because of my classes. I hope that I have made you proud and shown you that with determination and hard work, you can accomplish your goals.

Second, I would like to thank my extended family and many friends who have encouraged me along the way. It was easy for me to get caught up in the busyness of classes and forget how special this path was and the end goal of earning my doctorate. For those friends who continued to encourage me along the way and ask me how things were going, thank you for sharing this part of my life. To my colleagues and to those who have completed their doctorates before me, thank you for always being excited to discuss my classes and for sharing your wisdom with me along the way.

Third, I would like to thank my doctoral committee. I have not always produced my best work for you and I appreciate that despite this you all believed in me and were able to see the potential in me even when I couldn’t see it myself. Dr. Mulvihill, thank you for the experience that you’ve shared with me and your honest critique of my work. You pushed me to be better and dig deeper in my research. Dr. Latz, thank you for all of the encouragement you have given.
me throughout my doctoral program and throughout the dissertation process. The excitement you bring to the field of community college leadership has engaged me in ways that I never knew was possible. I’ve learned a lot from you about community college leadership and teaching in general. Dr. Steve Jones, thank you for your willingness to serve on my doctoral committee and for your belief in me as I completed this process. When I asked you to serve on my committee, I knew that you would be brutally honest in your feedback and at the same time would be that encouraging voice I needed to help me finish. A special thank you to Dr. James Jones for joining my committee at the last minute when one of my committee members was unable to participate in my dissertation defense. Dr. James Jones, I appreciate your willingness to be a part of my doctoral process and for your interest in my dissertation. Your questions and feedback were very helpful for me to further explore this topic of study. Finally, Dr. Glowacki-Dudka, thank you for all of your support throughout my doctoral program and for chairing my doctoral committee. I appreciate all of the time you have invested in me and for being a mentor to me. It has been a privilege working with you. Thank you all again for your dedication to helping me. I look forward to my future as a colleague in the field.

Lastly, I would like to give thanks to God for without Him, I would not be on this journey. He has sustained me during times of self-doubt and confusion about my educational goals. I know that He guides my path and I look forward to the seeing the next chapter in my life.
DEDICATION

I dedicate this dissertation to my husband, Jon, and my children, Kyle, Sean, and Emily. Without their support and encouragement, I would not have even attempted this process. I love you all and I am happy that I got to share this journey with you.
# Table of Contents

ABSTRACT ................................................................................................................................. iv

ACKNOWLEDGEMENTS .............................................................................................................. v

DEDICATION ............................................................................................................................. vii

Table of Contents ..................................................................................................................... 8

CHAPTER ONE  INTRODUCTION ............................................................................................ 14

  Significance of the Study ....................................................................................................... 15

  Purpose Statement ............................................................................................................... 17

  Research Questions ............................................................................................................. 17

  Assumptions ......................................................................................................................... 17

  Limitations and Delimitations ............................................................................................. 18

  Definitions ............................................................................................................................ 19

  Organization of the Study .................................................................................................... 22

CHAPTER TWO  LITERATURE REVIEW .................................................................................. 24

  Introduction ............................................................................................................................ 24

  Models Defining Disability ................................................................................................... 25

  Ableism ................................................................................................................................. 26

  Disability Movement .......................................................................................................... 28

  Highlights from Disability Movement ................................................................................ 29
Data Analysis ............................................................................................................................................. 60

Triangulation (Validity) ................................................................................................................................ 61

Ethical Considerations ...................................................................................................................................... 61

Appendices (Semi-structured interviews, Consent forms, Codes, Laws, Policies) ................................................. 62

Summary .......................................................................................................................................................... 62

CHAPTER FOUR FINDINGS .............................................................................................................................. 63

Considerations and Descriptions of Participants .................................................................................................. 63

Table 1: Codes and Subthemes ................................................................................................................................ 65

Disorienting Dilemma: Disability ......................................................................................................................... 65

Self-Examination .................................................................................................................................................. 69

Critical Assessment of Epistemic, Sociocultural, or Psychic Assumptions ............................................................. 73

Societal Views ....................................................................................................................................................... 73

Inclusion vs. Exclusion .......................................................................................................................................... 75

Relating Discontent To Others ............................................................................................................................ 76

Self-Advocacy ....................................................................................................................................................... 76

Social Activism ..................................................................................................................................................... 78

Exploration of Options for New Roles, Relationships, and Actions ......................................................................... 79

Planning a Course of Action ............................................................................................................................... 80

Accommodations .................................................................................................................................................. 80

Controlling One’s Environment .......................................................................................................................... 81
Acquisition of Knowledge and Skills for Implementing One’s Plans ................................. 81

Planning and Preparation ........................................................................................................ 82

Provisional Trying of New Roles .......................................................................................... 83

Building of Competence and Self-confidence in New Roles and Relationships ................ 83

Professional Roles .................................................................................................................. 84

Involvement (committees, research, conferences) .................................................................. 84

Reintegration of the New Perspective Into One’s Life ............................................................. 85

Approaches to Teaching ......................................................................................................... 85

Life-long Learning ................................................................................................................... 86

Discussion of Research Questions .......................................................................................... 86

RQ1. What impact does living with a disability have on the faculty member’s professional
career path? .............................................................................................................................. 87

RQ 2. How has living with a disability shaped the faculty member’s pedagogy? ............ 87

3. What impact does living with a disability have on the faculty member’s relationships at
work? ........................................................................................................................................ 88

Summary ................................................................................................................................ 89

CHAPTER FIVE  CONCLUSIONS ......................................................................................... 90

Overview ................................................................................................................................ 90

Adult Education ....................................................................................................................... 90

Critical Disability Theory ......................................................................................................... 91
RQ1. What impact does living with a disability have on the faculty member’s professional career path? ......................................................... 97
RQ 2. How has living with a disability shaped the faculty member’s pedagogy? .......... 99
RQ3. What impact does living with a disability have on the faculty member’s relationships at work? .................................................................................................................. 99

Implications of the Study .......................................................................................................................... 100

Higher Education .................................................................................................................................... 102

Implications for Future Research ............................................................................................................ 103

Final Thoughts ......................................................................................................................................... 106

Conclusion ............................................................................................................................................... 106

REFERENCES ............................................................................................................................................ 108

Appendix A – INFORMED CONSENT ................................................................................................. 114

Appendix B – LETTER TO COLLEAGUES/PEERS ............................................................................ 117

Appendix C – LETTER TO POTENTIAL PARTICIPANTS .................................................................... 118
CHAPTER ONE

INTRODUCTION

Faculty members in academe pursue a challenging professional career path and educational journey. This journey starts early as the student achieves multiple academic degrees. Upon their first appointment, faculty members begin to balance teaching, researching and publishing, and service to the institution in order to meet the expectations for tenure and promotion. Becoming tenured and getting promotion requires several years of researching, presenting at conferences, publishing, teaching, and service. However, this journey is not a solitary one. Professional relationships help develop and pave the path to tenured status.

Bartunek and Dutton (2000) discovered that professional relationships are not only a means to an end but they also provide emotional support to the individual. Niehaus and O’Meara (2015) described other benefits of these relationships as “providing information, influence, and allies that grow social capital” (p. 2). Social capital results in the individual taking ownership of their career advancement through strategic actions and relationship building. Many professors successfully manage these expectations; however, faculty members who live with a disability may feel that they are at a disadvantage. These individuals find it difficult to meet career related expectations within the same time frame or in the same manner as the non-disabled faculty member.

Some disabilities are more visible than others, such as wheelchair use or blindness, yet many disabilities are not readily visible, such as hearing loss, brain injuries, or neurodevelopmental disorders, like dyslexia or being on the autism spectrum. Beretz (2003) noted that for faculty members with a hidden disability, “the accelerating publishing clock, intense competition for jobs, and attrition of tenured positions heighten these problems” (p. 51).
Tidwell (2004) also discovered that having a hidden disability, like a hearing loss can be challenging for a faculty member when there are expectations of attending faculty meetings, committee meetings, and teaching in addition to the informal meetings of faculty parties, luncheons, office visits, and networking. Individuals with a hearing loss often experience difficulties hearing in crowded and noisy spaces. These challenges often result in individuals not hearing important information and they often feel left out of the conversations. Despite the advancement in laws that protect individuals living with a disability in the workplace, many faculty who have a disability fear that acknowledging a disability or asking for accommodations could threaten their professional standing.

**Significance of the Study**

Disability studies as a field of research has grown in the United States with the introduction of federal laws: the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. These two laws changed the landscape of employment and the world of academe. Despite these laws, disability awareness and equality are areas that still need to be examined. Society has championed the causes of equality based on race, gender, sexual orientation, and religion, but little attention has been given to the lives of people living with disabilities (Anderson, 2006; Clark, 2006).

Formal studies addressing issues of disabilities in higher education has largely been limited to students living with disabilities (Shigaki, Anderson, Howald, Henson, & Gregg, 2012). Little attention has been given to faculty members living with disabilities, but their stories are an important part of the conversation. Faculty members who live with disabilities face professional challenges that can negatively impact their jobs. Disability knows no boundaries and can be found in every gender, race, and culture. In addition, most people will experience some type of
disability that is due to the aging process. For example, age-related disabilities such as hearing loss can create difficulty for a faculty member. Tidwell’s (2004) study of age-related disabilities among faculty in higher education showed the struggles of one such professor with an age-related hearing loss. The professor experienced feelings of being invisible to his colleagues due to the inability to fully engage in conversations because of his hearing loss. Due to the social stigma attached to hearing impairment, the professor developed deliberate and non-deliberate coping strategies at work. One deliberate coping strategy used was avoiding social activities such as lunches or parties with colleagues. Avoidance of social situations results in being less involved verbally with others. Tidwell (2004) noted that students and colleagues assess intelligence based on verbal ability, “those who exhibit verbal cleverness are perceived as bright, and those who are less verbiage are too often perceived as less intellectual” (p. 203).

Hearing impairment along with other invisible or hidden disabilities creates professional challenges due to periods of acute symptoms. Psychiatric disorders are also considered part of the hidden disabilities because individuals living with these disorders can hide their disorders unless they experience acute symptoms. These periods of acute symptoms can result in loss of time and energy. Faculty who cannot perform at the expected levels at all times experience anxiety about their jobs. According to Beretz (2003), “tenured and untenured faculty alike are often pressured to resign” (p. 51). Faculty members with visible disabilities, such as a physical disability, also experience professional challenges despite the general awareness that their colleagues have about their disability. Stereotypes exist and influence how others view faculty members who have a visible disability. Kimbrough, Green, and White (2008) examined stereotypes of visible disabilities among faculty members within the field of physical education. Results of their study showed that students viewed the instructor in a wheelchair as “less of an
expert, a less effective communicator, and did not like her as much as the standing teacher” (Kimbrough et al., 2008, p. 10). The stereotype that a disabled person is somehow less competent than a non-disabled person continues to exist in academe despite the efforts to create a more equitable workplace for faculty living with a disability. In order to eliminate discrimination based on assumptions, change must be made at the individual level by challenging belief systems and old stereotypes.

**Purpose Statement**

Through this study, I seek to understand how living with a disability impacts the professional lives of faculty members in higher education. The limited research on this specific population leads me to believe that more research is needed in order to gain a deeper understanding of the relationship between a faculty member’s professional career and living with a disability. The purpose of this qualitative study is to examine the lived experiences of faculty living with a disability in higher education.

**Research Questions**

1. What impact does living with a disability have on the faculty member’s professional career path?
2. How has living with a disability shaped the faculty member’s pedagogy?
3. What impact does living with a disability have on the faculty member’s relationships at work?

**Assumptions**

While designing this study, I made the following assumptions. My first assumption was that faculty members with visible or physical disabilities were more likely to openly discuss their disability with administrators, peers, and students. I assume this to be true based on the
knowledge that a visible disability is already known to others or at least acknowledged in some way by others. My second assumption was that faculty members with invisible or hidden disabilities were less likely to openly discuss their disability with administrators, peers, and students. I believe that there was and remains a huge stigma related to disabilities and individuals living with a disability continue to struggle with being accepted in society and in their workplace, and that they worry about accessibility and equality. My third assumption was that faculty members living with a disability have experienced some form of discrimination such as negative comments or omission from professional opportunities. I believe that even faculty who have hidden disabilities experienced this; although, comments may not be directed towards them personally. Ignorance about disabilities can be found in office conversations through casual comments or jokes about a particular disability such as describing someone with Asperger’s as odd or eccentric. My fourth assumption was that faculty members living with disabilities experienced events throughout their educational journeys and in their professional roles as educators that have resulted in transformative learning. My final assumption was that faculty members living with disabilities felt that they have to work harder than their non-disabled peers in order to reach the level of professional status they seek. I believe that faculty living with a disability feels they must prove themselves to others in order to be accepted.

Limitations and Delimitations

My study focused on a specific population of faculty living with a disability in higher education and may not be generalizable to the larger population of individuals living with a disability outside of higher education. The sample size was relatively small due to the time constraints of the study, as well as the location of the participants. Data was collected over a
period of three months. Since the participants were all actively working in higher education, the
timing of the data collection was limited due to their availability.

Critical disability and transformative learning theories were used to frame this study that
resulted in specific analysis of the data. Using other theories would provide other types of
analysis. This study was conducted in a Midwestern state in the United States. This general
location may not be reflective of the experiences of faculty members living with disabilities
working in other states or countries. Disabilities may have similar symptoms, but faculty
members living with disabilities experience their disabilities in very unique ways partly due to
their interpretation of their experiences. The experiences of the participants may not be the same
as others with the same type of disabilities.

Definitions

or mental impairment that substantially limits one or more major life activities of such
individual; a record of such an impairment; or being regarded as having such an impairment.”
(para. 1).

Impairment: This term is often interchanged with disability in the literature; however,
impairment has been viewed as separate from disability by many researchers. Impairment refers
to the limitations of the disability. It reflects the personal pain and consequences of the
disability. Impairment is viewed as something that is broken and that needs to be fixed through
medical treatment (Linton, 1998).

Ableism: A form of discrimination based on having a disability. Disability whether it is
physical, mental, or developmental is seen as a defect and individuals with a disability are seen
as less than able-bodied individuals (Smith, Foley, & Chaney, 2008; Wolbring, 2012, Lalvani & Broderick, 2013).

**Corporeal:** The embodiment of experiences; how the body experiences phenomena. Coole (2007) noted that “bodies emit and decipher signs that do not necessarily pass by way of consciousness” (p. 416). The dualism of the mind and body as two separate but intertwined parts of the individual was introduced by Merleau-Ponty and has been used to examine the relationship between embodiment of the disability and social power (Coole, 2007; Cadwallader, 2010).

**Medical Model of Disability:** Previously the dominant model for understanding disabilities. The medical model is based on the clinical examinations of the disability and treatments to fix the bodily defects (Rocco & Fornes, 2010).

**Social Model of Disability:** Disability in the social model theory is socially constructed (Knoll, 2009). Hosking (2008) described disability as “the social disadvantage experienced by disabled people caused by the physical, institutional, and attitudinal environment which fails to meet the needs of people who do not match the social expectation of ‘normalcy’” (p. 7). Disability is not just a condition of the individual but rather it is caused by the limitations imposed by the socially constructed world.

**Disabled Identity:** Identity formation based on the cultural representations of disability. These representations are a negative view of disabilities thus inferring that individuals living with disabilities are abnormal (Oliver & Barnes, 2012).

**Social Capital:** Social capital is broadly defined as the resources gained from relationships. Ellison, Steinfield, and Lampe (2007) noted that resources can vary depending on the types of relationships and can include such things as useful information, emotional support, and access to
scarce resources. Social capital has the ability to create both positive and negative outcomes in the community. A decline in social capital often results in distrust among the community members and an increase in social disorder. An increase in social capital has the opposite effects where there is greater commitment to the community and an increase in community engagement.

**Critical Disability Theory (CDT):** A theoretical framework that examines disability by comparing the liberalism’s norms with that of the everyday life of disabled people (Hosking, 2008). CDT suggests that differences are not to be ignored and instead demands that differences be recognized and challenged (Hosking, 2008).

**Feminist Disability Theory:** Feminist theory examines the intersection of privilege and oppression with that of race, class, sexuality, gender, and religion. This theory expanded to include the disability experience in its examination of privilege and oppression (Knoll, 2009). Garland-Thomas (2005) eloquently states that feminist disability theory challenges stereotypes about disabilities, examines rights and exclusions of the disabled, and explores identity formation as a social process.

**Disability Studies:** A field of study dedicated to the study of disabilities through social, political, and cultural contexts. It crucially examines the assumptions, stereotypes, and norms of society (Linton, 1998).

**Adult Education:** Merriam and Brockett (1997) define adult education as “activities intentionally designed for the purpose of bringing about learning among those whose age, social roles, or self-perception define them as adults” (p.8). It simply reflects the adult status of students and a learning activity that is specifically planned for the adult learner.

**Narrative Inquiry:** A form of qualitative research that examines stories and storytelling as a means to understand the human condition. Narrative inquiry focuses on actual details taken from
stories, historical artifacts, documents, and interviews (Leavy, 2014). Storytelling is how people make sense of their lives.

**Transformative Learning:** Transformative learning has been described as a more mature, independent and critically reflective way of thinking (Mezirow, 1998; Merriam, 2004). This theory explains how individuals learn from their experience by first acknowledging a disorienting dilemma and then challenging their ways of thinking. This critical reflection resulted in revised ways of thinking (Merriam & Brockett, 1997).

**Self-directed Learning:** Merriam and Brockett (1997) defined self-directed learning as “adults assuming control of their learning” (p. 137). Knowles (1980) described adult learners as possessing the capacity to direct their own learning based on their life experiences and current learning needs.

**Faculty:** I define faculty as education professionals who teach either part-time or full-time in higher education. Teaching may occur in a physical classroom or in an online environment.

