

Chapman University

Chapman University Digital Commons

Educational Studies Dissertations

5-2014

Stuck Between a Rock and a Hard Place: Exploring the Lived Experiences of College Students Who Do Not Request Accommodations

Denise P. Reid

Chapman University, denise.reid@biola.edu

Follow this and additional works at: https://digitalcommons.chapman.edu/ces_dissertations



Part of the [Accessibility Commons](#), [Higher Education Commons](#), [Higher Education Administration Commons](#), [Other Education Commons](#), and the [Social and Philosophical Foundations of Education Commons](#)

Recommended Citation

Reid, Denise P. (2014). *Stuck between a rock and a hard place: Exploring the lived experiences of college students who do not request accommodations* (Doctoral dissertation). <https://doi.org/10.36837/chapman.000002>

This Dissertation is brought to you for free and open access by Chapman University Digital Commons. It has been accepted for inclusion in Educational Studies Dissertations by an authorized administrator of Chapman University Digital Commons. For more information, please contact laughtin@chapman.edu.

Stuck Between a Rock and a Hard Place:
Exploring the Lived Experiences of College Students Who
Do Not Request Accommodations

A Dissertation by
Denise P. Reid

Chapman University
Orange, California

College of Educational Studies

Submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy in Education

May 2014

Committee in charge:

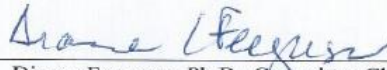
Dianne Ferguson, Ph.D., Chair

Dawn Hunter, Ph.D.

Michael Madrid, Ph.D.

Jason McAlexander, M.A., M.S., B.A.

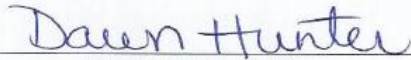
The dissertation of Denise P. Reid is approved.



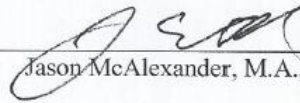
Dianne Ferguson, Ph.D., Committee Chair



Michael Madrid, Ph.D.



Dawn Hunter, Ph.D.



Jason McAlexander, M.A., M.S., B.A.

May 2014

Stuck Between a Rock and a Hard Place:
Exploring the Lived Experiences of College Students Who
Do Not Request Accommodations
Copyright © 2014
by Denise P. Reid

ACKNOWLEDGEMENTS

“Now, to Him who is able to do exceedingly abundantly above all that we ask or think, according to the power that works in us, to Him be the glory” (Ephesians, 3:20-21a, NKJ).

I dedicate this work to my beloved mother, Lucille Sampson, who instilled the love of reading and learning in me. It was because of my mother’s encouragement that I was confident enough to pursue higher education. I held all of her advice and words of wisdom in my heart as I completed my Ph.D.

During my doctoral studies, I had the support of three amazing family members. To my husband John, I thank you for your continued support and encouragement. I appreciate your patience and understanding during my hours of research, reading, studying, and writing. Earning my Ph.D. was only possible with your continued support, hard work and provisions.

To my daughters Amber and Angelica, I thank you for understanding my time restraints and your flexibility during my doctoral studies. Angelica, I appreciate your demonstration of concern for me by encouraging me to “just get out of the house for a while” after long periods of studying, reading and writing. Amber, I greatly appreciated your flexibility during the preparation of your wedding and meeting the timelines that worked for me. To both of you, I say “Thank you” for listening to my countless requests to ensure my graduation party was exactly as I wanted.

To Dr. Dianne Ferguson, my advisor and dissertation chair, I owe a lifetime of gratitude. I appreciate how you mentored me and took me under your wing as I navigated the path to becoming a public intellectual. I respect you as a professional and consider

you a friend. To my remaining dissertation committee members: Dr. Dawn Hunter, I appreciate the time you took with me to ensure I was aware of journals and organizations related to higher education. To Dr. Michael Madrid, I say thank you for your answering my many questions and providing endless writing support. I thank Mr. Jason McAlexander for the time spent discussing and answering questions related to disclosure and documentation policy in higher education. As well, I thank Dr. Susan Gabel for the early conversations that challenged me to align my vocabulary with the social model of disability. I also thank Dr. Barbara Tye for your continued encouragement and invaluable instruction on the many lenses by which to view the world.

I thank the staff of Leatherby Libraries, specifically Brett Fisher, David Goto, Lugen Rosen, and Jessica Bower for their continued efforts in making the library and resources accessible. To Andrea Tedford-Killian and Jason McAlexander, I want to express my gratitude for your professionalism and timely response when adapting my printed books and articles.

Lastly, but definitely not least, I thank Dr. Marni Fisher and Mrs. Kay Henry for proofreading my dissertation.

ABSTRACT

Stuck Between a Rock and a Hard Place:
Exploring the Lived Experiences of College Students Who
Do Not Request Accommodations

by Denise P. Reid

For this phenomenological study, thirteen participants from two private universities located in the western region of the United States shared their lived experiences of being a college student who does not request accommodations. The author used recursive analysis to analyze qualitative data from semi-structured interviews. Initial codes were combined to create interconnected families of codes. A second level of analysis resulted in seven spaces in which participants describe their lived experiences. Findings suggest participants experience various tensions, ranging from incompatible options to competing perspectives, as they negotiate their identity and environment, including the principle of opportunity cost. Recommendations for college administrators and faculty, including Universal Design in higher education are included.

TABLE OF CONTENTS

Chapter 1: Introduction	1
Purpose of Study	9
Institutions of Higher Education	10
Enrollment of Students with Disabilities	11
College Students Who Do Not Self-identify	13
Chapter 2: Review of the Literature.....	17
Stigma	17
Identity and Passing	26
Identity	26
Passing	27
My Positionality.....	30
Disclosure	33
Chapter 3: Theoretical Framework and Methodology.....	44
The Nature of Qualitative Research.....	45
Phenomenology.....	46
Culturally Responsive Methodology (CRM).....	49
Philosophical Roots of Phenomenology	53
Lived Experiences and Hermeneutics.....	55
Participants.....	57
Recruitment of Participants.....	60
Data Collection	61
Field Notes	61
Interviews.....	62
Poems and Narratives	65
Data Analysis	65
Ethical Consideration.....	69
Trustworthiness.....	69
Chapter 4: Who Occupies the Space Between a Rock and a Hard Place?	71
Which identity will I wear? Reaping the benefits of a disabled identity	72
No Documentation + No Cash = No Accommodations	78
Thanks Mom and Dad: Not Bothered by What Others Think of Me	85
Will the real Me please stand up: Knowing myself without medication.....	99
Trusting Others and Accepting Advice.....	107
I'm OK in a Not OK System.....	113
Maybe next time: Making choices I can live with.....	126
Chapter 5: Examining the Spaces Between the Rock and a Hard Place.....	135
Disability Studies	142
Negotiating Identities.....	147
Opportunity Cost.....	150

Conclusion: Are the stories the same?	153
Recommendations	156
DS Perspective in Higher Education.....	156
Faculty and Teaching Practices: Universal Design	159
Value of Study	162
References	165

TABLES

3.1 Description of Participants.....	55
5.1 Use of Accommodations.....	146

Chapter 1: Introduction

In the fall of 1981, driving our only vehicle, my mother proudly drove me to my first day of college. With aspirations that I might be her first child to graduate from college, she strategically pulled over, avoiding the swarm of college students heading towards the campus and temporarily parked in the farthest available space away from the bustling bus stop. Watching her put the car in park, I began to smile as she placed her right hand over my left hand and gently placed it over her heart and said, “I am so proud of you.” I smiled, leaned over, kissed her right cheek, thanked her for the ride, and anxiously grabbed my navy blue backpack that was snuggled between my feet. After closing the car door, I slightly bent over and waved to my mother in a manner that now reminds me how a kindergarten student would wave to their loved ones on their first day of school.