**Organization of the Study**

This study is discussed in length covering five chapters. Chapter one provided a brief introduction on the topic of disabilities and the rationale for examining the lived experiences of faculty members living with a disability in higher education. It also included definitions for terms used through the study as well as the research questions, and assumptions. Chapter two provides an overview of the exiting literature related to disabilities, the different models of disabilities, feminist disability studies, critical disability theory, self-directed learning and transformative learning within the field of adult education. Chapter three describes the methodology used for this study including the epistemological framework, qualitative theory, sampling procedures, data collection and analysis. Chapter four presents the findings of the
study and Chapter five provides a discussion of the literature and research questions, conclusions, and implications for further research.
Disability-as a concept and construct-keeps reminding us then of how complicated our bodies are, reminding us of the complicated, and often contradictory, “acceptance” and assessment and negotiation of our own (and others’) bodies.

(Brueggemann, Garland-Thomson, & Kleege, 2005, p. 32)

Introduction

The world has developed a sense of order – those who have and those who have not; those who do and those who do not; the able-bodied and the disabled. This dichotomous nature of our world has shaped our culture into a belief that some are better off than others and that having a body fully capable of working is better than having one that is not. Our world values wholeness and pities bodies that are incomplete or misshapen (Weiss, 2015; Wolbring, 2012).

This perception lingers in our educational system despite having programs in place to support students living with disabilities (Hehir, 2002). These programs speak to the student’s inability to perform as the other able-bodied students perform. The same perception is found among faculty members in academe. Little thought is given to creating processes that provide equal access to professional faculty status for those with a disability. The general attitude towards disabilities is to ignore it unless a request for accommodations is made. Although the law mandates equal access, many people choose to avoid addressing disabilities and accommodations until the individual living with a disability makes their request known (Pothier & Devlin, 2006). It is this omission that drives my study. I am curious to know about the lived experiences of faculty members living with disabilities. In order to understand their experiences,
we must first explore the concept of disability, where it originated, and what social forces shaped it into what is known today.

**Models Defining Disability**

Throughout history people have tried to find an answer to the question of why some people are disabled while others are not. These explanations were developed through the existing social norms and provided limited understanding of what it meant to be disabled. Two of the early models explaining disabilities were the religious or moral model and the medical model (Pelka, 2012). The religious or moral model viewed disability as a reflection of the individual’s and/or their family’s moral character. Disability was viewed as the divine judgement and was considered a punishment for wrongdoing by the individual or their family. This view of disability was prominent in the early Christian traditions, but was also found in cultures from around the world. The disabled were considered unclean and therefore unable to participate in the religious ceremonies of the community. They were marginalized or outcast from their communities.

The second model used to explain disability was the medical model. This model defined disability in terms of illness or pathology. The individual was defined by the disability and medical treatment was the cure to rid the person of the problems associated with the disability. Being cured was the expectation if the disabled individual wanted to be accepted in society. Disability was viewed as something that was broke and needed fixed. Individual who could not be cured were taken care of by their families or long-term institutions. Both the religious and medical models sought to explain disability through the belief that being disabled is negative and needs to be fixed in order for the individual to live a good life. Advancements in medical field have cured some diseases and improved the lives of individuals with disabilities through the use
of medicine, treatments, and technology. Although these advancements have improved the lives of individuals with disabilities, the foundational belief that a disability needs to be fixed perpetuates the limited view of what it means to be disabled.

Disability was redefined with the passing of the Rehabilitation Act of 1973 and The Americans with Disability Act (ADA) of 1990. These laws became the standard by which to determine what is considered a disability and what is not. These laws defined disability as the following:

Persons with a physical or mental impairment which substantially limits one or more major life activities, a record of such an impairment; or being regarding as having such an impairment. . . major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working. (ADA, 2009, section 3)

Although these laws were enacted to raise awareness and create equality for disabled people, the definition is pejorative. The primary focus is still on the lack of ability, which followed the medical model of disability. The belief that a person living with a disability was incapable of living a productive life was based on the medical model and has been fostered through the concept of ableism.

**Ableism**

Ableism is an ideology that reflects the belief that having a strong healthy body is preferable to being disabled. People are only aware of the body if there is something wrong with it and then the initial response is to figure out what is wrong and fix it. Society judges individuals based on their ability. People living with disabilities are considered less able and
viewed with a sense of pity and sometimes fear. They are avoided or ignored, as if the disability might be contagious. In reality, aging brings many forms of disability such as hearing and vision loss or mobility issues due to arthritis. The truth is that age-related disabilities may impact everyone at some point in their lives and this fuels society’s fear of being disabled. As a result, society views the able bodied as superior to the disabled. Hutcheon and Wolbring (2012) described ableism as “a concept describes, and is reflected in, individual and group perceptions of certain abilities as essential” (p. 40). This is reminiscent of the medical model’s belief that disability means weakness and needs to be fixed. McLean (2011) further described ableism as “discrimination on the grounds that being able bodied is the normal and superior human condition. In contrast, being “disabled” is linked to ill health, incapacity, and dependence” (p. 13). This definition implies a prejudice towards the disabled and, as Hehir (2002) noted, ableism is a result of “deeply held negative attitudes toward disability” (p. 10). These negative attitudes are based solely on the disability and give little thought to the abilities of the people living with a disability. The view that disability is a defect offers little space to consider disability as a dimension of difference between people (Smith et al. 2008). Ableism denies the belief that individuals living with a disability are capable of living a productive life and can contribute to society. It is a dualistic belief system that pits able-bodied against disabled.

Disability awareness programs are designed to eliminate these negative attitudes but in reality they perpetuate the perceptions that a disability is something to pity. Disability simulation programs claim to raise awareness of what it is like to have a disability but in fact “they create feelings of fear among nondisabled participants by temporarily allowing them to feel out of control” (Lalvani & Broderick, 2013, p. 469). Additionally, these simulations evoke feelings of pity for people living with a disability and result in feelings of thankfulness in the
able bodied participant that they are not saddled with a disability. Despite their good intentions, disability awareness programs fail to consider the individual differences among people living with a disability because the simulations are based on the assumptions that the disability is the same for all people. Although there are shared symptoms of disabilities, each individual experiences the disability in unique ways. It cannot be said that all people with epilepsy are depressed or unable to work. The disability may be defined by a set of symptoms, but it varies in the severity of the symptoms as well as the individual’s life perspective, support system, and access to resources such as medical care.

Another term that is often interchanged with disability is impairment. This term is also associated with the medical model of disability (Lalvani & Broderick, 2013). Impairment refers to the brokenness or defect caused by the disability. This term is often used in the literature as well as the daily vernacular to describe a disability. The language used to describe a disability such as impairment or even disabled is negative and reflective of the society’s view that to be able bodied is superior to that of disabled. The negative attitude towards disabilities has been perpetuated through discriminatory attitudes like ableism and developed over time as society grappled with trying to understand disabilities. The struggle to understand disabilities came to light with the early efforts of the disability movement and this struggle continues today.

**Disability Movement**

The disability movement began as early as 1817 when the first school for the deaf was established in Hartford, Connecticut (Zames, Fleischer, & Zames, 2011). The invention of the raised dot system, known as Braille came about in 1829 and was a vital step in making information available to the blind. Other important changes occurred in the 1800s to raise awareness of the disabled population, but it was not until Helen Keller published her
autobiography, *The Story of My Life*, that the disability movement really began to gain momentum. The disability movement has had many key moments in history which would be too difficult to include here in this chapter. Therefore, I hope to convey the highlights of the disability movement in the following section.

**Highlights from Disability Movement**

Historically, disability was viewed as a medical condition and individuals living with disabilities were often pitied or feared. There was no hope for a *normal* life, so little effort was made to promote education for the people living with a disability or to provide services to help these individuals seek gainful employment. Pelka (2012) described the isolation of living with a disability as a family secret that no one wanted to acknowledge, let alone share with the world. Children living with a disability were either kept at home or segregated into special education classrooms throughout their educational years. If families were unable to care for their child living with a disability, the child was placed in state hospitals or other long-term care facilities. Individuals with physical disabilities had additional challenges when they attempted to go out due to the physical infrastructure of cities. Buildings without ramps, no curb cut-outs, and difficult transit systems made it impossible for the physically disabled to move freely in their communities. People feared what they did not understand, and individuals living with a disability were the unseen members of our society. This perception was often perpetuated by secrecy. Even President Franklin Delano Roosevelt (FDR) who was a survivor of childhood polio, went to extreme measures to hide his disability from the country. It was his belief, as well as the belief of his cabinet, that he needed to appear strong in order to lead the country. Efforts were taken to conceal the fact that he used a wheelchair (Fleischer & James, 2011). The President and his cabinet promoted a false view of the President in response to the country’s
view of disabilities. The country wanted to believe that the President was an able-bodied man. Fleisicher and Zames (2011) described this mutual need for deception as “FDR and his circle strove to deceive a public that invited the deception, the President fell victim to the same dissembling that he was perpetrating: disability equals weakness; therefore, he is in fact not “really” disabled” (p. 4). The belief that disability meant weakness was a social norm and persisted for many years.

While FDR was President, the League of the Physically Handicapped formed in the 1930s with the primary purpose of identifying and ending discrimination against adults living with a disability in the government and the private sector of employment. This organization fought for the right to employment for the disabled. Although they made some significant advancements to end employment discrimination by fighting for equal access to government jobs through the Works Progress Administration, FDR disregarded their efforts and claimed individuals with physical disabilities were unemployable. Despite having a physical disability himself, FDR’s lack of support to recognize the employability of disabled adults further deepened the country’s view of disabilities as a weakness.

The March of Dimes was founded in 1937 in an effort to raise money for research to cure children who had contracted polio. This organization was part of the National Foundation for Infantile Paralysis. The March of Dimes experienced financial ups and downs throughout the early years; however, the organization’s efforts directly sponsored the research that Dr. Jonas Salk did which resulted in the polio vaccine in 1955. These organizations contributed to increasing disability awareness nationally.

Disability specific organizations were formed during the early 1900s with the purpose to promote equality and fair treatment to individuals with the specific disability. Organizations like
the National Association for the Deaf, Disabled American Veterans, and the American
Foundation for the Blind were just a few of the specialized organizations that were formed to
protect the rights of specific groups of disabilities. The Social Security Disability Insurance
program began in 1956 for individuals aged fifty or older who had a disability. In 1960 the age
requirement was changed to include people under age fifty. The Civil Rights Act of 1964
promoted equality based on race and this law significantly impacted disability rights legislation.
Nine years later the Rehabilitation Act of 1973 became a law. The Americans with Disability
Act was signed into law in 1990 and later amended to the Americans with Disabilities
Amendments Act of 2008. Since the passing of these laws, the disability rights movement has
gained momentum and discrimination lawsuits have increased. Individuals living with a
disability now had legal standing to demand equal rights and equal access to school, as well as
employment.

**Disability Theory**

As stated previously, disability has historically been viewed through the medical model
which defined it as “an individual defect lodged in the person, a defect that must be cured or
eliminated if the person is to achieve full capacity as a human being” (Siebers, 2008, p. 3).
People who were diagnosed with a disability were viewed as incapable of living a full and
productive life unless there was some cure or way to eliminate the disability. Disability theory
emerged as a model which challenged the medical model. This new way of viewing disability
defined it as “the product of social injustice, one that requires not the cure or elimination of the
defective person but significant changes in the social and built environment” (Siebers, 2008, p. 3).
The embodiment of a disability gave way to understanding the social meanings and stigmas
attached to disability. Disability theory challenged the socially constructed viewpoint of
disability and the resulting discrimination through exclusion and oppression. Many people living with a disability believed they could be employed, have families, and lead a full and productive life. They did not feel their lives were restricted by their disability but rather felt their oppression was a result of societal attitudes and lack of acceptance. It was this idea of oppression and exclusion based on an attribute of a disability that directed disability studies to look at disability much like other marginalized groups based on class, race, and gender.

**Corporeal**

Disabilities vary among individuals and the embodiment of the disability is unique to the individual. Social constructionism views disabilities and the body differently. Siebers (2008) believed that “the dominant ideas, attitudes, and customs of a society influence the perception of bodies” (p. 54). These dominant ideas and attitudes account for the prejudice that individuals living with a disability have experienced because they are different than other able-bodied individuals. Certain types of disabilities affect the physical body and are categorized as visible disabilities. Due to the nature of visible disabilities, one cannot hope to hide the differences in their bodily presence nor can one ignore how the disability shapes the perceptions of others. However, other corporeal theoretical views adhere to the belief that everyone experiences their world first through their physical self. Theorists like Piaget examined the learning processes in childhood development through the interaction between the child’s physical self and their world. This knowledge helped form their cognitive understanding of self and others. This awareness of the physical self in relation to the world and others continued to be present in each of Piaget’s stages of development including the stages of adulthood (Liben, 2014).

Merleau-Ponty (1958) also studied child development and theorized a similar learning process that involves the embodiment of self in relation to others. Merleau-Ponty postulated that
learning happens by doing. The bodily movement orients the self to the surrounding world not the cognitive representations that many theorists claim are involved in childhood development. The body embodies the interpretation of the world through the sensory functions of the body including visual, auditory, tactile, taste, and smell (Edwards, 1998). A key tenet of Merleau-Ponty’s theory is the notion of syncretic sociability which he claims occurs in infants before the age of six months. Syncretic sociability assumes the intertwining of self and others as if they were one. The child is aware of the physical self not separate from the other but as part of the other. Intentions and emotional states are interrelated between the two. As the child grows and develops a sense of one’s own body as separate from the other, the embodiment of self creates the means to compare the self to others (Edwards, 1998). Weiss (2015) explains this interaction based learning as

How behaviors are taught and understood occurs not through instinct or biology, Merleau-Ponty insists, but through our concrete interactions with others; these latter are in turn situated with broader cultural and historical context that incorporates, reflects, and reinforces the demands of the society within which an individual lives. (p. 85)

Merleau-Ponty’s theory clarifies how the body is critical to our understanding of the world around us. From our earliest interactions with others, we use our senses to relate to the world. Having a disability regardless if it is visible to others or not influences our interactions and the interpretation we place on those interactions. Disability theory examines these interactions and challenges the barriers that are created by socially constructed views of disabilities. A second theory that challenges social views of disabilities is Feminist Disability Studies.
Feminist Disability Studies – the Intersection of Social and Individual

In order to understand feminist disability studies, we must first examine the fundamental theoretical underpinnings of feminist theory. This critical theory examines the injustices found in society and historically used gender as the primary focus of its analysis. Feminism asserts that women have something valuable to contribute to the world, but fail to develop their full potential due to oppression (Ropers-Huilman & Winters, 2011). Feminist research examines phenomena through gender and challenges the societal norms that promote and perpetuate gender bias. The purpose of feminist research is to strive for equitable-oriented change for women. It is action oriented and focuses on understanding the experiences of women that had previously been omitted in social science research. Knowledge is re-examined by looking at the intersection of gender and social norms (Ropers-Huilman & Winters, 2011).

Feminist disability studies moves beyond examining the intersection of gender and social norms to include the place disability has in the relationship. Garland-Thomson (2005) described the purpose of feminist disability studies as

- It seeks to challenge our dominant assumptions about living with a disability. It situates the disability experience in the context of rights and exclusions. It aspires to retrieve dismissed voices and misrepresented experiences. It helps us understand the intricate relation between bodies and selves. It illuminates the social processes of identity formation. It aims to denaturalize disability. In short, feminist disability studies reimagines disability. (p. 1557)

Feminist theory investigates how power in society operates in relation to gender while critical theories examine power in relation to race. Both of these critical theories challenge
social norms that result in discrimination based on gender or race. A few areas that are challenged include social privilege, place privilege, and language.

**Social Privilege**

Able-bodied individuals are granted more social privileges than those living with disabilities such as “. . . recommendations for jobs, invitations to parties, and positive representation in movies, newspapers, and textbooks” (Knoll, 2009, p. 124). These privileges are shaped by society’s definition of normal and of the individual being accepted into society. Individuals living with disabilities have experienced numerous challenges to be accepted and included in society. Studies have shown that individuals living with disabilities have lower socioeconomic standing, less education, and live in poverty (Anderson, 2006). The lack of social privileges such as these create barriers for individuals living with disabilities and permeates every aspect of their lives. Without inclusion and acceptance, individuals living with disabilities miss out on opportunities for jobs, social engagement, and even political involvement (Oliver, 1996). This form of discrimination based on exclusion and omission can be just as destructive towards the individual as intentional discrimination. Vance (2007) reported feeling underutilized in her professional role as an educator due not to her physical limitations but due to “those with limited mental vision of my full potential” (p. 20).

**Place Privilege**

Place privilege refers to the physical space that is constructed by society. Able-bodied individuals are capable of navigating physical space that may create barriers for individuals living with disabilities, especially physical disabilities. Knoll (2009) claims, “all physical objects are manufactured for a certain type of body, mind, and/or emotion” (p. 124). Individuals living with disabilities cannot assume that all physical space will be accessible despite the legal
requirements for barrier free construction. Most businesses and institutions of higher education have made efforts to design new construction fully accessible; however, good intentions have at times failed due to lack of understanding the meaning of being fully accessible. Bowman and Jaeger (2007) identified the physical barriers they experienced during their job searches at various institutions of higher education. Aside from the physical barriers that they struggled to navigate during their interviews (snow covered sidewalks, transportation problems, and timing of the interviews), the lack of awareness from the prospective employers drove home the fact that living with a disability continues to be a challenge in today’s society. Individuals living with disabilities must plan more for interviews due to the logistics of navigating physical space and/or timing related to their needs based on the disability. Despite efforts to be inclusive and understanding of disabilities, “there will be instances of ignorance, discomfort, condescension, and bias to overcome among some of the faculty members doing the interview” (Bowman & Jaeger, 2007, p. 229).

Language

Language has the power to create opportunities or prevent acceptance. It matters. Social norms are defined and perpetuated through the language used to describe the belief. Merleau-Ponty (1958) stated that “. . . every word is a gesture, and it’s meaning a world” (p. 214). Language used to describe a disability becomes an attribute of the person living with the disability. The disability defines the person instead of being seen as one attribute of the person.

Titchkosky (2008) used narratives to examine “say-able things” or common stories that individuals share at the ready when discussing disabilities. These stories reflect the language that defines disability through omission or exclusion. The statements become reality because there is no reflection or thought about why the statements are treated as truth. When disabilities
or lack of accessibility in a physical space are discussed, individuals are quick to respond with justifications based on their truths. By examining the exclusion based on language, Titchkosky (2008) argued for “consideration of ordinary talk as constitutive power in creating the meaning of people” (p. 46).

**Tenure and Disabled Faculty in Academe**

The professional path for faculty typically culminates in obtaining a full professor status and tenure. These are the milestones that most faculty will strive to attain as they pursue their professional goals. The status of tenure and full professor “conveys the holder has reached the peak of their professional development and possesses significant wisdom and growth as a scholar” (Crawford, Burns, & McNamara, 2012, p. 41). Tenure protects academic freedom and provides faculty with security that they will not lose their jobs if they raise controversial subject. The process to complete tenure is a long one and requires years of completing research and teaching. Because this process is lengthy, faculty members have longevity in their jobs which allows them to develop mentoring relationships with their students (Dimaria, 2012). Completing the process for tenure and full professor is expected at four-year institutions; however, at many community colleges around the nation, the tenure process does not exist.

Community colleges are known for serving at-risk students that are first-generation and from low socioeconomic backgrounds. These colleges not only serve this population of students, they also serve the communities where they are located. Community colleges seek to work with employers in their communities to educate the workforce which will positively impact the communities in general. Because community colleges are focused on providing reasonable education to students they often have fewer resources and less funding than a traditional four-
year university. Many community colleges do not provide tenure process simply because they do not have the resources (Dimaria, 2012).

Individuals living with a disability are one of the largest multicultural minority groups in the world. This group is the only minority that anyone can join at any time. It knows no socioeconomic boundaries and can result from genetic causes or can be acquired through accidents or the aging process (Anderson, 2006). People living with disabilities often struggle with poverty, inadequate housing, lack of educational opportunities, and lack of transportation. The National Council on Disability (2011) found that between 1980 and 1988 the average household income with no person with limitations in the home was approximately $27,000 more than the household income of a home with a person with limitations in it. There was little change when they looked at the same information between the years of 2007 and 2008. The average household income of a home without a person with limitations in it was approximately $29,000 more than a household with a person with limitations in it. These statistics support the claim that individuals living with disabilities are not as equally represented in the workplace and/or they are earning significantly less money than their non-disabled peers.

As was previously discussed, people living with disabilities are often perceived as incomplete or inadequate as compared to the idea of an able-bodied person. Ableism is a concept that has become institutionalized through perceptions, language, and practices (McLean, 2011). Ableism perpetuates the belief of the superiority of being able-bodied not only in society but this belief is also found in academia. The belief has become so commonplace that many able-bodied professionals do not even recognize the constraints of disabilities with the system. “While professionals may be quick to recognize disability or difference in others, it is more
difficult for them to turn the gaze inward and recognize features of ableism within themselves or in a collective professional identity” (McLean, 2011, p. 17).

Passage of the ADA (1990) raised awareness about disabilities and access in the workplace; however, progress in this area has been slow. Universities have designed campuses with the expectations of accessibility as defined by the law; however, more attention has been given to making the campus and educational process accessible for students living with disabilities rather than faculty living with disabilities. The focus on students living with disabilities is a result of the laws governing education and equal access for students living with disabilities (Anderson, 2006). Milchus and Grubbs (2007) completed a survey of postsecondary science, technology, engineering, and math (STEM) educators with a disability. The outcomes of this survey showed that 24% of participants reported experiencing barriers in professional development, specifically attending conferences and accessibility of on-line education. Two other barriers reported in this survey included being promoted (19%) and finding job opportunities (16%). Despite meeting job requirements, many participants reported that they experienced “attitudinal or architectural barriers that negatively impacted their ability to find job opportunities and be promoted” (p. 248). Kimbrough et al. (2008) found that student attitudes towards disabilities influenced their perceptions of the instructor’s competency and ability to teach. The barriers that faculty living with a disability experience at work are found in all aspects of their professional lives.

Summary

Research in disability studies provides critical information on understanding disability through the various theories used to define it. The medical model defines disability as a defect and works to fix or treat the disability. As the disability rights movement gained momentum, a
new social model of disability was introduced. This new model defined disability from a socially constructed viewpoint stating that society created barriers, both in attitudes and in the physical space that disabled the individual. The social model of disability was further studied through critical studies in disability and in feminist disability studies. These critical theories are important to understand the true nature of living with a disability from a social and individual perspective.
CHAPTER THREE
METHODOLOGY

Overview

In the preceding chapters, I provided you with an introduction into the topic of my study and the contextual background through the literature review. This chapter now directs the focus to the design of my study. This chapter includes information on the theoretical frameworks and details of the study. This is presented through sections on: the epistemological framework and theoretical perspective, the qualitative research approach, narrative inquiry, sampling, data collection and analysis, and finally ethical considerations.

Epistemology Framework and Theoretical Perspective

The epistemological framework that guides this study is an interpretive constructivist paradigm. Epistemology refers to “how we gain knowledge of what exists and the relationship between the knower-in this case the researcher-and the world” (Spencer, Pryce, & Walsh, 2014, p. 82). It refers to the framework of what is considered knowledge and how one understands it. In order to design this study, I asked, what frames my understanding of this study? The qualitative research design results in data that must be interpreted. Therefore, the knowledge that I create from this study is based on my interpretation of the data in relation to my interaction with the participants and my own view of the world. According to Denzin and Lincoln (2003), constructivists “are oriented to the production of reconstructed understandings of the social world” (p. 247). The interpretive researcher focuses on how people view an object or event and the meaning they assign to it.

I used the adult learning theory of transformative learning to inform my study. Although there are several theorists in this field, I focused my discussion on three of the more notable
theorists who are Paulo Freire, Jack Mezirow, and Stephen Brookfield. Freire’s work in this field focused on emancipatory pedagogy through critical consciousness or conscientization. He believed that adults were capable of becoming “agents in their own learning process, overcoming oppression and transforming their lives” (Boucouvalas & Lawrence, 2010, p. 43). This idea of transforming lives was later integrated into Mezirow’s critical learning theory. Mezirow claimed that adult learners had the capacity to engage in critical thought about their experiences and this leads to transformative learning which permanently changes the person. Brookfield (2010) expanded on Mezirow’s transformative learning theory by postulating that transformative learning leads to social action. These three theorists have been instrumental in understanding adult learning in the larger context of community and social action.

Freire (2007) developed his pedagogical theory based on influences of liberation theology and critical theory while working with adult literacy in Brazil prior to the military coup of 1964. He understood that literacy was more than reading words, it was reading the world and understanding that people have a role in changing the systems of oppression that often guide their status in a hierarchical system. His theory focused on educating the masses to become subjects of their own lives and to rise up from oppression within structural systems. This radical approach to learning and teaching eventually resulted in his exile from the country. A key concept of Freire’s theory is the notion of developing a critical consciousness to transform one’s life. This was defined as the process of understanding that the way one views the world was shaped by social and political forces that may not have been in their best interest (Freire, 2007; Thompson, 2009). Freire’s passion was to improve the state of the Brazilian people by raising their level of critical consciousness, which could be accomplished through “analyzing one’s experiences to achieve independence from social and political forces” (Thompson, 2009, p. 465).
Mezirow was also a critical theorist who believed that critical reflection of perception and experience resulted in transformative learning. This process requires a higher level of thinking and openness to understanding other points of view. According to Mezirow (2000),

Transformative learning refers to the process by which we transform our taken-for-granted frames of reference (meaning perspectives, habits of mind, mind-sets) to make them more inclusive, discriminating, open, emotionally capable of change that will prove more true or justified to guide action. Transformative learning involves participation in constructive discourse to use the experience of others to assess reasons justifying these assumptions, and making an action decision based on the resulting insight. (pp. 7-8)

Key concepts in Mezirow’s theory of transformative learning include meaning schemes and meaning perspectives, disorienting dilemmas, critical reflection, and praxis (Mezirow, 2000). Meaning schemes are the beliefs, attitudes, feelings and expectations that directly shape an individual’s point of view. Meaning perspectives, or frames of reference, is made up of the meaning schemes (Mezirow, 2000; Ntseane, 2011). Disorienting dilemmas are experiences that do not fit into our existing framework of understanding. This causes the individual to critically reflect upon their assumptions (Mezirow, 2000; Brookfield, 2010). Praxis is the interaction between action, critical reflection, and dialogue (Freire, 2007, Mezirow, 2000; Mankey and Stoneham, 2012; Schapiro, Stevens-Long, & McClintock, 2005). Phases of Mezirow’s theory of transformative learning include the following:

- Disorienting dilemma
- Self-examination
- Critical assessment of epistemic, sociocultural, or psychic assumptions
- Relating discontent to others
- Exploration of options for new roles, relationships, and actions
- Planning a course of action
- Acquisition of knowledge and skills for implementing one’s plans
- Provisional trying of new roles
• Building of competence and self-confidence in new roles and relationships
• A reintegration into one’s life on the basis of conditions dictated by one’s new perspective (Mezirow, 1991, pp. 168-169)

Although transformative theory provides an explanation of adult learning, it has been criticized for its limited view of the learning process. Since its introduction, other factors of adult learning have been explored “such as the role of spirituality, positionality, emancipatory learning, and neurobiology” (Taylor, 2008, p. 7). Some theorists have argued that Mezirow’s theory failed to consider these factors and instead looked upon the transformative learning process as a singular event rather than multidimensional. Newman (2012) contends that transformative learning is a personal process that can only be verified by the learner, therefore making it impossible to confirm the validity of their claims of transformation. After all, how can you trust a person who claims they have experienced a transformative learning event based solely on their words? The very notion of transformative learning has come into question. Newman (2012) questioned if transformative learning was in fact just good teaching and a natural outcome of learning. Others argue that Mezirow’s theory overlooked the social action that has been attached to critical reflective movements (Taylor & Cranton, 2013; Kucukaydin & Cranton, 2012).

Critically examining theories like Mezirow’s transformative learning is important because it provides a better understanding of the theory and its limitations. These critiques often illuminate areas of omission which provide opportunities to further expand the theory. Although Mezirow introduced his transformative learning theory over 25 years ago, it has sparked a widespread following. There have been numerous researchers working in the field of transformative learning over the years since its inception. Additionally, transformative learning has a journal titled the *Journal of Transformative Education*. There is also an international organization that
hosts an annual conference titled International Transformative Learning Conference. So even though there are numerous critiques of Mezirow’s theory of transformative learning, it is clearly evident that this theory of adult learning continues to thrive. Because this theory continues to be a seminal piece in adult learning, I decided to use Mezirow’s theory as a way to analyze the data for my study.

Stephen Brookfield’s further development of transformational learning theory included many of the same tenets as Freire and Mezirow. One such tenet was critical reflection. Brookfield (2010) defines this as the practice of carefully questioning knowledge and perceptions that an individual accepts as truth. He identified four components of critical thinking which included challenging assumptions; challenging the importance of context; exploring alternatives; and reflective skepticism. Critical reflection in the context of transformative learning can then result in some form of social change.

Based on my assumption that disabled faculty have experienced transformative learning while navigating their educational journeys and careers, I decided to use the tenets of Mezirow’s transformative learning as a guide when coding the data for my study. These tenets were used as the initial coding for data and subthemes were developed from these codes. My assumption is based on the belief that the daily challenges of living with a disability often result in learning opportunities or disorienting dilemmas as Mezirow defined them. These dilemmas can be overt or more subtle and disabled faculty must learn to negotiate these events through critical reflection, self-advocacy, and social activism. These actions result in an individual challenging their worldview and examining their place in it. Critical reflection leads to reframing their worldview and learning how to negotiate living with a disability with this new awareness of their world. The participants in this study learned how to navigate their changing worldviews with
each move within their educational and professional journeys. They showed strong
determination to persevere regardless of what challenges or barriers they faced. They were
changed by their critical reflections of these experiences and they learned how to integrate this
new awareness in their approach to their roles as educators who happened to have a disability.

**Qualitative Approach**

Qualitative research is an approach that involves understanding how people place
meaning on a social or human problem (Creswell, 2014). This type of research provides a
deeper understanding of the data through its use of intimate interaction between the researcher
and the participant. The primary goal of qualitative research is to understand the meaning of the
phenomenon as experienced by the participant which is an extremely subjective experience.
Results are not meant to be generalized to the larger public; and instead, they tell the unique
experiences of the participants. The qualitative method focuses on understanding the complexity
of the problem and how participants make meaning of it. Emerging themes are uncovered
through an inductive process. Data is collected in the participant’s environment through various
methods such as semi-structured interviews and observations. This type of data collection allows
the researcher to have a deeper understanding of the participant’s reality (Creswell, 2014). The
researcher becomes in essence the instrument that collects and analyzes the data and therefore
personal biases must be acknowledged and bracketed. Bracketing requires that the researcher
acknowledge and set aside any biases or preconceived notions they might have about the
phenomenon (Leavy, 2014). Final analysis involves the researcher’s interpretation of the
meaning of the data. There are five different approaches to completing qualitative research.
Creswell (2014) identified these approaches as ethnographic, grounded theory, case studies,
phenomenological and narrative inquiry. The approach used for this study was the narrative research.

**Narrative Research**

In this approach, the researcher examines the lives of the participants through their storytelling and the retelling or reordering of these life experiences (Creswell, Hanson, Clark, & Morales, 2007). The focus of this approach is on the self. Bochner and Riggs (2014) described this approach as people telling stories and that by telling their stories they are giving meaning to their experiences. Meaning is uncovered as the story is told and retold. Bloom (2002) identified three goals for narrative research. These included using individual lives as the data; using narratives to generate social critique and advocacy; and deconstructing the self through reordering the storytelling.

Storytelling is influenced by the participant’s or narrator’s social position and how they want to describe their experiences. Their stories and the way they construct them meets a need for them based on their personal desires. It is up to the researcher to make sense of these stories and how the narrator shared their story. Therefore the focus is on the telling rather than the details of the story. The researcher and the narrator collaborate to identify meaning in these stories which allows for a validity check to the analysis. The second goal of social critique and advocacy is accomplished by examining the stories through social-cultural contexts. Using this critical lens helps create social action (Bloom, 2010).

Deconstructing self is the third goal of this research approach. Self is viewed as non-unitary and the researcher is encouraged to develop a more complex view of the self by examining the relationships with social norms. The narrator is influenced by social norms and their place in society which influences how they construct stories about themselves. Creswell, et
al. (2007) explained that by retelling or reordering the stories, the researcher can examine “personal and social (the interaction); the past, present, and future (continuity); and the place (situation)” (p. 244).

My interpretations were based on my understanding of the participants’ stories as they shared them with me. The participants have already placed meaning on their lived experiences which was taken into consideration as I examined their stories. I used a researcher’s journal to make notes and memos to help me bracket my personal biases and assumptions as well as to document my interpretations of the interactions with the participants of my study.

**Research Questions**

In order to examine the lived experiences of faculty members living with a disability, I have designed the following research questions:

1. What impact does living with a disability have on the faculty member’s professional career path?
2. How has living with a disability shaped the faculty member’s pedagogy?
3. What impact does living with a disability have on the faculty member’s relationships at work?

**Researcher’s Positionality**

Authors and theorists in adult education, including Malcolm Knowles, Sharan Merriam, and Stephen Brookfield shaped my philosophy of education. I believe that education is a process where an individual no matter the age or what life stage they are in, can learn through a variety of educational opportunities ranging from formal education found at a university to an informal community educational program. Knowles (1980) held the following assumptions about the adult learner:
1. As a person matures his or her self-concept moves from that of a dependent personality toward one of self-directing human being.

2. An adult accumulates a growing reservoir of experience, which is a rich resource for learning.

3. The readiness of an adult to learn is closely related to the developmental tasks of his or her social role.

4. There is a change in time perspective as people mature – from future application of knowledge to immediacy of application. Thus an adult is more problem-centered than subject-centered in learning. (pp. 44-45)

Merriam and Brockett (1997) described adult education as “activities intentionally designed for the purpose of bringing about learning among those whose age, social roles, or self-perception define them as adults” (p. 8). These assumptions of the adult learner resonated with me. I am an adult learner. I completed my graduate degrees as an older adult who worked a full-time job and had a family at home. I relate to each of these assumptions and believe that learning is indeed a life-long process that comes in many different forms. Brookfield (2005) later proposed that critical thinking was an important aspect of adult learning. He suggested that critical thinking and examining assumptions resulted in transformation and empowerment that can lead to social change. This type of critical reflection is an essential part of the transformative learning process as well.

My interests in this area of research stems from my background in the field of disabilities. Despite the laws that prevent discrimination based on a disability, I suspect that faculty living with a disability have had negative experiences at work due to unfair treatment or omission from professional activities. My experience with disabilities began early in my educational
experiences, as far back as when I was in High School. Little did I know, my life would circle around the field of disabilities in a variety of ways. I recall many interactions with students who were assigned to the Special Education classroom during my high school years. I was sympathetic to their situations, but never gave much thought to the struggles they must have faced in school. After high school, I attended a small private college and majored in Social Services. I had little knowledge about what that degree meant, but found the course work interesting. My first job after graduation was working with a local agency for disabled adults. I spent five years at that agency and was promoted from the Social Services Coordinator to Vocational Evaluator. I worked with clients who had a variety of disabilities such as developmentally delayed, emotional disabilities, and physical disabilities. Working with this population opened my eyes to the numerous barriers that adults living with disabilities faced on a daily basis. That was during the mid-1980’s and there were very few programs available to help adults living with disabilities attend college or find employment. I left this field for a few years working in various businesses and later as a mental health counselor. Although I occasionally counseled adults living with disabilities, it was not until I accepted a job in Disability Support Services at a community college that I found myself coming back full circle to the field of disabilities.