Securing my backpack, I quickly negotiated my space in the swarm of students. As I looked at the students ahead and those to my immediate left and right, I had my first surprise: I was completely overdressed. While I had on dressy slacks, a fancy blouse and heels, the other students had on jeans, T-shirts, sweatshirts, tennis shoes, shorts, and sandals. As I began to feel self-conscious, my thoughts immediately shifted to concerns about what the other students thought of me because of my attire decision that was so vastly different. So many questions raced through my mind. Did they think I was a professor? Did they think I was a staff member? Did they think I was trying to be better than them? Maybe they thought I was just some nerd who had no clue to the current fashion trend for college students. Since I did not know what they thought, I decided it would be best for me to change my clothing and fit into what seemed to be the acceptable attire standard for college students.

I suddenly thought to myself, “Maybe I could run back and see if I could catch my mother to ask her to take me home so I could change clothes.” Shortly after that thought, I realized my mother had probably left the temporary parking space, since she would return to pick me up at 3:30 p.m., the time we agreed upon. I thought I could catch one of those buses, go home, change clothes and return before my first class began. I then realized I would not know which bus to get on, because I had not yet learned the bus routes to and from the campus. It only took a few minutes before I realized that changing my clothes was not going to happen. I was stuck. Whether I liked it or not, I had to wear my dressy outfit the entire day.

I spent that day negotiating my identity as a student. While I knew I was a student, my clothing made me stand out as different. In my first class of the day, I was more dressed up than my biology professor who wore dark blue denim jeans and a green sweatshirt. Sitting in the student center during my lunch break, I felt and looked like I should have been eating lunch with faculty members. However, I knew if I attempted to enter the faculty area, they would identify me as a student. I felt as though I was in between a rock and a hard place.

While I was generally comfortable being in dressy clothes, in order to fit in with my peers, I would have to make a conscious decision to alter my style of dress. After eating what seemed to be the greasiest French fries I ever consumed, I wiped my hands, took out a sheet of paper and began to write down options for what I could wear the next day. Within several minutes, a sense of relief came over me when I realized that, in my bedroom closet, I had jeans and a couple of sweatshirts I would be able to select as my outfit for my second day of college. I placed the sheet of paper in the front pocket of my

backpack and prepared for my second class. Little did I know the events of that day would be a continual pattern throughout my undergraduate and graduate education.

I began my undergraduate studies during the third year of the prognosis that I would be blind in five years. During high school, my parents were not aware of accommodations or adaptations I could have received to enhance my education; however, they were proactive in preparing me with independent living skills for the day they did not want to experience—the day their daughter would go blind. My parents did what they thought was best and made decisions based on the information they were provided. As a result, I successfully completed high school. While my parents were diligent in preparing me for a future with no vision, I also had support from several of my high school teachers.

Even though I never received special education services in high school, I attribute my successful completion of high school to caring and understanding teachers who provided me with extra time to read and complete assignments. In particular, I recall my social studies teacher who would allow me to come to his classroom during lunch to read or complete assignments and tests. Similarly, my literature teacher would provide me with upcoming novels and materials far in advance to ensure I had time to read them. The drama teacher also facilitated my continued participation in school activities as a stagehand by placing masking tape on the floor to serve as a guide to aid my role in moving and adjusting scenes.

I entered college with the assumption that my professors would be as kind and caring as my high school teachers were and willing to work with me. I was neither aware

of formalized accommodations, nor did I identify myself as disabled. However, I would soon learn and acquire a disabled identity, an identity that I would carefully negotiate.

The university I attended was on a ten-week quarter system. It soon became apparent to me that I required more time to complete the reading assignments. In addition, reading material on the chalkboard and overhead projector proved to be additional challenges, which persisted for three quarters, resulting in a low grade point average (GPA) and academic dismissal. I did not ask for assistance from the professors because I was waiting for them to approach me. Upon my academic dismissal, a required meeting with the dean was scheduled. During this meeting, I told the dean about my visual difficulties and the prognosis I had received three years earlier. A caring atmosphere permeated the dean's office as I described in detail the nature of my impairment. After a lengthy conversation, I learned valuable information that changed the course of my academic career. The dean informed me of the Office of Disability Services¹ (ODS), an office responsible for providing services and accommodations for students with limitations, so long as those students showed appropriate documentation. As a requirement of potential reinstatement, regular meetings with the ODS staff were required. After I attained knowledge of assistive technology (AT), I realized I had the potential to excel academically at the postsecondary level.

In order to obtain services, accommodations, and adaptations, I provided medical documentation verifying the nature of my visual impairment. Providing this documentation was the first time I experienced an internal struggle of assuming a disabled identity when I did not identify myself as disabled. At the time, I was not aware

¹ The name of this office differs between universities. For the purpose of this study, ODS is used for all references regarding this type of office and services.

of what role taking on a disabled identity would play, having previously managed academic work successfully at the secondary level.

After my reinstatement, I was excited and prepared to continue my educational journey with my newly acquired AT skills. Although I began to excel academically, I was oblivious to the number of obstacles² I would soon encounter. My everyday life included rejecting the nondisabled identity with which I entered college and accepting a disabled identity, one I wanted to deny but had to accept in order to receive accommodation and adaptations from my professors. Having successful prior experience with my high school teachers' provision of accommodations, I thought a similar experience in college would occur. To my dismay, my obstacles came in, what I considered the least likely form, the form of resistant professors and non-supportive peers.

Within two weeks of reinstatement, I experienced my first obstacle in negotiating my new disabled identity. During my undergraduate education, the use of transparencies and overhead projectors were the latest technologies. On several occasions, I asked the math professor to make copies of the transparencies before each class so I could see the displayed material. His first excuse was that he was too busy. I then offered to come to his office and make the copies myself. It was then the professor revealed his true bias. As I sat across from him, he placed his elbows on the desk, interlocked the fingers of both hands, gently rested his chin on the linked fingers and stated, in a stern voice, "If you cannot see the board like all the other students, then you need to reconsider your purpose for pursuing a college education. This class will be difficult, if not impossible

² Something that impedes progress or achievement. (Merriam-Webster, 2014)

for you to pass if you can't see the board.” I was shocked. I could not believe what I was hearing. This was the first time I had experienced a negative reaction after disclosing my limitation. Having discovered the professor's prejudice, I left his office knowing I had the mental ability to pass the course as long as I could see the examples displayed in class. Once again, I realized I was stuck between a rock and a hard place.

Unaware my civil rights had been violated, I recorded the lectures and befriended a classmate who made copies of her notes at the end of each class. Not having copies of the notes and overheads from the professor, I had to later take the notes from my classmates and re-listen to the lecture for an understanding of the material. Having the support of classmates was helpful, and by the end of that quarter, I had established relationships with classmates who were supportive and instrumental in my successful completion of that course. Unfortunately, I had a second experience with a resistant professor. However, during my second encounter, I was better equipped to handle such resistance.

By my junior year, I was more aware of my rights and the campus's responsibility for the provision of accommodations to students with disabilities. At this point in my education, I was more proactive. I had an English professor who made my time in her course a living hell because I reported her lack of accommodations to the dean. This particular professor refused every accommodation I requested, even though I had documentation to verify my visual impairment. She would not provide me copies of her overheads or material she placed on the computer. It is important to state that in the early 1980s, screen magnification software was not as available as it is today. In her distaste of having me as a student, she “lost” every assignment I submitted. This proved particularly

problematic because I used a typewriter to complete my assignments. There was nothing saved to a flash drive. Having to retype lost assignments consumed valuable time, time that I needed to complete new assignments. As a result, I began making copies of all my typewritten assignments.

When my assignments were graded and returned, it was evident that this particular professor marked me down for concepts, terminology, and sentence structures that were also used by my nondisabled classmates who did not receive point deductions. Such an overt act of discrimination appalled several of my classmates. In fact, several of my nondisabled peers addressed this issue with the dean. Although I never felt as if this professor cared for me as a student, by the end of the quarter, I was earning my rightful points and grades.