While working on my doctoral degree, I had the opportunity to work on a class project that partnered with a local community college student success course. The instructor of this course disclosed to the class that she was diagnosed with Autism Spectrum Disorder, and throughout the course she candidly shared the difficulties she had with social interactions. I watched her students as they engaged with her week after week and was curious about whether other faculty members living with disabilities openly acknowledge their disabilities with their
students. I was curious about whether they used their disability as a way to engage with their students and to increase disability awareness among the student population. Were other faculty members living with a disability as open about their disability as this instructor? What types of experiences did faculty members living with a disability have in their professional careers? These questions are at the heart of my study.

**Research Design**

The purpose of this study is to examine the experiences of faculty members living with a disability in higher education through a transformative learning lens. In order to better understand how faculty members live with a disability in higher education, I chose a narrative inquiry approach. The researcher in qualitative studies becomes the instrument for data collection and analysis (Merriam, 2002). This type of study relies on the relationship that is developed between the researcher and participant through the interview process. I selected a qualitative research design, as a narrative study would provide a better understanding of the individual experiences of my participants.

**Population Sample**

Purposeful sampling was used to select participants for the study. From the several types of purposeful sampling, I used criterion sampling with participants who have experienced the phenomenon (Collingridge & Gantt, 2008). Using this type of sampling procedure helped provide content validity to the study by examining the participants’ stories of the phenomenon and checking for common themes among their experiences (Patton, 1990; Creswell, 2013). The selection criteria helped guide the selection process and ensured that the participants met the study’s criteria for inclusion. The criteria for participation in this study included faculty
members with a documented disability, 18 years or older, and currently employed or have been employed either part-time or full-time at a university or community college.

The participants for this study included educators with disabilities teaching in higher education. I chose this population for my sampling process because of my interest in adult education and what disabled faculty experienced in their educational path from student to faculty member. Faculty members are by definition adult learners as they continue to engage in formal and informal learning activities. They have professional expectations of completing research, publishing, teaching, and presenting at conferences. For some, they even engage in community activities that promote learning for members of the community. Their interactions with students, colleagues, along with the larger community of educators, provide educational opportunities for faculty members through critical reflection and learning from these interactions.

**Selection Process**

To find participants for my study, I contacted the disability support service offices and the academic affairs offices at a Mid-western four-year university, as well as at a Mid-western two-year community college. Using these connections, the letter requesting participation in this study was emailed to potential participants on my behalf. The academic affairs offices utilized a faculty-based email list serve to email my letters to all faculty members. The disability support service offices sent my letter to specific faculty that had self-disclosed to the staff that they had a disability. My letter to potential participants included details of my study along with my contact information. Faculty members who were interested in participating in the study were instructed to contact me by email or telephone. The optimum number of participants for this study was between six and twelve faculty members. I had twelve responses to my letter requesting participation in my study; however, I ended up having only seven participants complete my
study. The other participants contacted me by email asking for more information on my study. I replied to each email, but that was the last I heard from these potential participants. I did not try to contact them again as I felt that they made their choice to not participate by not responding to my email. Although it would have been beneficial to have those additional participants, Creswell (2013) noted that having a manageable sample size would ensure that the researcher would be able to collect and analyze an adequate amount of data. I felt that these interviews provided me with valuable information and informed my study adequately.

So when it was time to actually collect the data, I interviewed seven of these potential participants. Two of the participants had completed a PhD in their respective fields; two others were currently completing their PhDs and the rest had completed a Master’s degree or were currently working on it. Two of the participants also had administrative duties in addition to their teaching assignments. The participants included two men and five women. In order to respect their privacy and provide anonymity, I have included a list of disabilities that the participants identified during our interviews without identifying any specific disability with a specific participant. It is also important to note that some of the participants identified more than one disability, as is often the case with comorbidity. The participants with comorbid conditions, they self-identified which disability was primary for them. The following is a list of the identified disabilities by the participants.

**Disability Types Identified by Participants**

**Attention Deficit Disorder (ADD):** Defined by the American Psychiatric Association (2013) as “a neurodevelopmental disorder defined by impairing levels of inattention, disorganization, and/or hyperactivity-impulsivity” (p. 32).
**Autism Spectrum Disorder:** Defined by the American Psychiatric Association (2013) as “characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships” (p. 31).

**Blind:** One participant reported having retinisepigmatosa, a degenerative retinal disease. The other participant identified the cause of blindness as being born prematurely and having to stay in an incubator for several days which damaged the retinas.

**Cognitive Learning Dissonance:** Also referred to as Specific Learning Disorder which is defined as “disrupts the normal pattern of learning academic skills” (APA, 2013, p. 68).

**Chronic Migraines:** Defined by the National Institute of Neurological Disorders and Stroke (2016) as “An intense pulsing or throbbing pain in one area of the head with additional symptoms of nausea and/or vomiting, or sensitivity to both light and sound.”

**Dysthymia:** Also called Persistent Depressive Disorder which is defined by APA (2013) as “a depressed mood that occurs for most of the day, for more days than not, for at least two years” (p.169).

**Hearing Impaired:** Defined as the loss of partial or complete hearing. The participant reported this loss was a result of nerve damage at birth resulting in bilateral sensory hearing loss.

**Obsessive Compulsive Disorder:** Defined by the APA (2013) as “preoccupation with orderliness, perfectionism, and mental and interpersonal control, at the expense of flexibility, openness, and efficiency” (p. 679).
**Seizures:** Defined by the National Institute of Neurological Disorders and Stroke (2016) as “The normal pattern of neuronal activity becomes disturbed, causing strange sensations, emotions, and behavior or sometimes convulsions, muscle spasms, and loss of consciousness..”

**Somatosensory Disorder:** Defined by Harvard Catalyst (2016) as “Disorders of sensory information received from superficial and deep regions of the body. The somatosensory system conveys neural impulses which pertain to proprioception, tactile sensation, thermal sensation, pressure sensation, and pain”

**Traumatic Brain Injury:** Defined by the APA (2013) as “brain trauma with specific characteristics that include at least one of the following: loss of consciousness, post-traumatic amnesia, disorientation and confusion, or, in more severe cases, neurological signs” (p. 625).

**Data Collection**

In qualitative studies, emerging themes are uncovered through an inductive process. I decided to use semi-structured interviews to gather rich details from the participants. Semi-structured interviews are widely used in qualitative research and allow for the interaction between researcher and participant to guide the interview. The nature of semi-structured interviews allows for unscripted dialogue based on the interview questions and responses from the participants. The semi-structured interviews are designed to illicit a response from the participant while giving leeway for the researcher and/or participant to focus on whatever they deem important (Brinkmann, 2014). This open dialogue between researcher and participant resulted in rich data that I felt was meaningful for my study. I tried to create an atmosphere where we both felt comfortable discussing the topic and in the end felt that the majority of my interviews accomplished this. It was at times challenging to create the relaxed atmosphere needed to ask personal questions of the participants and respect not only their privacy on such
matters but also encourage them to be forthcoming. We were strangers to one another, and yet here I was asking them to share personal experiences from their lives that were painful at times. It was important to be cognizant of this and to be considerate when asking for more information. My background as a mental health counselor provided useful skills for my role as a researcher in these moments. The goal for these interviews was to provide a voice for the participants through their storytelling. Although I used a semi-structure interview technique, the conversational tone of the interviews resulted in participants freely sharing their stories and for some, their emotional reactions from their experiences. Listening to the interviews again and reflecting upon them, I found myself thinking of things I would have liked to have said or questions I would have liked to ask. At times, I found myself engaging in the conversations too much and getting off track from the interviews. Looking back on this, I can only hope that our conversational dialogues helped create a more relaxed atmosphere for the participants.

After initial introductions were completed, I reviewed my study’s purpose and design. I also discussed the informed consent and answered any questions the participants had about it. Once the participants verbally agreed to participate in the study and signed the informed consent, I asked their permission to start recording the interview. Two of the participants are blind so they gave me verbal consent to record their interviews, and I emailed them a digital copy of the informed consent that they electronically signed and returned to me. I interviewed the participants in person at mutually agreed upon locations. I interviewed one participant in my office. One participant requested that I meet her at her home. One participant agreed to meet me in a private room at a local library, and the other participants were interviewed in their respective offices. I audio recorded each interview with both my password protected cell phone and a digital recorder. I used two separate recording devices to ensure that the interviews were
recorded in case one of the devices failed to record the interview. Each interview lasted between 60-85 minutes with the exception of two participants who both required a second interview. I met both of these participants in their offices. Due to their schedules, we were unable to complete the interviews during the first meeting, so we scheduled a follow-up interview based on their availability. I met one participant at their office for a second interview per the participant’s request. The second participant requested to schedule the follow-up interview via a web conferencing program. This method proved to be more difficult due to the participant’s audio echoing on their computer, so the participant requested that we stop the web conference and finish the interview via the telephone. In order to record this interview, I used the speaker function on my cell phone and recorded the interview with my digital recorder. Although the interviewer spoke loudly, it was somewhat difficult to transcribe this interview due to inaudible comments at time. I was also unable to see the participant’s physical reactions during our interview since we were talking on the phone; however, the participant did use a lot of voice inflection and emphasis when sharing her story.

After the interviews were completed, I immediately downloaded the audio files onto my password protected computer as well as a flash drive for back-up. I transcribed the interviews, often stopping to make notes and memos, which were later used in my coding process and interpretation of the data. Data collection for this study took approximately three months.

**Interview Protocol**

I used a semi-structured interview process designed to illicit information from the participant while allowing for a more free flowing information sharing. I developed the interview questions based on knowledge gleaned from the literature, input from my chair and doctoral committee, feedback from a panel of four researchers who were not participating in the
study, and my personal experiences as a student researcher and counselor in the fields of mental health and disability support services. I also vetted the interview questions with a potential participant who agreed to complete a mock interview with me, but whose information would not be included in the final study. This interview allowed me to examine the interview questions for sensitivity towards the participants, questions that would elicit data rich responses, and to get a feel for how the interviews might go and how long they might take.

While the interview questions provided some structure for the interviews and helped guide the conversations, I attempted to create a safe and comfortable environment with the participants to allow for an open exchange of their experiences and my questions to help clarify their responses. My previous experiences as a mental health counselor helped me to enter into the interview process with a relaxed approach and the comfort of sitting in silence at times as the participants took time to reflect on my questions and formulate their responses. Although, there were a few times that I felt I was engaging too much in a conversation and strayed off topic with some participants. Regardless of our digressions, I felt the topics of our conversations still contributed to my study by helping me better understand the participants’ experiences and viewpoints. I also believe that our relaxed conversations during those times created a relaxed and comfortable space where the participants shared their experiences more freely. Building that rapport with my participants was a key in gaining their trust and resulted in valuable information that informed my study. The interview protocol can be found in Appendix D.

**Transcription**

After I completed the interviews, I downloaded the audio recordings onto my password-protected personal computer. I started transcribing these recordings within a few weeks of the interviews. I used transcription software and saved the transcriptions in a Word document. It
took me several months to complete all of the transcriptions. Once the transcriptions were completed, I deleted the audio recordings as indicated on my informed consent agreement. Throughout the transcription, I used pseudonyms to protect the identity of the participants as well as the institutions where they worked. The transcripts will be saved for use in future studies and written publications. I created a list of participant names and pseudonyms used for the study and have the list in a locked file cabinet separate from the transcriptions. The only individual who has access to this list is me.

**Field Notes and Memos**

The use of field notes and memos was an important part of the data collection and analysis. I wrote brief notes during the interviews to help identify key information that I wanted to examine more closely during the coding process. I also used memos to write down my thoughts, reflections and questions during the data collection and analysis processes. Bryant (2014) discussed the importance of using memos to help remember details as well as a way to reflect on the research process. I found this to be true during the transcription process as well as coding and analyzing the transcripts. It was especially helpful when the participants used inflections and emphasis when sharing stories that they clearly felt were important for me to understand. As I listened to the audio recordings, I could hear these vocal changes and remember the animated reactions of the participants as they talked. I paid attention to each change in tone of voice, volume, and inflections of the participants’ voices. My field notes included the non-verbal responses as well as the verbal responses of the participants throughout the interviews. Some participants were very animated throughout their interviews often using their hands to help tell their stories. Others would lean forward towards me as they shared a specific memory or experience. Many participants laughed at themselves and the stories that
they shared with me. Paying attention to these details offered a deeper level of meaning to their words. My memos included not only these details but my reflections and my interpretations of what I felt they meant. I used my detailed field notes and personal memos as a separate set of data which I analyzed and used as part of the triangulation process which I will discuss in a later section.

Data Analysis

Analyzing qualitative data can be completed using different methods. The purpose of analyzing is to “observe and discern patterns within data and to construct meanings that seem to capture their essences and essentials” (Saldaña, 2014, p. 584). This type of analyzing requires finding the core essence of the participant’s experiences. It involves looking for themes that may be found among experiences of the participants and then examining these themes to construct meaning. Because I framed my study using transformative learning, I used the tenets of this theory as initial codes. This resulted in a deductive analysis of the data. I also used transformative learning theory as a guide because of my initial assumptions for this study. One of my assumptions was that individuals with a disability experience disorienting dilemmas throughout their lives as they navigate the world with their disability. I read each transcript numerous times to help me identify possible themes that would reflect one or more of the tenets of transformative learning. I then reread the transcripts with these themes in mind to determine if there was data to support the theme. Corbin and Strauss (1990) noted the importance of using the initial codes was to help inform further analysis of the interviews. Although one method of coding is to use an open coding system where the researcher initially develops general codes, I chose specific codes based on Mezirow’s (1991) transformative learning theory.
**Triangulation (Validity)**

Using an interpretive constructivist paradigm, the ideas of internal and external validity are examined through authenticity and worthiness of the data analysis (Denzin & Lincoln, 2003). In an effort to prove authenticity and trustworthiness, I used Merriam’s (2002) method of reflexivity and triangulation. I cross-examined the data transcribed from the individual interviews along with my field notes and memos. An additional measure to prove my analysis is trustworthy was to use member check during my interviews. Because I planned to use the preset list of codes based on Mezirow’s transformational learning to analyze the data, I was also able to use member check during the interviews. During the interviews, I asked the participants to reflect upon some of the themes that I felt were applicable based on their initial responses to my interview questions. Although not every theme was confirmed during the member check, the participants were able to provide additional experiences that confirmed most of the themes.

**Ethical Considerations**

A few of the participants expressed concerns about their anonymity in the written outcome of this study and asked that any identifiable information be withheld on the chance that someone in their workplace might read this report and be able to identify them by their disability. We discussed in great detail how I would take precautions to protect the identity of the participants in all verbal and written presentation of the data. I read the informed consent agreement prior to each interview and answered questions from the participants prior to proceeding with the interviews. Participants were reminded that they could withdraw from the study at any time without repercussions. During the interviews, I was cognizant of the participant’s comfort levels in responding to my questions and stopped the interviews if the participant became uncomfortable at any point in the conversation. I used gender neutral
pseudonyms to represent the participants and a general description of their workplaces. Gender specific pronouns were randomly used without directly linking to a specific gender in an effort to adhere to proper grammar and to make the narratives easier to read. An additional level of confidentiality was used by not reporting specific demographic information that could be used to potentially identify the participants. Due to the nature of their disabilities and the small communities where they lived and worked, I felt it was best to restrict as much of this information as possible to avoid identifying participants through either personal knowledge of the participant or by process of elimination (unique disabilities could possibly identify a participant when they are the only one in the work place and community with that specific disability). Therefore, I did not include a specific demographic chart to represent the participants, but rather provided a general list of demographics not specifically tied to any one participant.

**Appendices (Semi-structured interviews, Consent forms, Codes, Laws, Policies)**

Copies of the Informed Consent, letters to my peers and potential participants, interview protocol, and the Ball State University’s Institutional Review Board approval letter can be found in the Appendices section of this report.

**Summary**

In this chapter, I described the design of my study that was shaped by the adult learning theory of transformative learning. Narrative inquiry was used to gather information rich data. I used the tenets of transformative learning as the a priori codes to initially analyze the data which resulted in discovering additional subthemes. The remaining sections of this chapter provided information on the selection process of participants, coding and analyzing, and ethical considerations. The following chapter provides an overview of the findings of this study.
CHAPTER FOUR

FINDINGS

In this chapter, I used the stages from Mezirow’s (1991) transformative learning theory to code and report the findings from the participants and my interviews with them. The participants are called by their pseudonyms throughout this chapter: Pat, Jesse, Taylor, Riley, Marty, Hayden, and Rowan. Throughout the findings, the participants describe their disabilities and share how they adapt in order to better understand how the disabilities may affect them. In each following section, I use the voices of the participants to share their stories and the challenges and coping strategies from throughout their teaching experiences. Through the narratives from the interviews, I hope that their stories come alive and impact the readers as much as they did for me.

Considerations and Descriptions of Participants

I felt a deep responsibility to honor the stories of the participants of my study. I have learned from my professional roles in mental health counseling and disability support services that sharing one’s private thoughts and personal experiences takes courage and trust in the person who is listening. It was imperative that I respect the participants’ time, experiences, and concerns for anonymity. I struggled with this responsibility and how I would report my findings without sharing too much information that could potentially breach their confidentiality. Although they were willing participants in a study that was going to result in a written document, the need to protect their identities was my first priority especially for those participants who shared concerns about this. All of the participants felt this study was a much-needed addition to the current literature but some were concerned about retaliation from colleagues and/or supervisors. These fears were based on their past experiences, and I did not know if these fears
were justified in their current positions. However, it was not my job to determine whether their fears were justified and my only responsibility to them was to honor their request for anonymity. I interviewed a total of seven participants for my study. The participants came from a Midwestern two-year community college and/or a Midwestern four-year university. They ranged in age and years of experience. Their professional roles ranged from full-time to part-time educators and some had additional administrative duties in addition to their teaching loads. Two participants had completed their PhDs and two others were currently finishing their PhD programs within the year. All the other participants had completed their Master’s degrees with the exception of one participant who was still working on their Master’s degree. The participants were predominantly Caucasian with only one participant identifying as African American and one identifying as another race. There were two males and five females in the study. The stages of transformative learning are ten codes of this theory and through my analysis of the data, I discovered thirteen subthemes, as seen in Table 1.
Table 1: Codes and Subthemes

<table>
<thead>
<tr>
<th>Transformative Learning Stages</th>
<th>Subthemes from Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Disorienting Dilemma</td>
<td>1a) Disability</td>
</tr>
<tr>
<td>2) Self-Examination</td>
<td>2a) Support Systems</td>
</tr>
<tr>
<td>3) Critical Assessment Of Epistemic, Sociocultural, Or Psychic Assumptions</td>
<td>3a) Societal Views</td>
</tr>
<tr>
<td></td>
<td>3b) Inclusion/Exclusion</td>
</tr>
<tr>
<td>4) Relating Discontent To Others</td>
<td>4a) Self-Advocacy</td>
</tr>
<tr>
<td></td>
<td>4b) Social Activism</td>
</tr>
<tr>
<td>5) Exploration Of Options For New Roles, Relationships, And Actions</td>
<td></td>
</tr>
<tr>
<td>6) Planning A Course Of Action</td>
<td>6a) Accommodations</td>
</tr>
<tr>
<td></td>
<td>6b) Controlling The Environment</td>
</tr>
<tr>
<td>7) Acquisition Of Knowledge And Skills For Implementing One’s Plans</td>
<td>7a) Planning And Preparation</td>
</tr>
<tr>
<td>8) Provisional Trying Of New Roles</td>
<td></td>
</tr>
<tr>
<td>9) Building Of Competence And Self-Confidence In New Roles And Relationships</td>
<td>9a) Professional Roles</td>
</tr>
<tr>
<td></td>
<td>9b) Involvement</td>
</tr>
<tr>
<td>10) Reintegration of the New Perspective Into One’s Life</td>
<td>10a) Approaches to Teaching</td>
</tr>
<tr>
<td></td>
<td>10b) Life-Long Learning</td>
</tr>
</tbody>
</table>

**Disorienting Dilemma: Disability**

As discussed in Chapter 3, I chose to use Mezirow’s Transformative Learning theory for coding the data from the interviews. The first step in this transformative learning process is the disorienting dilemma. Brookfield (2010) describes disorienting dilemmas as “situations that are disturbing and surprising because they contradict very dramatically what we thought were stable
understandings of how the world works” (p. 78). Simply put, disorienting dilemmas are experiences that do not fit into our existing framework of understanding. This causes us to take pause and try to make sense of these events. However, we are still looking at these experiences with the same understanding of the world, but after critical reflection, we gain a new perspective and a new level of understanding. Each of the participants experienced disorienting dilemmas at various times in their lives as they learned to navigate the world with their disability. Here are a few excerpts of these experiences.

Pat

Pat’s parents recognized early that there was something different about how he was learning. His parents requested testing early in elementary school, so they could get the proper support for him.

*They originally diagnosed me in second grade but I repeated Kindergarten because I wasn’t first grade ready. My mom knew I had a disability but they wouldn’t test me . . . she pushed for testing in Kindergarten, but they wouldn’t test me until second grade.*

Pat struggled to learn in the traditional classroom until one of the teachers developed a system to teach math that included touch bumps, which were physical representations of the numbers. This method was later integrated into other classrooms for all students to use. Pat went on to complete a Bachelor’s degree. At that time he again faced a disorienting dilemma as the school did not have a disability services office to help students with accommodations. When Pat was confronted by one of the professors, he self-disclosed the disability and history of receiving accommodations.

*I had issues in the English class because you had to do a writing component. One of the things we had to do was a portfolio and include an in-class essay. This was the weakest part of my portfolio. After I submitted it, I talked to my professor who said, “What’s up with this?” After I told him about my disability, he told me to write a letter about how I had accommodations in high school and he would add it to my portfolio.*
Pat had experienced a disorienting dilemma at each of the educational institutions he attended as well as the two educational institutions where he currently teaches part-time. Pat’s experiences were similar to the other participants when they were confronted with new places and new people.

**Marty**

Marty experienced a gradual decline in vision that resulted in gradual loss of independence. With each change in Marty’s independence, she experienced a disorienting dilemma forcing her to adapt with it.

_I first noticed about age 8-9 years old. I remember going in from out of doors where it was sunny and I looked up at the clock on the wall and it took me an unordinary amount of time for my eyes to adjust. So I knew something was askew. . . I was able to drive a car for a couple of years, but only during the day. I adapted to just using a bike, but I could never ride at night . . . the bike became too dangerous, so I would just walk. I walked unassisted until, well, I’ve been working a guide dog for 25 years now._

The gradual decline in vision required Marty to adapt, but it was still a difficult change to make. With each decline in vision, Marty took time to reflect on the changes and began to critically reflect upon the impact of these losses. She remained positive throughout the gradual decline and stayed focus on work.

**Rowan**

Rowan’s disorienting dilemma was a result of a diving accident at a local swimming pool. During the accident, her neck broke after hitting the bottom of the pool. In moments, Rowan’s life changed drastically and suddenly did not know what the long-term effects of the accident would be. In addition to the traumatic brain injury, Rowan now suffers from mild to severe seizures.

_The surgeon informed my parents that if the seizures persisted for more than six months then I could have them for the rest of my life . . . it’s been eight years later and I still deal with that among other things . . . I have balance issues which can cause migraines which can then cause seizures as well._
Rowan tried to return to the same job but was unable to keep working due to having numerous seizures per day. Faced with numerous bouts of unemployment, she applied for disability and continues to receive this benefit while teaching part-time.

*I was 36 at the time and I was helping raise my two kids so finances were a concern. I couldn’t hold down a job because of my seizures. So I was dealing with a lot. It was just causing a lot of strain on my marriage at the time.*

**Hayden**

Hayden’s hearing loss first became noticeable during elementary school, although the family knew of the disability soon after birth. Hayden’s culture viewed disabilities as taboo, so Hayden’s parents refused to acknowledge his hearing loss. Hayden was eleven years old before services were provided and he received hearing aids at that time as well.

*So coming from that mentality, I was told from a very early age, roughly around kindergarten or first grade that I needed to hide the fact that I could not hear. And I needed to perform well enough that no one would suspect that I had it . . . I had to perform better than everyone else.*

Hayden’s view of disabilities as undesirable was shaped by the culture, and it was not until several years later that he was able to live an authentic life and found self-worth. Hayden no longer hides the hearing impairment and has become a voice for the disabled by advocating for students with disabilities and by creating a support group for these students.

The participants’ experience understanding that they had a disability served as disorienting dilemmas that refocused their lives. They were forced to critically reflect upon the assumptions of the world that they knew, in order to make sense of what occurred. Mezirow (2000) believed that adults transform when they examine and critically reflect on their assumptions after undergoing a disorienting dilemma. Living with a disability is full of disorienting dilemmas because individuals must learn how to navigate a world that is different from the dominant culture and may be unfamiliar. Critically examining our understanding of the
world, changes what we know and how we know it. This new knowledge cannot be unlearned. These experiences change individuals permanently (Boucouvalas & Lawrence, 2010).

Self-Examination

Reflexivity is a central theme in qualitative research and transformative learning. As previously discussed, a disorienting dilemma creates a space for the individual to critically examine viewpoints and worldview. Self-examination is that process where an individual reflects upon their experiences. Merriam, Caffarella, and Baumgartner (2007) describe Mezirow’s step of self-examination as three stages of reflection that includes content reflection, process reflection, and premise reflection. Content reflection examines the actual experience while process reflection examines the individual’s problem-solving strategies. How does the individual view the disorienting dilemma and what are they going to do about it? The final stage of reflection is premise reflection that challenges the beliefs, assumptions, and values that society places on the experience. Throughout the interviews, I found the following examples of self-examination.

Marty

Marty has a positive outlook on life that began at an early age. Marty’s gradual decline in eyesight resulted in gradual loss in independence, but despite this Marty’s self-identity seemed intact.

I finished my doctorate before my 26th birthday and I did that as an insurance policy for my future, whatever that was going to be . . . very self-directed, self-studied . . . I am definitely disabled but I am also abled (emphasis) to work around the disability . . . I was determined (emphasis) to be a person who was blind not a blind person. I did not want blindness to define me . . . I wanted to function in a sighted person’s world. My career defines me not the fact that I was a blind person.

Marty’s self-examination focused on abilities, rather than the limitations that might come from a disability. At each stage of vision loss, Marty re-examined immediate needs and future
goals. Marty continues to strive to be better and is renowned for research. Like Marty, Taylor met the challenges of being blind with a strong-will and determination to overcome any obstacles that came along.

Taylor

Taylor was a premature baby and the time spent in an incubator as an infant resulted in damage to the retinas. After numerous surgeries, Taylor lost all vision by the age of ten (10). During elementary school, she was placed in a few regular classes but was withheld from classes such as gym. Taylor knew early on being excluded from some classes diminished the opportunities to make friends. This pushed her to excel at academics that later proved beneficial. Taylor was nominated for various extracurricular activities based on the scholarly activities.

We had friends but generally they were not close relationships except with other people with disabilities. That was always something of a challenge. We started high school but did not get the supports we needed so after half a year we were able to transfer to the School for the Blind. It was the first time I was out of my hometown and we got to participate in sports. It was the first time I got to travel the country. I had to learn to be more independent. When I went to college, I learned a lot about being self-determined.

Taylor’s school experiences and the decision to leave family and go to the School for the Blind was full of reflection and consideration of the level of support needed to meet future goals of education and work. However, self-examination is not always easy. Jesse struggled with accepting the disability despite knowing that something was not right. Even after spending months discussing this with a colleague who was a social worker, Jesse still found the diagnosis somewhat unsettling.

Jesse

Jesse recognized that something was different from others after spending all night copying an entire textbook for study notes. Jesse was officially assessed at the end of 8th grade. Although autism was suspected the school identified the disability as a learning disability with
It was not until Jesse worked as a teacher in a K-12 system and spent time talking with a colleague who was a social worker, that things became more clear.

*I was working with a social worker as part of my job and they were just beginning to understand the hypersensitivity and the meltdowns. People just thought I was crazy. The official diagnosis of autism came a couple years ago . . . So when you’re working with the school’s social worker whose emphasis is on special education, the group of kids I had been avoiding because it hits too close to home. When I started working with those kids, I was starting to understand myself better which helped me work with the kids better . . . The funny thing was, looking back, somebody put a pamphlet about Asperger’s in my mailbox. I went off (emphasis) on my principal. I mean we all knew something was going on but nobody understood it. I was still more productive and got more done with better results than anyone else in the school despite of all of the difficulties I had to deal with.*

Jesse struggled with the idea of having a disability. This was demonstrated with the comments about working with the children in special education and feeling that this was too close to home. The process of self-examination and premise reflection took some time for Jesse. Examining the social beliefs of what it meant to have Autism or Asperger’s was difficult for Jesse, even with the symptoms of meltdowns, sensitivity, and having to work harder in school than anyone else to learn new information. Jesse now openly acknowledges the disability and has learned to challenge every interaction with this new awareness.

**Support Services**

Developing professional goals required self-examination for each of the participants. Living with a disability meant that the participants needed to critically examine their professional goals and the steps that would be needed to accomplish their goals. Relocating to a new university and starting a graduate program involved finding appropriate support services. For some participants, this meant time spent searching for services on their own. During Taylor’s graduate program, support services were not easy to get and the services that were available were cumbersome.
At the time there was no law in terms of accessibility. So we were dealing with me having to buy the book. The university worked with different organizations and would have people come in and read the books. They would record this. So sometimes you would get a great reader but sometimes it would be someone who would be choppy . . . With that model you are always working behind. About the time a professor decides to select the book, it could be a week before the semester. So you get the book and you find someone to read the book, you are always working behind everyone else.

Despite these struggles, Taylor completed a doctoral degree and pursued a tenure-track position at a university. It appeared that Taylor’s struggles with support services were somewhat reflective of the time period. Rowan’s educational goals began with completing an Associate’s degree at a local community college before transferring to a 4-year university to complete a Bachelor’s degree. The support services available to Rowan proved to be less cumbersome than what Taylor had experienced.

I’ll say right off the bat, that without the help of the network I have out here, the group of people and my disability accommodations in place, I was able to be extremely successful.

Rowan’s positive experiences with accommodations and a supportive network of professionals encouraged Rowan to pursue an advanced degree, which unfortunately was delayed due to health reasons. Marty, on the other hand, decided to pursue a graduate degree while still capable of completing the requirements with little support.

I finished my doctorate before my 26th birthday . . . I wanted to get my schooling out of the way while I still had some capacity to do it without a lot of technology. . . So I was able to finish my academic preparation without any adaptive technology; however, at the back end of my PhD, I needed bright lights, I needed to use a felt tip pen and a yellow legal pad so that there was a nice contrast.

Each of these participants critically examined the support services of the universities they attended, knowing that these services could help or hinder their professional goals. For some participants, the support services were not sufficient or easily accessible which required them to be actively involved in developing the kind of support needed to successfully complete their education.
Critical Assessment of Epistemic, Sociocultural, or Psychic Assumptions

The next stage in transformative learning is the critical assessment of social constructs, views, and assumptions. Brookfield (2010) described this process as pondering one’s discomfort and critically examining not only the disorienting dilemma, but also society’s view of it. It is at this point that individuals begin to challenge what they have always accepted as truths and begin to search for new meanings. Several of the participants found themselves critically examining society’s view of disabilities at different moments in their lives.

Societal Views

Disability had long been viewed as a medical defect that needed cured or eliminated under the well-established medical model. This model pitted the able bodied individual against the disabled claiming that disabilities prevent individuals from living to their full potential (Siebers, 2008). Additionally, the term disability is often used as an identity, which Siebers (2008) noted is a social category that is controlled by sociocultural constructs. This social construct and medical model viewpoint is best seen in Hayden’s story

*My culture viewed disability as a taboo topic. There was a lot of shame about it. There was actually a law that stated all babies that were suspected to be born with a disability or a possible disability later on would be left to die. Thankfully someone took pity on me and I wasn’t one of those babies. But those that were disabled and needed help, they were institutionalized in the city. . . . Basically you were abandoned by your family and your parents never spoke about you . . . I was told from a very early age that I needed to hide the fact that I could not hear. I needed to perform well enough that no one would suspect that I had it.*

Hayden also struggled with a similar attitude from some faculty in the graduate program. Despite discussing the need for accommodations, Hayden felt the professors did not see accommodations as their responsibility.
Its fine to quote articles, disability models, but it’s not reflective of the reality that disability students face. I think the education needs to be geared at this and what their experiences are like and this is what you can do to help. I think they think that disability accommodations are the responsibility of disability offices and not everyone else. They don’t want to be bothered with it. Making a video accessibility, a PDF accessible is a waste of their time and somebody should be doing it for them. That’s the general attitude. And even higher up in administration, it was a nuisance. It was going to cost them money to get the accommodation for one person. It usually comes down to cost, resources and time being consumed just because of one person.

Riley is a disabled veteran and noted that, although there is more help for disabled veterans now, a soldier still does not acknowledge certain types of disabilities such as psychiatric or neurodevelopmental disorders during active service because of the military view of disabilities.

In military you would never acknowledge a disability or weakness that would put you out of play or sent to the infirmary . . . I was only active duty for one year, the rest was reserve. I later went in and got help. The only place I would be afraid to say is among veterans. Because it’s not a disability that would honorable. I didn’t lose my leg in a war. I wasn’t on the battlefield or overseas. The only time I’m ashamed of my disability is among veterans.

Pat’s disability was non-visible and often misunderstood. Having parents advocate for accommodations was important to Pat’s success; however, there was still a misconception about Pat’s abilities.

It was the same things I heard in private school too from either other parents who would say things to my parents or the kids would say things to me about how it’s not fair because my parents did my homework for me. It’s just a lack of understanding and people kind of assume that if you have accommodations then someone else is doing the work.

Taylor had a similar experience with peers at the university who assumed that Taylor did not have the same testing requirements in classes as they did.

That’s one of those things that you get accommodations, accommodation traps I call them, if you are not sitting with everybody else they think you are getting a pass. A student told me that. I had missed class one day and I came back and we were sitting in the hallway waiting for the door to open and I asked a student what the lesson was about. She said, “What do you need to know for; you don’t have to take the exam.”
These examples provide a glimpse of how disabilities are often viewed in negative ways. Reminiscent of the medical model, these views show how misinformed people can still be and the need for an increase in disability awareness.

**Inclusion vs. Exclusion**

The disability rights movement has continued to challenge the socially constructed view of disability and to push for inclusion in all aspects of society, not just in the education system. The path to inclusion started with integration. Oliver (1996) noted that integration was the acceptance and tolerance of those individuals afflicted with a disability because these individuals were to be pitied. However, this was later criticized for its lack of true acceptance of disabilities as another human variation. Taylor experienced moments of exclusion beginning with elementary school.

*At the time we were primarily mainstreamed into regular classes. I don’t think there was any significant thing, except from the beginning I wanted to participate in gym and other classes where those with visual impairments and physical disabilities were excluded. But those were the classes where you made your friends.*

Taylor later experienced moments of exclusion in professional jobs.