Other professors were not deliberate in their denial of accommodations. However, professors often neglected to have my exams available to me in large print or to bring copies of the overheads to class. Some professors would insist I take exams in their office because they questioned the security of their exam taken outside of their presence, which caused me to realize that providing accommodations was a new procedure for them. While such experiences could have resulted in some students with a disability giving up their pursuit of a college education, it only made me more determined to successfully complete the required courses and subsequent degree.

It is worth mentioning that at the five-year mark of my prognosis, I was enrolled at this university and did not go totally blind. However, I did lose a portion of my central vision during my first two years of undergraduate studies. Ten years after earning my bachelor's degree, I enrolled in a master's program with a special education emphasis.

Here, my experience with professors was different from my undergraduate years. During this program, the faculty members were very accommodating, ensuring I had access to all instructional material. However, to my surprise, several of my nondisabled classmates were very vocal and boldly expressed how they did not think it was fair for me to get extended time on exams and to have copies of the professor's notes and PowerPoint presentations. As I utilized accommodations and services and excelled, several of my classmates began to question my true academic/intellectual abilities. Working in groups was an isolating experience. I had to prove my academic abilities to earn the respect of my peers.

I specifically recall one assignment in which I was assigned a partner to conduct an interview. As a team, we agreed to interview a staff member of a non-profit organization. Toward the end of the interview, the interviewee noticed my use of magnification and asked about the nature of my visual impairment. As I began to explain, my partner stood up, grabbed her purse, and said, "This interview is not about you. No one really cares about what you can and can't see." To my dismay, she abruptly departed the organization, leaving me with no transportation back to campus. Thankfully, I was familiar with the area and used local bus routes to return to campus.

Although I have legitimate reasons to dwell on the obstacles, I need to also emphasize my gratitude for these experiences during my postsecondary education. These obstacles led me to this dissertation topic and study. Thirty-three years after my mother drove me to my first day of college, I wondered if my lived experiences were similar to the experiences of current college students.

Purpose of Study

The question guiding this study is, “What meanings do college students who do not request accommodations assign to strategies or techniques used to negotiate their identity and environment in higher education?” This study seeks to understand the participants’ lived experiences as they navigate higher education. Through an examination of the negotiation of disabled, nondisabled identity and the environment, the concepts of stigma, passing, and disclosure are addressed.

From this study, I would like to hear if stories of college students have changed since my experience in the 1980s. Despite apparent disparity in the function and purpose of research and telling stories, Ferguson, Ferguson, and Taylor (1992) consider the two compatible, making the following distinction:

It is not just the stories themselves whose value the student must appreciate; the *telling* of the story is equally important. For, it is only in ‘the telling’ that both a speaker and an audience are implicitly included, and that is where interpretation comes in (pp 1-2).

Following this premise, in the current research, college students told their stories. I used the interpretations of the stories to compare the experiences of current college students to my own and to determine if the stories have changed and learn why they do not request accommodations.

For the purpose of this study, the terms *postsecondary education*, *higher education*, *postsecondary institutions*, and *institutions of higher education* are used interchangeably and may refer to community colleges, vocational schools (including trade and business schools), or public and private colleges and universities.

In pursuit of discovering whether the stories were the same as mine, 13 participants told their stories. Some students, like Angela, were unable to get accommodations due to lack of documentation. With no documentation and no financial resources to acquire appropriate documentation, students receive no accommodations. Other students, like Regina, experience negative reactions from professors when requesting documented accommodations. This type of attitude and bias does not cultivate an atmosphere for success. Students like Candice do not see themselves as disabled, and find themselves forced to assume a disabled identity in order to access minor accommodations. This creates tension between the student's *disabled* and *nondisabled* identities. Still other students, like Jacob, continuously negotiate inaccessible facilities lacking ramps and elevators, thus isolating them to limited sections of campus.

How can this be? Thirty-three years after I first attended college, students are telling stories similar to my own college experience. While I vividly remember not being able to utilize accommodations or services until I submitted my medical documentation, I sought through this research to discover what differs between the participants' stories and my experience. However, prior to an interpretation of stories being employed, I consider it is necessary to gain a general knowledge of the setting in which the lived experiences occurred.

Institutions of Higher Education

Current federal mandates ensure institutions of higher education do not discriminate against students based on disability. The mandates also ensure equal access and the provision of reasonable accommodation. The *Americans with Disabilities Act*

(ADA) of 1990 and *Section 504* of the *1973 Rehabilitation Act* are examples of such federal mandates. Specifically, Section 504 states

No otherwise qualified person with a disability in the United States . . . shall, solely by reason of . . . disability, be denied the benefits of, be excluded from participation in, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Additionally, the ADA requires postsecondary institutions to provide “appropriate academic adjustments as necessary to ensure that it does not discriminate on the basis of disability” (Office for Civil Rights [OCR], 2005). Therefore, colleges and universities have established disability-related support offices for students with disabilities that address specific needs through the provision of various accommodations and services (Hunter, Reid, & Nishimura, 2014). Colleges and universities provide services and accommodations including, but not limited to, physical, cognitive, emotional, psychological, sensory, and orthopedic conditions or impairments (Prowse, 2009).

Enrollment of Students with Disabilities

The enrollment of students with disabilities into colleges and universities has continually increased (Leyser, Greenberger, Sharoni, & Vogel, 2011; Olney, Kennedy, Brockelman, & Newsom, 2004; Raue & Lewis, 2011; Rehfuss & Quillin, 2005; Shackelford, 2009; Snyder, Tan, & Hoffman, 2004; Wagner, Cameto, & Newman, 2003) from 15% in 1987 to 32% in 2003 (Newman, 2005). Furthermore, 88% of degree-granting institutions reported having students with disabilities enrolled during the 2008-09 academic school year (Raue & Lewis, 2011). In 2003, nearly one-third of out-of-school youth with disabilities had attended a postsecondary school after leaving high

school (Newman, 2005). In 2004, nearly 1.7 million undergraduates and graduate students had disabilities (Snyder et al., 2004). Similarly, Olney et al. (2004) indicated the population of college students with disabilities had tripled and, by some estimates, quadrupled over the past 25 years. In addition, the enrollment of college students with disabilities increased from 26% in 1990 to 46% in 2005 (Newman, Wagner, Cameto & Knokey, 2009). Of the nearly 21 million students attending degree-granting institutions during the 2007-08 academic school year, 11% were students with disabilities³ (National Center for Education Statistics [NCES], 2012).

Although the same postsecondary education experience available to nondisabled students is available to students with disabilities (i.e., community college, vocation, trade or business schools, and four-year colleges and universities), community colleges have experienced greater growth than four-year colleges (Hunter et al., 2014). Essentially, students with disabilities are more likely to enroll in public two-year colleges than nondisabled counterparts (Horn, Berkthold & Bobbitt, 1999; Newman, 2005).

Although reasons for selecting community college may vary among students, 2 of the 13 participants for this study reported attending a public two-year community college after high school. Candice reported, “I did not want to spend money on or take the SAT or ACT test. Community College was the only college that I could attend without taking these tests.” While Regina did not indicate other reasons for selecting community college, she did state she learned the invaluable skill of self-advocacy during her enrollment in community college. Regina stated, “The staff at the ODS on my community college campus helped me to learn skills to advocate. When I learned I was able to help other

³ Students with disabilities were students who reported they had some type of physical, social, sensory, mental, or psychological difficulty.

students understand why they should advocate for themselves, I would use opportunities to do so. I think it is the student's responsibility to let the professor know about how they learn."

These data reflect the perspective of college students with disabilities, whether observable or non-observable, who disclosed and provided appropriate documentation to verify their claim of disability (US Department of Education, (USDOE), 2009). Students who decide against disclosing and forego requesting accommodations are under-accounted in reported data. According to one study, their academic accomplishments are not appropriately documented (Low, 1996). Therefore, these data are inaccurate or at the least, misleading. I suggest there is a discrepancy between documented and actual completion rates of students with disabilities.

College Students Who Do Not Self-identify

As noted, the preceding data represented college students with disabilities who disclosed their disability through self-identification. Low (1996) maintained that the number of students with disabilities is an approximation because "not all students with disabilities make themselves known" (p. 237). Although Low's study was specific to McMaster University, I believe this statement applies to a large percentage of universities.