*I had a meeting with the Provost, high level folks, Vice Presidents of a program because this is a new program and the university is very protective of who is coming into their classes. We had a committee with very high level folks on that committee so you had to come really prepared, not just looking good but crossing your t’s and dotting your i’s. My director sent me something that wasn’t accessible ten minutes before the meeting . . . We still haven’t made a whole lot of movement towards inclusion. When we talk about being included, that means that things are developed from the start with a diverse group of folks in mind. . . You talk about race, you talk about ethnicity, and all of this stuff, but we never talk about people with disabilities. . . We are not going to move towards inclusion until we create an atmosphere where people are collaborative. . . With everybody saying we will get you an accommodation, well while you are busy getting me an accommodation, you are setting a trap. Because once I accept that accommodation, things never change. . . You know I wouldn’t need this extra GA to read all of these documents to me if you would just send them to me electronically. Right?*

Hayden experienced exclusion while completing the graduation program, as well as at professional conferences.
At the previous university, my professors were sensitive that they did not know how to really incorporate that into diversity training. For some reason multicultural does not include disability. . . I’ve been to twenty conferences now and they ask at the registration process if you need special accommodations. Since I don’t always follow the schedule, I just tell them I am disabled but I’m not going to ask for accommodations. The rooms are small and cramped depending on the symposium. The setup of the room is not always good so you have to be careful where you are sitting. Sometimes the way they have the slides and the presenter, it is hard to look at the presenter. I don’t remember any videos being captioned.

Jesse experienced exclusion during the graduate degree program surprisingly from the very faculty members who promoted inclusion.

You know that is just the way it is. I get that a lot. We talk a lot about diversity. We talk a lot about x, y, z and we talk about breaking down institutionalized barriers or institutionalized oppression and yet within the academy we maintain it.

Inclusion provides equal access for all involved and can promote a better understanding of disabilities. Hayden was involved in teaching an interactive learning classroom using a universal design approach that made the educational content accessible to all students regardless of abilities.

They are aiming to try universal design and I’ve been involved in that and that’s been fantastic. The classroom has movable chairs and everything moves. So I’ve set it up to help me hear better. My students will roll their chairs up to me or I move around to talk with them. It’s been phenomenal teaching these classes.

Relating Discontent To Others

It is not enough to just identify areas of concern but in order to change things, these concerns must be shared with others. The participants identified moments in their lives where they experienced exclusion or other negative experiences because of their disabilities and each one used those moments for self-advocacy and educating others.

Self-Advocacy

Self-advocacy is defined as the knowing one’s rights and speaking up for those rights. In terms of disabilities, self-advocacy refers to knowing personal rights such as equality and
accessibility, fighting for these rights, and educating others about disability awareness (Zames et al., 2011). Most of the participants in my study voluntarily self-identified as having a disability with their students, some were more hesitant to share with their colleagues and reserved this information until there was a need to self-disclose like Jesse.

It depends on relationships. Sometimes like when people don’t know people with disabilities with x, y, z, I will say “Really (emphasis) because I’m one of those people.” It’s just like when I’m teaching and people would say stupid. So I was like, “Why are you calling me stupid? I know I’ve got some issues but I don’t think I’m stupid.”

Jesse was selective at times about when and how the disability was shared. For example, Jesse applied for a position on a research team to go to on an expedition to another country and did not disclose the disability on the application.

There was a reason why the Department of State sent me. Of course I didn’t disclose a disability until after I had been chosen. They weren’t very happy about it, but I wouldn’t have been chosen to go otherwise . . . They were disappointed because there was stuff I couldn’t fill out. There were super small spreadsheet being handwritten in and they were unwilling to find a way to work or to let us figure out a way to make it work . . . So you say you want your diversity, but you don’t want what comes along with it . . . You have this idea of what your person looks like, well guess what people, I don’t look like that. You want your diversity within whatever that framework you want it in.

Marty often used humor to break the ice when teaching as well as when interacting with colleagues.

Most of the time I’d use humor a lot to help students feel comfortable. The dog is a great ambassador for blindness but humor is as well, and I would use it maybe at the front end of a semester, this is one of my legacy stories. I would ask my students, “If you ever see me walking towards the desk and bump the lectern where my laptop sits, I want you to do this.” I’d kind of do this running motion and put my hands out to catch it . . . That was just an example, let’s just claim the elephant in the room. I’d tease students and say “Don’t raise your hand, that’s going to be a long isometric contraction.” Make it light, you had to bring confidence, personality, interpersonal skills to make it work.

Rowan also claimed the elephant in the room right at the beginning of class. Rowan’s need to control the environment required an explanation to the students.
Yes from the get go I have to because I have to manage my environment. I write up on the board, I don’t know when there would ever be a situation for this but I write “No bright flashes.” I almost caused myself to have a seizure because I was messing with the overhead projector and then the light came on and then the migraine started. I immediately took my medication and it passed. . . So right from the beginning I let them know for two reasons. One for practical reasons but the other reason is that we cover wellness in the class. It really gives me an opportunity to explain to them that we all have obstacles. I really try to do it in a spirit of love and encouragement.

Social Activism

The definition of self-advocacy includes some level of social activism. Some participants became active in the disability awareness movement while others limited their activism to a more individualist approach when confronting misconceptions of disabilities with colleagues.

Taylor learned to self-advocate at a young age and continued to advocate for individuals with disabilities throughout the graduate degrees as well as professional roles held at different institutions of education.

At the time I taught middle school and high school. That was a learning experience for me with how to manage a teacher’s assistance and not just a teacher’s assistance but one who had been there for 30 years. She wanted to do things the same old way so we struggled for a few months. . . The first time I observed there, I couldn’t figure out why the students were sitting and the teachers were running around putting the Brailer in front of them and getting everything for them. The first couple of days I had to get oriented and I changed the room around that made sense to me. I arranged it so they could get their own stuff. Others said it would be too hard for the students but I told them if students got their own things then the teachers could teach.

Taylor later accepted a job at a local university and was program manager for a grant funded support program for students with disabilities. Taylor completed needs assessments and developed curriculum to help support these students and to educate the university community as well. “We developed programs and helped them develop self-advocacy and self-determination.” Taylor immediately got involved with the diversity program as well developing a curriculum for faculty on how to teach students on the Autism Spectrum. “With the workshop, I had the opportunity to discuss the macro and micro aggressions that go on and that make it difficult for
students with disabilities at a graduate level programming.” Both of these programs allowed Taylor to continue advocating for students with disabilities as well as improving disability awareness at those campuses. Taylor joined some friends in the doctorate program and helped create an organization for students with disabilities in an effort to provide support to students but also to help raise awareness at that university.

Some friends of mine, they had learning disabilities, we formed the Association for Students with Disabilities. That was one of the first organizations to push the university to pass policy that faculty had to select books a semester in advance to give students an opportunity to get those materials. The other big thing that was in place was setting a policy in terms of priority scheduling and getting some issues resolved to get us out of the position of constantly playing catch-up.

Likewise, Hayden expanded the self-advocacy needed to gain accommodations for classes to a broader community program to help raise awareness and support students with disabilities.

I have gotten the lovely nickname of troublemaker because I have spoken so loudly. But I have spoken loudly because I will not be ignored. As far as me promoting the educational shift, it’s not being heard, not from a diversity perspective, not from a disability perspective. There is almost a mentality that this is a student’s problem. They need to go to a diversity club or disability club to work it out. What I have done is create a space for disability students. It’s an informal group where we learn to advocate for one another, cry, scream, acknowledge, and validate each other. It’s a safe place. We help each other get through it.

**Exploration of Options for New Roles, Relationships, and Actions**

Transformative learning up to this point has focused on a critical examination of self and others and voicing discontent to others. The knowledge that one gains upon critical examination provides an impetus for further action. The old self has been enriched with a new awareness, which urges the individual to take action in some form. Taylor discovered the importance of being an active participant in accommodations and developed reciprocal relationships that helped foster collaboration. Riley found that the best way to live with the disability was to just be authentic and to find ways to work with others.
One of my close friends was a track star and didn’t have the time to do everything, so I would read the books, and she would do the drawing and other things needed in class then we would study together. Vocational Rehabilitation would help me buy the textbooks, so I would buy the books and she would read the books and record it. So we helped each other out. . . I think it has helped me even today, to have a reciprocal relationship with my colleagues. One of the things I am studying is self-determination. I try to instill this into students with disabilities. You can’t be in the position to sit back and receive. That is the culture that folks with disabilities have to be cared for.

Taylor continued to look for ways to be reciprocal with colleagues and was able to develop collaborative relationships with several people because of this. Riley found that living authentically was important and acknowledging the limitations created by a disability allowed for opportunities to educate others.

They (disabilities) are challenges to me for whatever my goals are at work or home. I do not see them as impediments like something that would cease or keep me from accomplishing from whatever I set out to do. . . The normalizing and the fact that realizing everybody no matter how polished they appear to be, have their own challenges. For me, being open first with myself, completely bare bone honest, but also with other people eliminates all that wanted energy of covering, being, projecting. I am a good hard worker and I have learned to work around or compensate for those things. Yes there are challenges, yes they cause problems, nothing I can’t work around.

Planning a Course of Action

The next step in transformative learning is developing a plan of action. How will the individual use the new awareness and knowledge gained through critical reflection of self and societal viewpoints? A first step is to make sure you have equal access to information or to a physical space. Each of the participants were skilled in self-advocacy and were proactive in working with others to get accommodations.

Accommodations

Critical to the next step of transformative learning for individuals with disabilities is attaining accommodations. Individuals with disabilities often know best what they need to be successful in their studies and/or jobs. Accommodations provide a modification that allows equal access to the information or to a physical space for these individuals. Rowan recognized
the need for accommodations in order to be successful in classes and sought out the supportive services that could help provide this type of support, “With all of that in place and my disability accommodations in place as a student, I was able to be extremely successful.” Rowan successfully completed a degree and is now teaching and continues to use accommodations.

**Controlling One’s Environment**

It was important for some of the participants to make changes in their physical space due to their disabilities. The participants learned quickly what they needed in their classrooms and made these adjustments immediately upon entering the room. Their student often helped with the changes that provided an opportunity to discuss disability awareness with the students. Riley became a master at controlling the environment in the classroom.

*Very, very, very rigid about where things go (in reference to coping mechanisms) . . . So I created an insane structure, highly over cognitive . . . I can’t have the door open when I teach, no body (emphasis) has a side conversation in my class because I can’t think.*

Rowan found ways to adjust the classroom to accommodate the disability and explained to students the importance of controlling the environment to avoid accidentally causing a seizure, “Yes, from the get go I have to because I have to manage my environment. I write up on the board, I don’t know when there would ever be a situation for this, ‘No bright flashes’.”

Hayden also found the need to change the space to better accommodate the disability. As discussed previously, Hayden taught in a classroom where the students used movable chairs and they were able to move around to work collaboratively. This also allowed Hayden to move around to better hear the students.

**Acquisition of Knowledge and Skills for Implementing One’s Plans**

There is a learning curve for individuals with disabilities in each new environment and situation that they encounter. As individuals mature and have more life experiences, they learn what accommodations work best for them but sometimes it becomes a bit of a trial and error
process. Even with accommodations, individuals with disabilities often find that they have to do a great deal of planning and preparation to make sure they have what they need to be successful. The participants of this study found this to be true for them as well.

**Planning and Preparation**

Many of the participants in this study found they needed to spend a great deal of time preparing when completing their graduate courses and later when they were teaching or presenting at conferences. They also noted that they were always disadvantaged even with accommodations when compared to their non-disabled peers. None stood out more for me than Taylor’s and Marty’s personal experiences.

*So you get the book and you find someone to read the book, you are always working behind everyone else. This is where you learn to put in more effort than everyone else and not really evaluating how much effort everybody else is doing.* . . The other big thing in my field of education, a lot of times we are really reliant on journals and articles, so getting the library system up to date. I would have friends literally in the bowels of the library pulling articles.

Marty spent more years practicing and perfecting lessons and presentations than non-disabled colleagues.

*The way I give presentations is I’ve got my own laptop and I put that on the lectern. It has my notes to all my slides. There’s got to be another computer which will have the projector hooked up to it which has the PowerPoint on it.* . . *When I give a presentation, to keep it fluid, you have to put a lot more practice in it to any sighted presenter. What I’ve got to do is listen to the text coming in my ear and speak at the same time so that it sounds conversational.* . . *It’s got to be smooth. The way I operate that repetition, I learned through practice over and over.* . . *It took years of practicing and perfecting it.*

Both Taylor and Marty present at professional conferences within their fields of expertise. Traveling requires extensive planning in order to them to not only arrive at their destination, but also to be able to navigate the environment.

*In this job, I have not gone alone but I have gone alone in my other jobs. Generally what happens is I work with the Compliance Office, they will pay for an assistant to go if I need that. I try to coordinate with colleagues if they are going.*
Likewise, Marty’s trips to conferences required a lot of planning and preparation starting with the travel arrangements. Until recently, Marty would go through the standard security check point like other passengers and had a variety of experiences with the TSA staff that were not trained to work with someone who was blind. These airport experiences ranged from the TSA staff showing up with a wheelchair or the airline agents who forget to get Marty to preboard the airplane. After arriving at the hotel, Marty immediately meets with hotel staff to get oriented to the hotel and the general area.

Once I get to the hotel, I will make it to the counter. Then I start applying a bunch of other techniques. I tell them ahead of time so they can plan for it and so they don’t act surprised. I tell them I need oriented to the property. How do I get to my room? Where do I go to take the dog out? Where is the fitness room? Where is the restroom? Those kinds of things. We will actually rehearse that. They will show me around and I say “Ok let me rehearse this, you walk behind me.” Where are the buttons on the elevator, how are those set up, like columns of three and so on and on and on. They are set up in Braille but for me not a proficient Braille reader, the elevators going to be going up and down 100 times before I figure it out . . . My hotel door, I put a little rubber band around the door know which helps confirm that the right door. I have a little corner cut off of my key card to know where to face it. They will orient me to the room . . . So it is a lot of memorizing a lot of things.

**Provisional Trying of New Roles**

The result of learning new skills and gaining a new awareness often leads individuals to make changes in their lives, which include trying on new roles. The participants in this study showed great determination in pursuing their educational goals despite barriers they encountered even when they were self-imposed.

*I was amazed when I got into a Bachelor’s program. I honestly didn’t think I would be successful enough to get a Bachelor’s degree. So the idea of getting an advanced degree never really occurred to me. I spent the first year of my Master’s program kind of amazed that I hadn’t failed.*

**Building of Competence and Self-confidence in New Roles and Relationships**

Trying new roles allows individuals to explore new opportunities and expand their world. The participants in this study continued to gain self-confidence with each success they
experienced in their educational paths. Experiencing success in their graduate programs encouraged them to pursue careers as educators.

**Professional Roles.**

Pat always had an interest in teaching beginning in the high school resource room where Pat often tutored other students. This interest in teaching continued as Pat completed a graduate degree, “I always liked teaching . . . I really, really enjoyed this. This is what I want to do.”

**Involvement (committees, research, conferences).**

Pursuing a career in education requires ongoing research and looking for opportunities to increase one’s knowledge and expertise in the respective field of study. Each of the participants in this study were teaching in higher education and some were completing their doctoral degrees with intentions of working towards a career as a tenured professor. Whether they were still completing their degrees or currently working as a professor, these participants were engaged in activities that further develop their professional knowledge such as research, professional conferences, and committee work. For example, Hayden estimated attending twenty professional conferences throughout graduate school and also helped create a support group for students with disabilities at the university.

_I think I’ve been to twenty now, they ask at the registration process if you need special accommodations . . . I tell them I am disabled, but I’m not going to ask for an accommodation. Sometimes I’m tired, sometimes I change my mind and I feel bad to have them do all of that work if I don’t follow through._

Riley uses service learning as a core requirement of classes where Riley teaches. Riley initiated this program and received a grant to promote service learning across other disciplines.

_There are lots of ways to do service learning . . . I lay it out to the learning objectives. You have to work with the community service that is helping someone. You have to work directly with the person, not just sorting clothes . . . It is appalling the amount of students who have never volunteered. My students love the choice. They are empowered by allowing them to choose where they went. That is just another layer of self-advocacy. . . I would really like to develop a service learning online class._
Reintegration of the New Perspective Into One’s Life

The participants each have unique life experiences both when they were students themselves and in their current roles as educators. Living with a disability brings challenges and at times barriers that require self-advocacy and educating others about disability awareness topics such as inclusion. Because the participants in this study are educators, they continually face new challenges as they meet new students in their classes and new professionals in their field of study at their campuses and at professional conferences. They each have a stake in the current state of disability rights and policies that can help create a more inclusive environment for everyone.

Approaches to Teaching

Malcolm Knowles is a system for teaching adults often referred to as andragogy (Merriam, et al., 2007). I use the terms pedagogy, the way one teaches children and andragogy interchangeably in this study as both words are used to describe teaching. The participants referred to their teaching styles often noting that they try to make their classrooms accessible for everyone not just for students with disabilities. Riley felt the best way to help all students was to keep them engaged in the lessons and holding them to a high standard of being prepared before coming into the classroom.

So much of my teaching is organic. They don’t see it . . . You’ve got your book and every chapter has a study guide in the back. Here you come for the experience. I don’t have to tell you what’s in the book . . . My lectures are online, they could have looked at it ahead of time, printed it, and have it with them in class. I feel like I have accommodated for anyone who could walk into the room compared to most people.

Rowan expressed similar sentiments noting that having a disability created an overall change in the approach to teaching and relating to students, “I wouldn’t have been able to relate to students like that before all this happened. I have to take into consideration that many of the students are coming from really bad backgrounds”.
Life-long Learning

King (2010) discussed the notion of life-long learning as a dynamic process that flows throughout an individual’s life in each new situation and context. A few of the lifelong learning skills discussed included self-directed learning, critical thinking, coping strategies, and flexibility. The participants in this study exhibited these skills daily as they navigated their professional careers with their disabilities but also as practicing educators through continued research in their fields of study. Taylor and Marty are examples of this as they both are engaged in research projects, traveling to conferences as presenters, and collaborating with students and colleagues on various projects.

Taylor works collaboratively with colleagues from other universities and is an active board member for one of the association who is hosting a national conference this year. “I have a colleague from Ohio that I do a lot of collaboration with and we have published articles together. I have gone with her . . . I’m on the board for the conference in Missouri.”