The Common Application⁴ provides member colleges and universities the opportunity for applicants to distinguish themselves in their own voice through the completion of an essay. Rather than answering "yes" or "no" to disability specific questions, applicants may select one of the following options:

⁴ The Common Application membership association was established in 1975 by 15 private colleges that wished to provide a common, standardized first-year application form for use at any member institution.

Recount an incident or time when you experienced failure. How did it affect you, and what lessons did you learn?

OR

Discuss an accomplishment or event, formal or informal, which marked your transition from childhood to adulthood within your culture, community, or family.

Students with disabilities who decide not to identify or mention a disability during the application process may later self-identify by informing the ODS or going directly to the professor. The general policy to receive accommodations at most institutions of higher education is to provide appropriate documentation to ODS and work directly with their staff to determine services and accommodations for which one qualifies.

Not all students with disabilities identify themselves as disabled and requiring accommodations (Low, 1996). Low described how individual college students with disabilities had to negotiate their identities “in the face of definitions placed on them by non-intimates in the largely impersonal world of the university campus” (p. 235).

Although the terms *visible impairment* and *invisible impairment* are used in the literature (Lingsom, 2008), the terms observable and non-observable are used. For the purposes of this study, the term *disability* has two main categories: observable disabilities and non-observable disabilities. It is estimated over 40% of persons with disabilities have non-observable disabilities (Matthews & Harrington, 2000). Non-observable disabilities refer to conditions that are “not readily apparent to the untrained eye” (Lingsom, 2008, p. 2). The vagueness and lack of visual markers are often associated with and are not limited to “cognitive and neurological impairments, hearing loss, speech impediments, mild learning difficulties, mental illness, asthma, epilepsy and chronic pain” (Lingsom,

2008, p. 2). Likewise, Rehfuss and Quillin (2005) provided a similar, non-exhaustive list of conditions considered as non-observable disabilities: learning disabilities, psychological or mental health issues, depression, bipolar disorder, anxiety, HIV/AIDS, and chronic fatigue.

Literature supports that among the categories of non-observable disabilities, some are more commonly subject to stigmatization. For example, Lingsom (2008), concluded conditions such as hearing loss and chronic pain as less subjected to stigmatization compared to mental illness and epilepsy.

There are two primary differences between these groups. First, those with observable disabilities are subject to the predetermined thinking related to the disability and visible attributes. Secondly, in the absence of visible or physical traits, those with non-observable disabilities are initially not described as disabled (Lingsom, 2008) and they may have opportunities to reflect on if, when, and to whom, to disclose.

According to the Newman, Wagner, Cameto, Knokey, & Shaver (2010), only 35% of college students with learning disabilities considered themselves to have a disability and actually requested accommodations, while 56.7% did not consider themselves to have a disability and 7.8% thought they had a disability but chose not to disclose their disability. The literature suggests various reasons, many of which are related to stigma, for not disclosing their disability and/or requesting accommodations and services (Cawthon & Cole, 2010; Lightner, Kipps-Vaughn, Schulte, & Trice, 2012; Shackelford, 2009). Research conducted by May and Stone (2010) revealed that students with learning disabilities believed peers would view their intellectual abilities as less than

average if their disability were disclosed. As well, these students believed their peers would perceive the use of accommodations as *cheating*.

Chapter 2: Review of the Literature

Until recently, studies on *passing* have primarily focused on race, gender, and sexuality while failing to consider disability as a “fundamental, destabilizing component of a person’s identity” (Brune & Wilson, 2013, p. 2). Having an understanding how the act of *passing* occurs on an interpersonal level, is valuable to the issue of stigma and the decision to disclose and request accommodations. This chapter will discuss: (a) stigma, (b) the concept of identity and passing, (c) my positionality, and (d) disclosure.

Stigma

Disability stigma is the most significant barrier to “ongoing success and access to college for students with disabilities” (Trammell, 2009, p. 106). Stigma is defined as “a sign of social unacceptability; the shame or disgrace attached to something regarded as socially unacceptable” (Encarta Dictionary, North American version, 2007). The word *stigma* originated from the Greeks who used the term to signify something undesirable through branding a visible mark on the skin and its bearer was stigmatized (Goffman, 1963).

The variations of human differences are the basis of stigma and a person can only feel stigmatized when they are compared to another person; therefore, “stigmatization or feeling stigmatized is a consequence of social comparison” (Coleman, 2006, p. 142). Research indicates that as a result of stigmatization related to disability, countless students with disabilities decide to conceal their disability during their pursuit of higher education and thereby are not included in the percentages of students with disabilities attending colleges as previously presented (Brune & Wilson, 2013; Coleman, 2006; Darling, 2013; Davis, 1995; Goffman, 1963).

Research conducted by Vogel, Bitman, Hammer, and Wade (2013) measured the perception of two stigma types: *public stigma* and *self-stigma*. Vogel et al. (2013) determined that over a period of time public stigma internalized as self-stigma. Public stigma generally comes to mind in discussions of stigma and refers to “the negative attitudes held by members of the public about people with devalued characteristics” (Vogel et al., p. 464). Self-stigma occurs when people internalize these public attitudes and suffer numerous negative consequences as a result (Corrigan, Watson, & Barr, 2006).

The internalization of prejudice and acts of discrimination are not necessarily or naturally occurring consequences of stigma (Corrigan & Rao, 2012). However, implications of self-stigma are noteworthy. People who experience self-stigma experience a significant loss of self-esteem and self-efficacy (Corrigan, Kosyluk & Rusch, 2013). A central fact regarding stigma is that the stigmatized person may have the tendency to hold the same beliefs about themselves that the non-stigmatized group imposed on them (i.e., self-stigma) (Corrigan et al., 2013; Corrigan & Rao, 2012; Goffman, 1963; Vogel et al., 2013). The imposition of beliefs derived from societal expectations based on norms. More importantly, “the idea of a norm is less a condition of human nature than it is a feature of a certain kind of society” (Davis, 1995, p. 24).

Albrecht, Walker, and Levy (1982) explained two general stigma types: *deviant* and *disability*. Deviant referred to “conduct which violates sufficiently valued norms that, if it is persistent, is assigned a special (negative) role” (Friedson, 1965 as cited in Albrecht et al., 1982, p. 1319). Disability referred to “chronic physical impairment that reduces a person’s capacity to function or perform social activities” (Albrecht et al., 1982, p. 1319). Results indicated the stigmatized were a differentiated group and

perceived as having “varying grades of offensive characteristics” (p. 1325). These results conveyed the public stigma which, internalized, could result in self-stigma (Corrigan & Rao, 2012). While the previous statements are not to imply all uses of classification are unfortunate, there are classifications that minimize confusion of social functions (e.g., the role of a firefighter and an accountant) (Jaeger & Bowman, 2006). However, the classifications used to identify students with disabilities can potentially have adverse effects and are worthy of investigation.

Stigma has a long-standing history as the most persistent attitude toward disability (Brune & Wilson, 2013; Bryan, 2006; Connor & Gabel, 2010; Darling, 2013; Davis, 1961; Davis, 1995; Jaeger & Bowman, 2005; Longmore & Umansky, 2001; Stroman, 2003). Phelan, Link, Stueve, and Pescosolido (2000) documented an increase in stigmas related to people with mental health illnesses occurred since 1950, and the impact of stigma can have serious implications for this population. Although research conducted by Wahl (1999) did not specifically examine stigma in postsecondary education, the results provided additional insight into the stigma and people with mental illness. Here, sources of stigma affecting co-workers, the general public, churches, and mental health caregivers were revealed. Such insight allowed researchers to understand that stigma can originate from people in various positions. In relation to institutions of higher education, the sources of stigma may generate from staff, including admission and financial aid staff, faculty members, and peers (i.e., classmates and students in the general student body).

Research conducted by Green (2007) revealed students with and without disability expected individuals with disabilities to face discomfort and social

awkwardness from others in the community, but they were not expected to experience devaluation from others. Stigma by association addresses the relationships between people with disabilities and their nondisabled peers. Companions of members in a stigmatized group can acquire courtesy stigmas resulting from their relationship and/or friendship with those who are stigmatized (Pryor, Reeder, & Monroe, 2012).

According to Green (2007), ascribed stigmas can range from “the strong to enduring bonds of kinship to the arbitrary occasions of one seen in the company of someone who is stigmatized” (p. 224). Students who conceal their disability may have experienced stigma by association, thereby justifying the decision to conceal their disability. This may be especially true for students with disabilities who recently transitioned to college from high school. In contrast to their K-12 experience, college students may make the choice to separate themselves from a former stigmatized identity associated with special education. It is important to emphasize that not all associations with members of stigmatized/devalued groups are negative. For instance, a study conducted by Bogdan and Taylor (1992) revealed that nondisabled people in their study considered severely disabled people (a stigmatized group) as fellow humans. Here, there were no devaluations of those with membership in the stigmatized group.

Given that a notion of what is *normal* is held in all societies (Davis, 1995), the notion of normal means conforming to the present standard of behavior (Towler & Schneider, 2005) and the values of the dominate group determine what is acceptable and what is deemed a deviation (Coleman, 2006). The historical conceptualization of norms were applied to the *law of error*, which was an averaging technique used in astronomy. The notion of the normal as imperative derived from the contributions of the French

statistician, Adolphe Quetele (1796-1847) (Davis, 1995). Quetele later noticed the *law of error* used outside of astronomy and applied to the distribution of human features such as weight and height (Davis, 1995). The concept of the *average man* resulted from an additional step in the formulation of this concept. Although the average man was abstract, Quetelet maintained this as the “average of all human attributes in a given country” (Davis, 1995, p. 26). The error curve later re-conceptualized to the normal curve, which is a current method used to determine how far one deviates from the norm on a range of intellectual, physical, and economical attributes.

When stigma was conceptualized, an identification of the power possessed by the dominant group became evident (Coleman, 2006). The power given to the dominant culture is problematic because members of the dominant culture then can determine social markers to indicate what human differences are desirable and what are not. As a result of this power, people with disabilities have experienced and continue to experience a human rights tragedy of epic proportions (Charlton, 1998). Further, Davis (1995) argued that the “problem is not the person with the disabilities; the problem is the way that normalcy is constructed to create the problem of the disabled person” (p. 24). This construction connects to the manner disability is defined. For instance, if disability were considered a tragedy, the result would be that disabled people would be treated as victims (Oliver, 1993). However, if the definition of disability indicates it is a form of social oppression, the perception of disabled people changes. Oliver purported, “disabled people will be seen as collective victims of an uncaring or unknowing society rather than as individual victims of circumstances” (p. 62).

Additionally, a person with a severe physical disability would not be cast into a “deviant” role if it were not for society’s devaluation of these attributes” (Davis, 1961). Due to the societal value placed on physical attractiveness and intelligence, these traits are among *highly valued* attributes in American society (Darling, 2013; Wolfensberger, 1988), and stigmatization is the result of those who deviate from such valued attributes. Furthermore, the classification of devalued attributes encompasses the “beliefs, assumptions, and stereotypes by members of a society that create a generally accepted set of social perceptions about a particular group of people within the society” (Jaeger & Bowman, 2006, p. 10). One example of classification of devalued attributes is the addition of classification categories to the U.S. Census of 1880.

In 1880 members of the U.S. population, who met criteria that were essentially a deviation of the norm, were identified as being members in one of the following stigmatized groups:⁵ *dependent*, *defective*, or *delinquent* were counted and included in the census (Kotz, 1985). These categories were new census classifications. The criteria included the blind, insane, prisoners, deaf-mutes, idiots, paupers, and homeless children. Fredric Howard Wives was instrumental in the supervision of this process and referred to members of these stigmatized groups as “burdens that civilization would have to bear” (Kotz, 1985, p. 135).

Similarly, Goffman’s (1963) categorization demonstrated a classification of stigmatized conditions. The first category was *abominations of the body*, such as physical disabilities. *Tribal identities* made up the second category and included factors such as race, gender, nationality, and religion. The last category was *blemishes of individual*

⁵ Terms used reflect the terminology of categories in the late 19th century.

character. Here, homosexuality, unemployment, and mental illness were identifiable factors. A consideration of Goffman's description of stigma indicated that all human differences could potentially be a source of stigma (Coleman, 2006).

Although the work of Robert Bogdan and Steven Taylor (1982) emphasized the sociocultural study of intellectual disability, the implications related to labeling is applicable to this study. To see the world from a person's point of view describes the ability to empathize, however, when labels are assigned, this ability is lost. From their research, Bogdan and Taylor (1982) stated, "the label *mentally retarded* creates a barrier to our understanding people on their own terms" (p. 222). An awareness of its adverse connotation of such hurtful terminology, the U.S. government recently changed the law regarding its use. On January 28, 2013, the Federal Register replaced the term "mental retardation" with "intellectual disability" in their Listing of Impairments (Federal Register, 2013). The replacement of *mentally retarded* with any other label (all of which have connotations) used to identify a person with a physical, sensory, mental, or psychiatric disability would yield similar barriers. One implication of the use of labels is that they generate binaries such as us-them and normal-deviant, which in turn may broaden the affective responses such as "dislike and disgust to include the emotional reaction of fear" (Coleman, 2006, p. 143).

Supporting literature suggests gaining information from infants and children and their response to strangers (Brooks & Lewis, 1976; Sigelman & Singleton, 1986; Sroufe, 1977). According to Sroufe (1977), infants and children develop a natural wariness of strangers as they acquire the ability to differentiate between familiar and unfamiliar objects. When infants are approximately seven months of age, developmental psychologists suggest they develop a universal phenomenon of stranger anxiety

(Coleman, 2006). The anxiety is the result of an unfamiliar person entering the space of the infant and caregiver.

Infants read the caregiver's verbal and non-verbal cues to indicate the infant's interpretation of the new object, event, or person. There is a tendency for stranger anxiety to decrease with age; however, conditions in which a child learns to respond to human difference, and to stigmatize, results when stranger anxiety is combined with self-referencing (Coleman, 2006). The concept of self-referencing refers to "the use of another's interpretation of a situation to form one's own understanding of it" (Coleman, 2006, p. 144).

The idea of understanding, based on how another person interprets a situation, person, or event is similar to the concept of stigma. The similarity exists in that with stigma, one's actions and perceptions are based on how the dominate culture views and refers to a stigmatized group. Hence, the prototype for stigmatizing may connect to the reactions of the infant and/or the cues received from the caregiver (Sigelman & Singleton, 1986). The research on stranger anxiety led me to recall my earliest recollection of self-referencing. My thoughts return to my elementary school years in the late 1960s and early 1970s.

It was during elementary school when I became aware of short yellow school buses that brought students to an isolated section of the campus. As well, I was aware those students remained there the entire day and they never played with us. One day, pointing to the far corner of the campus, I asked my teacher, "Why don't those kids play with us?" My teacher replied, "Those kids are crippled and they have their own teachers and they play in their own playground." Due to my teacher's response, I imposed a

disabled identity onto *those* students who rode the short bus and stayed in the far corner of campus all day (i.e., my interpretation of *those* students was based on the cues from my teacher). As a child, I learned social markers (i.e., the short bus and isolated classrooms and playground) and imposed a disabled identity on *those* students and a nondisabled identity to those who did not ride the short bus and played on the main part of campus. Although, during my time on my elementary school campus, I never had the opportunity to play with *those* students, I unconsciously constructed a normal/disabled binary based on the response of my teacher.