Marty has worked diligently to make the presentations flow smoothly while presenting at conference. Research continues to be one of Marty’s focuses as part of the job. “I’ve been outstanding researcher in the country, outstanding teacher in the country, outstanding service awards in the country. . . That’s who I wanted to be defined as, those outcomes not the blindness.”

Discussion of Research Questions

This study examined the lived experiences of faculty living with a disability. Their stories illuminated the challenges that faculty who have a disability may have as they pursue their educational and career goals. My study focused on three research questions related to these goals.
RQ1. What impact does living with a disability have on the faculty member’s professional career path?

All of the participants had completed or was completing their educational degrees while learning to navigate the higher education system with their disabilities. Most received services through the disability support services offices at their campuses, although these services were not all equal. Early on in college, Taylor was discouraged from the original educational path by an advisor because of Taylor’s disability.

*Unfortunately I got talked out of education by my freshman advisor. He said “nobody was hiring people with disabilities and you can’t see so how would you supervise a classroom?” And I had no clue in how to answer those questions. My teacher was the same way. He thought I would be bet by going into psychology because I like working with kids and I was taking some psychology courses and liked them. So I switched to psychology and got to my senior year and found out that you have to have a Master’s in order to get a job. Nobody told me that.*

Hayden experienced a struggle with disability services since the office and the educational department fought over that should provide the accommodations. In the end, Hayden to figure out how to get them.

*There’s not only a lack of accommodations been provided, but there is a disconnect between who should provide them. You know, “go talk to the office of disability services . . . no you need to talk to your professors.” I’ve been in a real struggle to get what I need.*

RQ 2. How has living with a disability shaped the faculty member’s pedagogy?

Participants in this study acknowledged that living with a disability helped shaped their pedagogy, having a better understanding of the needs of all of their students not just the students with disabilities. This was evident in the passion for teaching and engaging students in the learning process that each participant shared as part of their stories. Pat openly acknowledged this as well, “*I feel that I’m one of the instructors who are more in tune with accommodations because I know how important they are.*”
Rowan also found that personal experiences of living with a disability provided an opportunity to share with students, “. . . hey, you’re all going to have obstacles . . . That yes I did have all of these issues and its difficulty and any of you can do it regardless what you are dealing with.”. The participants were role models of determination even if they did not see themselves in this role. Each person experienced challenges at times during their journey and instead of giving up, they pursued their goals with tenacious determination.

3. What impact does living with a disability have on the faculty member’s relationships at work?

The effects of ableism were evident in many of the participants’ stories and the participants noted the lack of self-awareness in their colleagues during those times. It is often the case that people are able to identify negative attitudes towards disabilities in others and yet they fail to examine their own attitudes towards disabilities even when interacting with a colleague who has a disability (McLean, 2011). Despite the advancements made in disability rights and the increase in disability awareness at educational institutions, there is still a stigma about having a disability especially as a professional educator in higher education. With the exception of the apparent disabilities, most of the participants in this study did not voluntarily self-disclose their disability to their colleagues. Those who chose to self-disclose did so in response to interactions with their colleagues where they felt a need to advocate for students with disabilities and/or correct a colleague about a misinformed understanding of disabilities. Riley felt it had to be relevant to the conversation in order to self-disclose, “It just doesn’t come up. If it came up or it was pertinent to the conversation, I wouldn’t have any qualms or reservations to talk about it.”
Stigma and micro-aggressions were evident even for the participants with apparent disabilities such as Taylor who is blind. Taylor experienced a variety of affronts while working in a professional capacity. With each incident, Taylor learned how to self-advocate better. The most common offenses came when colleagues ignored the disability and expected Taylor to be able to access important information without considering the need to make this information accessible.

*My director sent me something that wasn’t accessible ten minutes before the meeting . . . When they would hand me something in a meeting, I would just hand it back to them. I wouldn’t say word . . . When someone needed a report, I typed it and emailed them. They said, well when I’m in my office you can just stop by and tell me what you’re doing. Well first of all, I don’t know when you are in your office, I can’t see you.*

**Summary**

This chapter provided an overview of the findings. The data was analyzed by using the a priori codes from the tenets of transformative learning theory. Additional subthemes emerged as the data was analyzed. A review of the research questions and the data found which answered these questions were included at the end of the chapter. In chapter five the findings are further analyzed by examining the literature and theoretical frameworks for this study.
CHAPTER FIVE
CONCLUSIONS

Overview

Faculty who live with a disability and teach in higher education settings often undergo personal growth that can follow the stages of Mezirow’s transformative learning theory. This study utilized this framework as its guide. Disability studies and adult education undergirded this study, as this group of professionals often goes unnoticed and are not the focus of much research. Whereas, most literature on disabilities in the higher education setting focuses on students with disabilities, the stories in this study help illuminate the ongoing need for continued work in disability awareness for faculty and students.

Adult Education

Adult education as a field of study focuses on the adult learner and endeavors to “equip adults to effectively engage in the world through individual and collective actions within the spheres of family, work, and community” (Kasworm, Rose, & Ross-Gordon, 2010, p. 4). Adult learners come from a variety of backgrounds and often have responsibilities outside of their educational classes such as having a family and working either part-time or full-time. The educational opportunities for adult learners are not always held at traditional institutions of higher education but can be found through informal programming within the community at the local high schools, churches, or community centers. Self-directed learning is an aspect of adult education. Adults assume control of their learning based on their current needs (Merriam & Brockett, 1997; Knowles, 1980). Faculty members are adult learners who continue to seek out professional educational opportunities through their research and teaching. Freire (2007) identified adult learners early on when working with the oppressed people of Brazil. His
pedagogy of the oppressed later became one of the seminal works for education for social action. Freire’s work became a critical theory that looked to transform lives through educating the masses about oppressive forces and how these forces influenced how the oppressed saw their world. Mezirow later developed the transformative learning theory that promotes individual growth and a critical review of social constructs of reality as they are known by the individual. Mezirow’s theory was more individualized although there was a small part that looked toward social activism. Transformative learning theory involves a change in the individual’s worldview based on an experience that shakes their reality (Boucouvalas & Lawrence, 2010). Brookfield later added a more critical lens to transformative learning theory and focused on a broader social action for change. Using this theory to analyze the data of my study, I found that the participants experienced a disorienting dilemma when faced with their disability. They also encountered the other stages of transformative learning as they came to terms with their disability and sought accommodations from their institutions and colleagues. Their capacity to teach while living with disabilities often served as a model and encouragement to students who may have similar situations (Beretz, 2003).

**Critical Disability Theory**

In addition to using adult education as my framework for this study, I also used critical disability theory to examine the data. Pothier and Devlin (2006) claimed that critical disability theory challenges the assumptions that disabilities are a misfortune and that able-bodied people are the norm and with normalcy comes privilege. People who do not have privilege cannot fully participate in society. According to McLean (2011), “Normalcy is embedded in the beliefs, actions, and discourses that make up the fabric of everyday life” (p. 18). An outcome of this
attitude is ableism, which is a form of discrimination and believes that being able-bodied is superior to living with a disability (Hehir, 2002).

**Ableism**

Ableism views disability as a defect instead of “a dimension of difference” (Smith et al., 2008, p. 86). Despite efforts to increase disability awareness and to promote diversity and inclusion made in higher education, this attitude towards disabilities continues to exist on campuses across the country. “Professional relationships are often one-sided. While professionals may be quick to recognize disability or difference in others, it is more difficult for them to turn the gaze inward and recognize features of ableism within themselves or in a collective professional identity” (McLean, 2011, p. 17). Several of the participants in this study experienced this attitude from colleagues, some which were intentional while others were not. The most notable example of this social attitude towards disabilities came from Taylor’s struggle with a supervisor and colleagues. Taylor’s negative experiences were a flagrant disregard for inclusion despite Taylor’s interest in collaborative relationships. The atmosphere and culture within the department exhibited signs of ableism. Marty’s experience with ableism was less overt but it was still a sign that even in a supportive and inclusive environment negative attitudes towards disabilities exist. Despite Marty’s previous success in research and teaching, the disability became the focus and doubts arose as to whether Marty could handle the rigor of working through the tenure process. Ableism shadows the abilities and potential for success of individuals with disabilities and promotes the culture of the superiority of being able-bodied (Lalvani & Broderick, 2013).
Corporeal

Disabilities are often described as a dichotomy, either visible or non-visible to others. The visible disabilities such as wheelchair users or visually impaired are easy to identify while the non-visible disabilities like attention deficit disorder or a learning disability may not be as apparent to others. Regardless if the disability is visible to others or not, the individual experiences the embodiment of their disability which influences how they experience their world. Coole (2007) discussed the importance of the body in social interactions and for individuals with a physical disability they can often feel excluded from engaging in social interactions. All of the participants acknowledged the embodiment of their disabilities and how this shaped their interactions with others. The participants who were blind provided the best examples of this embodiment. They learned how to navigate their environments and how to engage both students and colleagues in their work. However, both participants also shared stories where their disabilities prevented them from fully engaging with others, mainly due to the lack of awareness from their colleagues. The participants with non-visible disabilities also experienced challenges from the embodiment of their disabilities. Seizures, attention deficit disorder, and chronic migraines all impact how the individual interacts with the world. The participants struggled at times to engage in social interactions at the office due to their disabilities and the need to limit stimuli from their environment. The embodiment of disabilities often impacts the social interactions with others which can then negatively impact social position.

Social Action

As with any critical theory, there is a component of social action. Critical disability theory critically examines the social beliefs that by their very nature create privilege for some
groups. By challenging these social beliefs, critical disability theory works to eliminate social constructs that create barriers for individuals with disabilities. In essence, critical disability theory seeks to change social norms. Hosking (2008) contends that critical disability theory “privileges the voices of disabled people and relies on their voices to challenge the negative attitudes toward disability commonly expressed by able bodied people and so often reiterated in print and visual media” (p. 17). The social action described here was also evident in the stories of the participants in this study. All of the participants identified times when they challenged a colleague’s disparaging or misinformed comment about individuals with disabilities while some became more involved through groups that strived to be a voice for change. Hayden and Taylor both helped create groups for individuals with disabilities at the university to provide a safe place for them to find support and work together to enact change at the campus.

**Feminist Disability Theory**

Feminist disability theory adds another layer to critical disability theory by examining the identities created from the intersection of differences such as gender, race, class, sexuality, and disability (Knoll, 2009). Garland-Thomas (2005) explained that feminist disability theory “scrutinizes how people with a wide range of physical, mental, and emotional differences are collectively imagined as defective and excluded from an equal place in the social order” (p. 1558). Individuals are not one dimensional; they are a composite of a variety of roles. A woman with a disability is not defined by her disability alone. She may be a mother, a daughter, a sister, a wife/partner, along with her status as an employee, student, or volunteer in the community. Feminist disability theory recognizes that identities are complex and social oppression through negative perceptions of disabilities often intersect with other negative social constructs related to the other roles such as gender, race, or class. Although my study did not specifically examine
the intersection of gender, race, and disability, I could not help but notice that two of the participants appeared to have experiences that were so glaringly different despite having a similar disability. The participants were varied by gender, and that caused me to question why they had such different experiences in their professional careers. Marty described positive interactions with colleagues and a general sense of inclusion at the university. Taylor on the other hand described numerous accounts of exclusion by both supervisors and colleagues and seemed to struggle with most interactions with colleagues at the university. Feminist disability theory can analyze these examples more closely by recognizing how gender and disability may have contributed to Taylor’s struggle for inclusion.

**Social Capital, Privilege, and Place Privilege**

Social capital, social privilege, and place privilege were all evident in the stories of the participants of this study. Ellison, et al. (2007) examined the influence of social capital and found that those with high social capital are often more engaged in their community. Social capital is a result of the relationships that one forms within their community whether that is in school, at work, or in their larger community of professional associations. An outcome of this study showed that individuals can have varying levels of social capital depending on the community. Hayden identified a strong sense of community within the professional association but struggled with gaining this same degree of community within the workplace. Marty on the other hand, showed a strong sense of community and a high level of social capital in the workplace, the classrooms, and in the professional associations. Developing these communities can be challenging for disabled faculty especially if their disability prevents them from participating in communal activities like lunches or casual office gatherings. Taylor and Jesse both experienced this sense of exclusion based on their disabilities. Little effort was given by
their colleagues to encourage participation in these events. Because Taylor and Jesse never participated in the social gatherings at the office, their colleagues developed negative attitudes towards them describing them as unfriendly or mean.

Social privilege and place privilege are both connected to social capital. Knoll (2009) described the challenges that disabled individuals face with the physical barriers to space as well as the lack of social privilege. Without these privileges, disabled faculty may struggle with job expectations like the tenure process or other professional opportunities. Rowan’s disability required significant planning and preparation when attending professional conferences. Without the social privilege of a strong support system, Rowan would not have been able to attend the conferences.

**Analysis of Transformative Learning for Faculty Participants**

As discussed in Chapter 3, transformative learning theory (Mezirow, 1991, pp. 168-169) postulates that individuals who experience disorienting dilemmas will critically examine their beliefs and social views. This critical examination and reflection typically results in some form of change, whether it is a better understanding of their beliefs or a change in their beliefs. This process transforms the individual by changing their understanding of social constructs and challenging the individual to enact some type of social change. The stages of transformative learning theory were imposed as the initial codes for analyzing the data from this study in an effort to examine whether disabled faculty have experienced some form of transformative learning in their careers.

Transformative learning theory is based on “humanistic and constructivists assumptions” (Taylor & Cranton, 2013, p. 39). The humanistic assumption claims that humans are free beings and intrinsically good. This assumption emphasizes the individual and the potential for growth
or self-actualization. Once individuals reach self-actualization, this is supposed to result in the individual contributing to the overall good of mankind. The constructivist assumption describes “learning as a process of creating meaning from experience” (Taylor & Cranton, 2013, p. 39). Meaning can come from a variety of perspectives which include the individual and the social constructs of meaning. Each of the participants experienced some form of transformative learning throughout their educational and professional journeys. Beginning with the disorienting dilemma all the way through to the social action stage, the stories of their lives touched upon each of the transformative learning theory tenets. Although there was data found to support each one of these tenets, one could argue that my interpretation of the data was biased by my focus on transformative learning. There was some data not used as it did not directly apply to the a priori codes of transformative learning or because the participant requested that the information not be used in the final product of the study. I will address this as I continue this research and reanalyze the data with a variety of lenses.

**Discussion of Research Questions**

This study examined the lived experiences of faculty living with a disability. Their stories illuminated the challenges that faculty who have a disability may have as they pursue their educational and career goals. My study focused on three research questions related to these goals.

**RQ1. What impact does living with a disability have on the faculty member’s professional career path?**

The participants of this study had completed different educational and professional journeys. However, each participant completed their Bachelor’s degree while having a disability. They learned to navigate the educational system with some level of support and work
towards their professional goals. For some that meant completing a doctorate degree while others were content with completing a Master’s degree. Faculty members at the four-year university identified tenure as their ultimate goal. The faculty members who worked at the two-year community college seemed content to stay where they were despite not having a tenure process available to them. Tenure was created for the “purposes related to academic freedom” and it meant lifetime employment (Premeaux, 2012, p. 122). The process for tenure is a grueling one and junior faculty members face numerous challenges such as “learning to understand campus culture and the community, teaching new courses, advisement, gaining licensure, and understanding tenure requirements” (Magaldi-Dopman, Marshall, Rivera-McCutchen, & Roberts, 2015, p. 37). Completing this long process can be challenging especially for those with disabilities. Hidden disabilities often create professional difficulties when trying to compete for tenured positions due to “loss of time and depleted energies” (Beretz, 2003, p. 51). Taylor shared similar challenges when trying to complete the tenure process and noted that his supervisor was not helpful. The campus culture was difficult to navigate and Taylor ended up being identified as “mean”. Dimaria (2012) identified the difference between tenure track at the four-year university with that of the two-year community college. Many community colleges do not even offer this process often due to lack of funding. The participants who worked for a community college reported that the tenure process was not available to them; however, they did have the opportunity to complete faculty development training in order to obtain associate faculty status. Despite this, the participants identified that their colleagues at work and their physical work space created a positive experience for them.
RQ 2. How has living with a disability shaped the faculty member’s pedagogy?

Each of the participants reported that their pedagogy was indeed shaped by their experiences of navigating their professionals goals with a disability. They felt more open to students with disabilities and several noted that they created their courses in such a way that anyone regardless of ability would be able to access the educational information. Rowan in particular felt a strong sense of duty to provide a supportive environment for students with disabilities and often shared personal experiences to help students feel at ease with their own disability. Pat struggled throughout his educational journey because of the hidden disability. He felt like no one understood him and became a strong advocate for disability rights. Pat also prided himself for being intuitive with students with disabilities and being able to recognize when they were struggling and too afraid or embarrassed to ask for help. The overall pedagogical approach for the participants was creating accessible and inclusive learning environments for all students.

RQ3. What impact does living with a disability have on the faculty member’s relationships at work?

One of the challenges for any new faculty member is to learn the campus culture and to begin to develop professional relationships with their colleagues. Faculty members who have a disability may be at a disadvantage when trying to accomplish these steps. The stigma of disabilities is still prevalent in higher education and “claims of disability are considered inflated, or false altogether” (Beretz, 2003, p. 52). It can be difficult to understand the challenges that a disability may create for a faculty member especially if that faculty member chooses not to disclose the disability to their colleagues. Tidwell (2004) experienced a decline in hearing over time and tried to hide this from colleagues and students. As a result, Tidwell avoided social
situations with his colleagues which left him feeling isolated and unsure about his professional standing. These challenges were evident in a few of the participants’ stories. Taylor struggled with social interactions due to his disability and as a result expressed feelings of isolation and exclusion. Likewise, Jesse found it difficult to interact with colleagues and felt that they were not supportive or understanding of the issues that were created by Jesse’s disability.