Today, I understand the interpretations of *those* students were influenced by characteristics and stereotypes assigned to the specific stigmatized group. However, by hearing the voice of the person with the disability minimizes the stereotypes. Moving beyond the study of people with disabilities and valuing the lived experiences and the telling of stories is a valuable aspect of the interpretive paradigm (Ferguson et al., 1992). In addition to qualitative measures, there are quantitative measures developed to assess stigma. Specific to higher education, the *Postsecondary Student Survey of Disability-Related Stigma (PSSDS)* supports the post-ADA efforts to reduce disability stigma in higher education (Trammell, 2009). Trammell (2009) focused on the development of a Likert-type survey in preparation for testing and wider use. Students from a variety of institutions completed the survey. Results indicated that disability stigma was quantifiably evident.

Identity and Passing

Negotiating the dual roles of disabled and nondisabled force a convergence of the concepts of *identity* and *passing*. The introduction of a social marker, in conjunction with this negotiation, can be instrumental in defining positionality.

Identity

According to Darling (2013), identity is closely related to self-concept. In an attempt to make the concepts of society and self-researchable, Stryker and Burke's (2000) work in identity theory began. The common discourse of *identity* is made difficult by the ever-present use of the term in the behavioral and social sciences (Burke, Owens, Serpe, & Thoits, 2003).

Erikson (1968) used the term to signify a subjective personal sense of sameness, sense of being or belonging. According to Erikson, an identity crisis will occur when this sense is threatened. It is during the late adolescent years that Erikson described as being a time of identity and identity diffusion. Identity development is based on the influence of how the conflict is resolved. This conflict is resolved when one emerges from each developmental stage (Erikson, 1964). The development of the ego (i.e., the part of the personality that brings order out of our experiences [Torres, Howard-Hamilton, & Cooper, 2003]) is central to Erikson's theory.

Although the work by Torres et al. (2003) described the identity development of diverse populations, students with disabilities were not included in this diversity classification. The authors defined diversity as being a broad definition that includes race, ethnicity and multiple identities encompassing gender and sexual orientation. The exclusion of disability as diversity is consistent with the work of Davis (1995) along with

Connor and Gabel (2010) who state that disability is often not among the groups (i.e., race, gender, ethnicity, sexual orientation, social class, etc.) considered as diverse.

For the purpose of this study, the term *identity* will parallel Stryker (1980) which viewed identity from a social and individual perspective. From an individual perspective, identity is “contained in the meaning of the self—what it means to be who one is” (Burke et al., 2003, p. 1). Here, how one internalizes the meaning of who they are is in consideration. This meaning is learned from cultural knowledge and from a person’s own experiences. Being part of a group, either stigmatized or not, also provides a framework for the establishment of one’s meaning of self.

According to Safilio-Rothschild (1970), people with disabilities in U.S. society share characteristics that are common among other minority groups; first, how they are encouraged to interact with *their own kind* and relegated to a separate place in society; second, the separate place or segregation in society rationalized as being *better for them*; third, the majority considers people with disabilities as *inferior*; fourth, as with members of a minority group, people with disabilities are evaluated on their *membership to a particular category* rather than on their individual characteristics. The negative connotations of these similarities may result in people with non-observable disabilities deciding to *pass* as nondisabled (Safilio-Rothschild, 1970).

Passing

Individuals with disabilities must determine how they will “engage in the active manipulation of their identity” (Carey, 2013, p.142), i.e., (a) should one try to pass as not having a disability; (b) should they resist passing through the development of disability

pride; or (c) should one deconstruct and disregard the binaries? Whatever the decision, people with disabilities are faced with decisions that may be challenging for some.

When it comes to disability and non-disability identification, the topic of disability passing reveals the dynamic nature of disability and identity (Brune & Wilson, 2013). In order to understand disability and identity in modern America, an examination of the issue of *passing* is necessary (Brune & Wilson, 2013). According to Barreto, Ellemers, and Banal (2006), *passing* is an identity management strategy for members of devalued groups who anticipate discrimination resulting from their membership. Devalued groups include but are not limited to people with disabilities, individuals experiencing poverty, members of the lesbian, gay, bisexual, and transgender (LGBT) community, people from a minority ethnic background, and people experiencing homelessness (Goffman, 1963; Sedgwick, 1990).

For some, the belief that limitations of freedom and opportunities accompany the disability label was a motivating factor in the decision to pass (Brune & Wilson, 2013). These beliefs have influenced our society, including expecting parents. In fact, the idea of having membership in a devalued group has drawn attention to how some parents are influenced to use “enhancement or reproductive technologies to avoid disability or to make better children” (Harris, 2007, p. 86). It is through this process that parents believe they can prevent their child from being in a stigmatized and devalued group.

The strategy by which a person selects to manage their identity may occur through *passing* or *covering* (Darling, 2013). While passing, *covering* attempts to minimize the *obtrusiveness of physical attributes*, involve the concealment of attributes that are potentially stigmatizing. Although nonprofessionals with disabilities pass on a frequent

basis, the carefully constructed public image of former President Franklin D. Roosevelt (FDR) as a cured polio survivor provides a worthy example of covering and passing to appease American society (Brune & Wilson, 2013).

In his goal to convince other politicians and potential voters that he was no longer disabled, FDR appeared to stand and walk. During his presidency, FDR took great efforts to learn to walk without crutches. The crutches were social markers that evoked “fear, revulsion, and pity” (Brune & Wilson, 2013, p. 15). He covered his difficulties in walking by holding firmly onto the arms of family members and Secret Service Aides and when standing, holding firmly on or leaning against a podium that had been bolted to the floor.

One implication of FDR’s passing was his portrayal of being a *cured crippled* that set the standard that all other polio survivors could be cured as well. The images of FDR standing, walking, or sitting in an ordinary chair conveyed a *normal* status that was free of social markers such as leg braces, crutches and wheelchairs. The nondisabled society of that era considered FDR as the ideal *super cripp* whom children and adults with polio were expected to emulate (Brune & Wilson, 2013). Numerous polio survivors later developed post-polio syndrome. This syndrome was the result of forcing oneself to stand and walk. Such strenuous acts took a physical toll on the bodies of those with polio. Brune and Wilson (2013) reported significant implications of passing are the physical and psychological pains that accompanied post-polio syndrome.

During the act of passing, a nondisabled identity was acquired and the observable reality of post-polio syndrome placed them in a position in which they could no longer deceive others as well as themselves. There came a point at which the physical strain and

the toll taken on the already weakened muscles could no longer be covered. In a world of *normal*, passing in one's own thinking is a crucial step in passing (Brune & Wilson, 2013). Those who passed and later developed post-polio syndrome, at the same time accepted the "normal" standard, which ultimately had detrimental effects.

Brune and Wilson (2013) provided another definition of passing. Here, disability passing referred to a "management of one's identity and the way people conceal social markers of impairment to avoid the stigma of disability and pass as *normal* and may include the exaggeration of a condition to obtain some type of benefit or care" (p. 1). Disabled and nondisabled identities are developed in connection with social markers that are socially constructed and imposed on people (Brune & Wilson, 2013; Davis, 1995).

My Positionality

The *white cane* social marker is one with which I have chosen not be affiliated. During my adolescent years, I received mobility and orientation training for my expected and continual vision loss. During my training, I wore dark glasses and held a white cane. It was during my first training session that I became aware of the stares and gazes from people as my Mobility & Orientation teacher and I walked down the street. I recall the feelings of inadequacy and being a spectacle as I heard one person say, "She looks so normal." At that moment, I decided that I would take an active role in how others perceived me (i.e., my way of managing my identity). I realized the white cane was the instrument of how others viewed me. I decided I would forego the use of the white cane to aid my mobility.

I prefer the totality of my identity by the nondisabled world be connected to my personality, intelligence, and sense of humor, rather than tied to my visual impairment.

Although when I was an adolescent I was not aware of “social construction” and “passing,” I did know something was not acceptable with the way others perceived me.

Although, I was not aware of supporting literature at the time of my decision to forego the use of the white cane, I now connect my decision to the realization that large portions of our society possess the idea that people with disabilities have the “inability to perform any adult social function and there are no other descriptors needed by the public” (Gliedman & Roth, 1980, as cited in Fine & Asch, 1988, p. 23). I am now conscious of the normal/disabled binary created by the white cane. As with the binaries of straight/gay, black/white, rich/poor, the binary of disability/nondisabled is part of an “ideology of containment” (Davis, 1995, p. 4).