**Implications of the Study**

Although the data was analyzed using a preset list of codes, the participants’ stories clearly identified examples of exclusion and discrimination. Their stories compel us to critically examine our own beliefs about disabilities and challenge us to be mindful of inclusiveness in all aspects of our work. The following suggestions for creating an inclusive environment was developed from the conversations with the participants and examining negative experiences in their professional journeys.

**Disabled Faculty**

These stakeholders face multiple challenges in their professional journeys starting when they are students in their graduate programs. Requesting accommodations as a student is often the first experience with self-advocacy. This skill is critical for someone with disabilities because they become the experts in knowing what accommodations they need. Disabled faculty face the additional challenge of meeting the expectations of the job as well as their supervisors when they are working in higher education. For faculty working towards tenure, they often struggle with meeting the demands of this process. Having a supportive and understanding supervisor can help alleviate the stress related to the tenure process and to the job in general. Disabled faculty do not always choose to self-disclose their disabilities to their supervisors sometimes due to concerns that they will be negatively viewed. For those who are comfortable
self-disclosing, they can provide valuable education to their department on disability awareness and inclusion. They can also provide this same education to students in their classes by including discussions on disabilities in their curriculum. An additional suggestion for these faculty members is to get involved on a local or national level with programs that provide education on disability awareness.

**Supervisors and Colleagues**

To be truly inclusive, these stakeholders must plan and prepare all job related activities and classroom assignments for anyone who might need accommodations. Considerations must be given to accessibility of the room location, room atmosphere such as lighting and temperatures, and accessible content whether it is in print form or audio/visual format. For faculty with vision or hearing impairments, consideration must be taken in providing access to meeting information prior to and after staff meetings and can be provided through electronic versions of meeting notes, training materials, and other information used in the meetings. The causal impromptu meetings that often occur in professional settings should also be mindful of inclusiveness through active engagement with everyone and consideration of any barriers that might prevent participation from disabled faculty. A final suggestion for these stakeholders is to critically examine their views on disabilities and avoid making assumptions about their disabled peers. One way to avoid assumptions is to engage more with the disabled faculty in order to better understand their personal needs based on their disabilities. Attending and participating in educational programs on disability awareness can also help these stakeholders to better understand disabilities and how they can promote inclusiveness in their department and on a larger scale the university campus and community at large.
University Compliance Offices

Although I did not examine the role that University Compliance Offices have in the practice and policy aspects to raise disability awareness and increase inclusion, they are a vital part of this work. These offices monitor the work place accommodations for faculty with disabilities, therefore they could also provide additional educational opportunities on campus for disability awareness. A few of the participants in this study indicated that although the Compliance Office at the campus worked with their initial request for accommodations, the participants felt that they were on their own to deal with any problems that arose in the department related to their accommodations. This was not true for each participant so a general suggestion for the Compliance Offices is to help increase disability awareness on their campuses through educational programs and including disabilities in the conversations of diversity.

Higher Education

The field of higher education needs to continue to provide research in the field of disabilities and education. The literature and research on the specific population of disabled faculty in higher education is somewhat limited and therefore needs to continue to be a focus for researchers. Engaging experts in the field of disabilities and higher education in national and international educational programs will provide critical information to this area of study. As more and more research is completed, disability awareness will continue to increase and promote more inclusive environments.

These suggestions were intended to increase the need for inclusion and to help initiate conversations about disability awareness within the stakeholder’s environment. This list of suggestions is not all inclusive and must be examined more closely based on the stakeholders, their environments, and with an increased understanding of disabilities. The following
implications for further research examines possible research studies using different epistemologies, theories, and methods.

**Implications for Future Research**

This small study was just a glimpse into what living with a disability is like for faculty in higher education. A much larger sample is needed to provide a more substantial collection of stories and personal experiences in this area that can be examined for common themes. Limited research in this area allows for numerous possibilities of studying this topic through different lenses.

Although limited demographic information was collected in this study, it was enough to raise questions whether specific demographics impacted the experiences of the participants. One example of this was two of the participants with similar disabilities shared vastly different experiences in their pursuit of educational degrees and professional jobs in higher education. Marty and Taylor were both visual impaired but had totally different experiences related to their disability. As I examined their responses, I could not help but wonder if other variables were at play here. How could a seemingly similar disability result in such different experiences?

Future studies are needed to account for other variables that could impact an individual’s experiences. My study included five females and two males so future studies could examine how the disabilities, whether they are the same or different, are impacted by gender differences. Does gender influence how an individual manages a disability and how the world interacts with them? Another possible variable is current age and age at which the disability was diagnosed.

We know that maturity improves an individual’s ability to manage stressful situations, based on the assumption that over time an individual will have learned healthy coping skills. However, having a disability diagnosed at an early age may result in a much different ability to
cope than having acquired a disability such as a traumatic brain injury at a much older age. The learning curve of living with a disability would seem to be better if an individual is diagnosed at a younger age and has more years of experience of living with their disability. This also leads to a question of how an acquired disability impacts an individual or a chronic degenerative condition influences an individual’s life.

Rowan’s traumatic brain injury resulted in a chronic seizure disorder that impacted his ability to maintain a fully independent life. Rowan could no longer drive or work full-time. The type of disability is yet another variable that can be further examined. Do individual experiences differ based on the type of disability? Are certain disabilities more accepted in society than others? Do apparent or visible disabilities garner more support than the non-apparent or invisible disabilities? For example, are people more willing to assist an individual who is blind versus an individual who struggles with a cognitive disorder?

A final thought about these personal demographic differences is race and/or culture. Does race or culture make a difference on how an individual with a disability is perceived and how they manage their disability? How does the individual’s culture influence their perception of disabilities in general? Hayden’s cultural heritage viewed disabilities as a taboo subject and despite Hayden’s apparent disability at a young age, the family was encouraged to hide this from the school and their local community.

My study focused on a specific sample of educators in higher education. This is a specific population so future studies may want to examine other sample groups outside of education. This specific population raised questions of other variables that might influence the outcomes. I specifically chose participants from 2-year and 4-year institutions of higher education. The differences between these two types of institutions could provide another basis
for a study to examine the experiences of individuals with disabilities across these institutions. Are there notable differences in experiences between the two institutions? Would individuals with disabilities experience more support in a 2-year institution versus a larger 4-year institution?

Along these same lines, is there a difference in levels of inclusion and support among the various fields of study? Riley’s background and field of study was in psychology. Could this have contributed to Riley’s resiliency and positive interactions with colleagues? Did this particular field of study have a better understanding of disabilities in general and were professionals in this field more intuitive of inclusion?

Another thought in this area of possible future studies are the subgroups of professional colleagues and students. Additional studies need to focus on the perceptions from professional colleagues to gain a better understanding of how the workplace views disabilities and what efforts they make for inclusion. A similar study could be done with students to understand how students view disabilities in general as well as how they view a professor with a disability. What are their perceptions and comfort levels? Do their perceptions influence their ability to learn in that class?

A final area of possible future studies includes examining this topic through different theories. My study was framed by the adult learning theory of transformative learning and critical disability theory. Using different theories would likely have different outcomes. In addition to this, future studies could be completed using different epistemologies to frame the study. I used an interpretive constructivist paradigm to frame my study. This approach allowed me to construct meaning out of the data based on my interpretations. Other approaches could be used that would provide a different interpretation and understanding of the data. Lastly, I designed this study using a narrative inquiry approach. Future studies could be completed using
other qualitative types of research such as case studies or possibly ethnography especially if written from a personal experience of living with a disability.

**Final Thoughts**

Analyzing the narratives through Mezirow’s (1991) transformative learning theory, I found many common issues among the faculty participants. I then sought subthemes for each of the ten steps of the theory in order to show how the participants experienced some level of transformative learning as they navigated life with a disability.

Then I reexamined my data through the lens of the three research questions and found that each participant adapted their career path, pedagogy, and professional relationships to accommodate their special needs depending on their disability. Although I used these preset codes to determine subthemes, one overarching theme comes to mind as I reviewed my outcomes. This theme was **resiliency**. Each participant experienced challenges throughout their educational paths and their roles as professional educators. Despite the challenges, each participant showed great resiliency; overcoming barriers with personal fortitude and determination. Resiliency is the ability to bounce back from a stressful event stronger than you were before (Langer, 2004). Marty summed up this important bit of wisdom as “One is resiliency. That’s a critical life lesson.”

**Conclusion**

Disability rights and disability awareness have come a long way in the last 26 years since the signing of the Americans with Disabilities Act in 1990 (ADA, 2009). Yet despite the advancements of this cause, stigma, exclusion, and misconceptions are still pervasive in the educational institutions that claim to promote diversity on their campuses. The experiences shared by the participants of this study included powerful examples that showed how much we
as a country still need to understand disabilities and how much work we still have to do in order to create a truly inclusive environment for all.

I was humbled and honored to work with my participants and to hear their stories. It was a great learning experience for me and challenged me to examine my own assumptions of disabilities and my interactions with individuals with disabilities. I have learned that in order to really understand the individual’s needs, I must let go of my assumptions and be willing to learn from the individual with the disability. Until then, I could not claim to be an advocate for disability rights.

One of the more enlightening moments for me during this study was my interviews with the participants who were blind. I did not ask about their disabilities when we discussed scheduling an interview and never considered that the participants may need electronic versions of my Informed Consent form prior to our meetings. This blunder taught me the importance of creating environments that are inclusive which can be as simple as making sure that all information is accessible in multiple formats. I hope that the outcomes of this study provide lessons for all who read it. We must challenge our assumptions, our actions, and strive to do better if we are to create a society where everyone, regardless of their abilities are accepted as an important part of the community.
REFERENCES


Appendix A – INFORMED CONSENT

UNDERSTANDING THE LIVED EXPERIENCES OF FACULTY MEMBERS LIVING WITH DISABILITIES IN HIGHER EDUCATION

INTRODUCTION
You are invited to join a research study to examine the lived experiences of faculty members who have self-disclosed to their employers and students that they have a disability. This study is for fulfillment of the requirements of the Doctorate of Education degree at Ball State University.

PURPOSE
The purpose of this narrative study is to examine the lived experiences of faculty members in higher education who have self-disclosed that they have a disability. I will explore how their disability has influenced their pedagogy, peer and student relationships, and their professional status within the university or college setting.

WHAT IS INVOLVED IN THE STUDY
If you decide to participate in this study, you agree to participate in one interview which will be audio recorded. A second interview may be scheduled if needed. Each interview will take approximately 30-60 minutes each. Data collection will begin mid-November 2015 and last through March 2016.

INCLUSION/EXCLUSION CRITERIA:
To be eligible to participate in this study you must be older than 18-years-old, teach or have taught at a university and/or college and have a documented disability.

VOLUNTARY PARTICIPATION
Participation in this study is voluntary. You have the right not to participate at all or to leave the study at any time. Deciding not to participate or choosing to leave the study will not result in any penalty. If you decide to leave the study, none of your information will be used in the study.

The investigator may stop the study or take you out of the study at any time she judges it is in your best interest. She may also remove you from the study for various other reasons. She can do this without your consent.

RISKS
This study may involve the risk of emotional or psychological harm from sharing your story. There may also be other risks that cannot be predicted. If emotional or psychological harm is experienced, you may contact Meridian Services at (765) 288-1928 for mental health services.

BENEFITS TO TAKING PART IN THE STUDY
There are no direct benefits to the participants from engaging in this research. There may be unexpected benefits to you of a deeper understanding of your own lived experience and critical reflection based on your narrative elicited as part of the study. Yet the larger benefit of
participation in the study is for the field of higher education and has a broader focus than an individual benefit.

CONFIDENTIALITY
I will take the following steps to keep information about you confidential, and to protect it from unauthorized disclosure, tampering, or damage: all written notes and interviews will be destroyed after they are transcribed from the audio recordings and saved in electronic form. The electronic files will be kept on my password protected personal computer. No identifying information will be used in the final written paper or presentation. Additionally, your affiliated institution’s name, or any other identifying information mentioned during the interviews, will not be used in any written products related to this study. Pseudonyms will be used for participants’ names and all identifiable places and/or persons and will not disclose the location of the study in any drafts or iterations of the written products of the research.

INCENTIVES
There is no incentive provided to participating in the study.

YOUR RIGHTS AS A RESEARCH PARTICIPANT
If you have any questions or concerns about your rights as a research participant, contact the Director of Office of Research Integrity, Ball State University, Muncie, IN 47306 at (765) 285-5070 or irb@bsu.edu.

RESEARCHER CONTACT INFORMATION
If you have questions regarding the research study, please contact Lois Weiss, Principle Investigator, at (765) 748-4903 or laweiss@bsu.edu. You may also contact Dr. Michelle Glowacki-Dudka, Faculty Advisor at (765) 285-5348 or mdudka@bsu.edu

CONSENT:
I, _______________________________, agree to participate in this research project entitled, “Exploring the lived experiences of faculty living with disabilities in higher education using a phenomenological approach”. I have had the study explained to me, and my questions have been answered to my satisfaction. I have read the description of this project and give my consent to participate. I understand that I will receive a copy of this informed consent form to keep for future reference. To the best of my knowledge, I meet the inclusion/exclusion criteria for participation (described on the previous page) in this study.

I give my permission to audio-record the interviews. _____ Yes _____ No

________________________________ _________________
Participant’s Signature                       Date

________________________________ _________________
Researcher’s Signature                       Date
Researcher Contact Information:

**Principal Investigator:**
Lois Weiss, MA, ABD  
Doctoral Candidate  
Department of Educational Studies  
Ball State University  
Muncie, IN 47306  
(765) 748-4903  
laweiss@bsu.edu

**Faculty Supervisor:**
Michelle Glowacki-Dudka, Ph.D.  
Associate Professor of Adult, Higher, and Community Education  
Department of Educational Studies  
Teachers College, Room 809  
Ball State University  
Muncie, IN 47306  
(765) 285-5348  
mdudka@bsu.edu
Appendix B – LETTER TO COLLEAGUES/PEERS

Dear ______________:

I am interested in learning about the experiences of faculty living with disabilities in higher education and what impact the disability has had on their professional career. I would like your help in distributing my letter requesting participants for my study.

The study will consist of one interview lasting approximately 30-60 minutes. A second interview may be scheduled if needed. These interviews are part of my dissertation under the direction of Dr. Michelle Glowacki-Dudka, Associate Professor of Adult Higher and Community Education, in the Department of Educational Studies. Data collection will begin mid-November 2015 and last through March 2016. Participants may choose to stop their participation at any time without any penalty.

The study has been approved by Ball State University’s Institutional Review Board and they can be reached at (765) 285-5070 or at irb@bsu.edu if there are any questions about the study or human subject rights. You may also contact me with questions at (765) 748-4903 or at laweiss@bsu.edu.

Thank you for your assistance with my study. I appreciate your help.

Lois Weiss, MA, ABD
Ball State University
2000 W. University Ave.
Muncie, IN 47306
(765) 748-4903
laweiss@bsu.edu

Dr. Michelle Glowacki-Dudka
Ball State University
2000 W. University Ave., TC 609
Muncie, IN 47306
(765) 285-5348
mdudka@bsu.edu
Appendix C – LETTER TO POTENTIAL PARTICIPANTS

Dear Participant:

I am interested in learning about the lived experiences of faculty living with disabilities in higher education and what impact the disability has had on their professional career. This study is for my dissertation and is under the direction of Dr. Michelle Glowacki-Dudka, Associate Professor of Adult Higher and Community Education, Educational Studies. Literature about faculty members living with a disability in higher education is very limited. Your participation will contribute to the existing literature on disability studies and help promote a deeper understanding of living with a disability in higher education.

This study will include one interview lasting approximately 30 - 60 minutes each and will be audio recorded. A second interview may be scheduled if needed. Data collection will begin mid-November 2015 and last through March 2016.

Your participation in this study is completely voluntary and as a participant, you are free to stop participating at any point or skip any questions you choose not to answer. If you choose to participate, the information you provide will be confidential and your identify and the identity of your institution will be protected by the use of pseudonyms in any written product.

If you are interested in participating in this study, please respond to this email to arrange an interview time that is convenient for you. Before the interview begins, we will review the Informed Consent and I will provide you a copy of the signed form for your records.

Ball State University’s Institutional Review Board has approved this research and can be contacted by phone at (765) 285-5070 or by email irb@bsu.edu for further questions about your rights as a research subject. I am also available to answer any questions and can be reached by phone or email.

Thank you for your willingness to participate in my project.

Lois Weiss, MA, ABD
Ball State University
2000 W. University Ave.
Muncie, IN 47306
(765) 748-4903
laweiss@bsu.edu

Dr. Michelle Glowacki-Dudka
Ball State University
2000 W. University Ave., TC 609
Muncie, IN 47306
(765) 285-5348
mdudka@bsu.edu
Appendix D – SEMI-STRUCTURED INTERVIEW GUIDE

UNDERSTANDING THE LIVED EXPERIENCES OF FACULTY MEMBERS LIVING WITH DISABILITIES IN HIGHER EDUCATION

Interview #1 Questions:

1. Please tell me a little bit about yourself?

2. What does it mean to you to live with a disability?

3. Please describe your experiences of living with a disability?

4. In what ways does your disability impact your professional life?

5. How did you make the decision to disclose your disability to others?

6. What does being successful in your profession mean to you?

7. How do you see yourself as a member of your department? What has been the biggest challenge and what opportunities have you experienced at the school where you teach and/or in the department where you work?

8. Please describe your classroom and approach to teaching and how your disability has shaped your pedagogy and teaching style.

9. Tell me a story about a time when someone behaved or spoke something appropriately or ignorantly about your disability.

10. What else would you like to share regarding your experiences of living with a disability and working in higher education?

Interview #2 Questions:

A second interview may be scheduled if needed. The questions for the second interview will be informed by the analysis of the data collected during the first set of interviews. Questions will be designed to clarify responses from the first set of interviews as well as to further examine participants’ experiences of living with a disability in a professional work environment.