The stigma of the white cane has inevitably influenced my identity. I conceal my disability in some settings and disclose in others. After thinking it through, I realize that I conceal when the nature of my disability will not have an impact on the setting or expectations. However, if the nature of my disability will hinder the expectations, I disclose my visual impairment. I acknowledge that when I conceal, I am in fact *passing* as a non-visually impaired person. I also acknowledge the traits of my particular disability are non-observable and I can decide in which settings I will conceal and disclose. However, that is not the case for people with observable social markers such as wheelchairs, some traits of autism, and physical conditions such as amputations (Lingsom, 2008).

The decision to conceal and pass as normal situates in a person’s knowledge of a disability and a conscious decision to conceal this information from others. As a result, the impaired self is silenced (Lingsom, 2008). Enveloped in the silence is impairment and

disability experience. Silencing the disability can be problematic because, along with expectations of being *normal*, there are “conventional expectations as to behavior and stamina” (Lingsom, 2008, p. 14). Due to physical, cognitive, or psychological limitations, the person attempting to pass may not be capable of meeting the expected or required standards in that particular setting. The psychological toll can also reinforce or fail to challenge the stigma of disability. For instance, college students who decide to conceal their non-observable disability potentially place themselves at a disadvantage because their concealment results in them not having access to potentially beneficial support services and accommodations available to them (May & Stone, 2010).

The issue of passing crosses the boundaries of a range of disabilities (Brune & Wilson, 2013). For example, passing for people with psychological disorders includes appearing sane and lacking psychological distress (Cox, 2013). Cox’s experience on public transportation resulted in the development of rules to appear sane. Of the six rules, one demonstrates the conscious efforts put into passing as sane. Cox (2013) stated,

Avoid eye movements that are too fast or too slow. Do not stare at a person, although staring at the ground or toward the middle distance is fine. Try not to show your agitation by looking repeatedly around the vehicle. If you are concerned about someone or something coming into the vehicle, look up from your book or focus point every ten seconds, fix your eye in the middle distance, and scan using your peripheral vision (p. 99).

Passing was not restricted to the concealment of a disability. Some enslaved blacks in the Antebellum American South displayed perceived characteristics of various disabilities to adopt an identity of being useless and thereby, not being placed among the working

slaves. Slaves, who used strategies to pass, utilized the plantations, jails, and auction blocks to display visible signs of disabilities. For example, Jacob D. Green pretended to be deaf when he fell out of a hayloft in which he was hiding after he ran away from his plantation (Boster, 2013). By not responding when the plantation owner asked what he was doing in the hayloft, the assumption was he was *deaf and dumb*.

Disclosure

Nearly all people with disabilities, particularly those with non-observable disabilities, are confronted at some time with the decision to disclose or conceal their impairment (Brune & Wilson, 2013; Lingsom, 2008). Such decisions are the reality for college students with non-observable disabilities. To disclose means to “reveal something previously secret or to reveal something previously covered. In contrast, conceal means to “prevent a person or thing from being found” (Encarta Dictionary, North American version, 2007). The act of individuals who decide to conceal a disability and/or pass as nondisabled are described in various ways.

The use of metaphors often describes the concepts of disclosure and concealment. In addition, metaphors often describe things not meant literally. For example, *being in the closet* does not mean that a person is literally in a physical closet. The *closet* metaphor, once mainly applied to the homosexual community (Sedgwick, 1990), is now being applied to other groups including people who decide to conceal a disability (Brown, 2006; Samuels, 2003). Brown (2006) used the *closet* metaphor to describe the action of entering into a preliminary closet to conceal or deny a particular identity or practice. Hence, *coming out of the closet* implied disclosure of the identity or practice. To remain *in the closet* is equivalent to the concealment of disability or a particular practice.

While literature suggests “the sharing of personal information with others through verbal communication is an integral part of social interaction” (Chaudoir & Fisher, 2010, p. 236), it affirms there is a “therapeutic value” of disclosure (Persson & Richards, 2008, p. 73); others outlined a disclosure process model (DPM) to address the question of when and why disclosure is beneficial (Chaudoir & Fisher, 2010).

While it appears disclosure is advantageous, this is not always the case. According to Fresko (2001), the decision to disclose is a *double-edged* sword. On one hand, disclosure can lead to increased stigmatization, stress, and the disruption of personal relationships. However, disclosure can also lead to increased emotional and social support including services offered through ODS.

The Disclosure Process Model (DPM) framework was instrumental when attempting to answer two questions: “When and why is interpersonal, verbal disclosure beneficial for individuals who live with concealable stigmatized identities?” (Chaudoir & Fisher, 2010, p. 250). The DPM suggests the most beneficial results for disclosing a concealable and stigmatized disability directly relates to the goals of disclosing. For example, when the goals are approach focused, obtaining positive outcomes are the goals. In contrast, when the goals are avoidance focused, the person is attempting to avoid negative outcomes and rejections.

Members of this group still need to decide what to do and/or how to handle circumstances when their disability is not recognized or is intentionally overlooked by others. According to Davis (1961), interactions with *normals* go through three stages: fictional acceptance, when the nondisabled person pretends not to notice the stigmatizing

feature; breaking through, when there is an emergence of a normalized projection of self; and when a normal, moral definition of self emerges.

Unfortunately, the autonomy among people with disabilities to decide whether to disclose is not equitable. According to Davidson and Henderson (2010), disclosure is irrelevant for those individuals assumed so obviously different and unlikely to pass as normal. Now, consider people with disabilities that are concealable, stigmatized, and not readily apparent to others (e.g., mental illness, HIV/ AIDS diagnosis, epilepsy). Upon disclosure of this information, these individuals run the risk of unfavorable outcomes, rejection, and discrimination (Chaudoir & Fisher, 2010).

Students with non-observable disabilities, who decide to disclose their stigmatized disability, chance ostracizing by faculty members and peers (Shapiro & Margolis, 1998). In addition, a study conducted by Vogel, Leyser, Wyland, and Brulle (1999) revealed various factors related to faculty members' willingness to provide accommodations depending on the request. Faculty members were more willing to provide copies of lecture notes compared to accommodations related to test taking (e.g., extended time or taking exams in sections). Students with non-observable disabilities indicated struggling over decisions to use in-class note-takers, and risk classmates noticing the accommodation (Marshak, Van Wieren, Ferrell, Swiss, & Dugan, 2010). Shapiro and Margolis (1988) noted common and inaccurate stereotypes held by teachers that students with learning disabilities were "dumb, lazy, spoiled, and hopeless" (p. 133). In addition, the review of the literature on attitudes toward students with learning disabilities revealed individuals hold overwhelming negative perceptions of students with learning disabilities (Shapiro & Margolis, 1988).

College students who conceal their disabilities constitute an unaccounted-for and underrepresented group in the student body. The first concern is that there may be negative implications to being a college student with a disability who conceals a disability and does not seek out potentially beneficial support and accommodations. There is research to support that students with disabilities who seek disability-related services/accommodations and received academic support have higher GPAs and graduation rates (Cawthon & Cole, 2010; Lightner, Kipps-Vaughn, Schulte, & Trice, 2012; Trammell & Hathaway, 2007; Troiano, Liefeld & Trachtenberg, 2010).

The second concern is two-fold and directly related to the reasons college students with disabilities do not request accommodations and ultimately how their decision influences the reported percentage and perceived outcomes of college students with disabilities. The *campus climate*⁶ toward students with disabilities warrants an examination. The fact that countless students with disabilities decide to forego requesting accommodations may be an indication that these students are aware of stigma or perceived stigma of being members of a devalued group and avoid the stigma assigned to that particular group. As a result, these students may attempt efforts to *pass* as nondisabled.

On the other hand, if the perceived outcomes imply college students with disabilities are less successful (i.e., have lower graduation rates and higher dropout rates) than their nondisabled peers, then the exclusion of those students who conceal their disability and graduate adversely impacts continued stereotypes of the intellectual capabilities of students with disabilities.

⁶ Campus climate is used to refer to the real or perceived attitudes and stereotypes (positive or negative) towards stigmatized groups, including students with disabilities.

Consider the following hypothetical example. In May 2013, ten universities in the state of Texas all had total graduation rates of 2,000 students, none of whom self-identified as having a disability. For the purposes of this example, assume that ten percent of each graduating class actually had hidden disabilities they concealed. As a result, 2,000 students with disabilities would have successfully completed a program of study at the postsecondary level. However, the correct percentage would have been unreported. Having an additional 2,000 students with disabilities excluded from the annually reported graduation rates would sustain the belief and support research that indicate students with disabilities are less successful than their nondisabled peers.

Moving beyond my example to an examination of the literature, Newman (2005) reported there was a gap between the college graduation and retention percentage of students with disabilities and their nondisabled peers. Furthermore, the attendance of students with disabilities was less than half of their nondisabled peers (i.e., 19% versus 40%). Although the literature reports a disparity between graduation rates (Blackorby & Wagner, 1996; Getzel, 2008; Horn, Berktoed & Bobbitt, 1999; Murray, Goldstein, Nourse, & Edgar, 2000), I argue these rates are inaccurate or at least misleading.

According to deFur, Getzel, and Trossi (1996), the presence of a disability decreases the likelihood of earning a college degree. Similarly, research by Murray et al. (2000) indicated students with disabilities were less likely than students without disabilities to graduate. For example, in 2009 the dropout rate for students with disabilities between the ages of sixteen and twenty-four was approximately twice that of their nondisabled peers, that is 7.8 % and 15.5 % (Chapman, Laird, Ifill, & KewalRamani, 2011; Raue & Lewis, 2011). The percentage of students with disabilities

who graduated from college dropped to 12 % in 2000. As with the previously stated data, I question if the drop in graduation rate is accurate. It is possible that students who once self-identified as having a disability decided to no longer self-identify with the ODS and continued their education. Again, an implication of concealment is the difficulty in obtaining accurate data on school outcomes. Access to accommodations and services is made available to students who disclose their disability to the ODS. Here, students may request disability-related accommodations and other potentially beneficial services.

When a student with a disability enrolls in an institution of higher education, he has sole responsibility to disclose his disability and request accommodations (Ankeny & Lehmann, 2010; Martin & Marshall, 1995; Pennell, 2001). Although the process to request accommodations may appear easy, one should realize that it is extremely difficult for many students with disabilities to do so. Unfortunately, issues shared by many students with disabilities are the frustrations and inconveniences associated with switching from being a recipient of services to a manager of individual accommodations offered by postsecondary institution (Quick, Lehmann, & Deniston, 2003). The contrast between the K-12 special education system and the provision of services at the postsecondary level may be part of the frustration.

The *Individuals with Disabilities Education Act* (IDEA, 1997), mandated the K-12 system take responsibility for the education and transition of students with disabilities. As a result of IDEA, beginning at age fourteen, students with an Individualized Education Program (IEP) must be invited to attend their IEP meetings at which the transition planning should focus on the students' needs, preferences, and values (McGuire, 2010). Attendance at IEP meetings should serve as a starting point in which

students with disabilities begin to learn valuable skills to facilitate their postsecondary transition (Hunter et al., 2014).

Regardless of the reason students do not request accommodations, an investigation of their decision is worthy of investigation. According to West, Kregel, Getzel, Zhu, Ispen, and Martin (1993), many students failed to disclose their disability because they believed faculty members and their peers might lower their expectations because they believe the students are incapable of completing college coursework. For this reason, it is important for faculty members, college staff and administrators to understand the potential inner turmoil some students with disabilities may experience when faced with the decision to disclose or conceal their hidden and stigmatized disability. Therefore, educators and school officials would be wise to consider the degree of personal information they would disclose to others upon communicating with a person with disabilities. For the majority of people, personal information is not disclosed or shared with others until a relationship is and boundaries regarding the amount of information shared are established. For a significant percentage of nondisabled people, the disclosure of personal information upon initial meeting would be difficult. Likewise, some students with disabilities may struggle with the ability to utilize their acquired knowledge of accommodations and services in an effective manner.

According to Barnard -Brak, Lecthenberger, and Lan (2010), the disclosure of personal information may be therapeutic for some students while challenging for others. For this reason, approximately 79% of institutions reported they had encouraged students to identify themselves as disabled through the distribution of material designed for that particular purpose (Raue & Lewis, 2011). When considering factors that influence the

disclosure behaviors of students with disabilities, Braithwaite (1991) identified the following four factors: their relationship with the able-bodied other; the relevance of appropriateness of disclosure dependent upon the context of the situation; the appropriateness of the able-bodied person's response; and the perceived appropriateness of disclosure, based upon their own personal feelings about their disability.

Research conducted by Norton (1997) described accommodations that benefit students with disabilities, such as extending the time to complete a task. Specifically, students indicated time and a half was adequate, whereas 12% indicated they needed more time to complete math exams and another 12% required more time to complete essays. Eighty-nine percent of the students reported needing a quiet environment during testing sessions. In addition, 16% of the students requested spell-check software.

Additionally, Norton proposed the following accommodations that would benefit students with learning disabilities: (a) enlarged print for math problems; (b) answers written directly on the test or on a blank sheet of paper as opposed to on an electronically scanned form; (c) test printed on blue paper; and (d) explanations of test questions and/or test directions. Furthermore, Norton's research (1997) documented the benefits of accommodations. Because of the use of accommodations during their second enrollment in a class previously failed, 68% of the students successfully completed the class.

As a focus of their research, Thurlow, Ysseldyke, and Silverstein (1995) specifically addressed testing the issue of accommodations and found the provision of accommodations was a practice that would facilitate learning by students with disabilities. Thurlow et al. (1995) identified various testing accommodations.

Accommodations include, but are not limited to, (a) presentation format, such as Braille,

large print, oral reading of direction, and signing of directions; (b) response format, including marking responses in test books, pointing to response and using computers for responding; (c) setting of test, such as being alone in test carrel, in a small group; and (d) timing of test, including extended time, breaks during testing, and extending testing session over several days. Similarly, Hunter et al. (2014) identified accommodations and services that may facilitate students' success in college. The accommodations include: "(a) continued eligibility for financial aid despite disability-related reduced course enrollment; (b) books on tape, (c) assistive listening devices, (d) registration assistance, (e) sign language interpreter, (f) mobility assistance, and (g) CCTV magnifier" (p. 192).

In addition, Hunter et al. (2014) advised students to utilize various resources when determining who will provide and pay for these supports and services. Once accepted into the college or university, the expectation is that the student takes responsibility to identify and request accommodations, supports and aides (Barnard-Brak, Lechtenberger, & Lan, 2010; Norton, 1997). Hence, awareness and the ability to effectively request available accommodations and services are instrumental in the academic success of students with disabilities (Barnard-Brak et al., 2010). However, such actions may be challenging for students who are accustomed to parents, teachers and school personnel taking the initiative.

Despite the variation of recommended services among college students with disabilities, researchers have indicated the following as critical to success in college: (a) testing accommodations, (b) priority registration, (c) counseling, and (d) self-advocacy training (Brinckerhoff, 1994; Greenbaum, Graham, & Scales, 1995; Vogel & Adelman, 1992). Furthermore, Kowalsky and Fresko (2002) found special support was needed by

students with disabilities to facilitate integration into college life. Similarly, Field, Sarver, and Shaw (2003) emphasized the importance for students to locate and use support services. As well, Troiano, et al. (2010) found students with disabilities who had used academic support centers more consistently, had higher GPAs than students with inconsistent use of support services. In 68% of cases studied, the degree of attendance was a predictor of higher graduation rates. Students with failing grade point averages typically attended less than 50% of their scheduled appointments.

In 2001, Mull, Sitlington, and Alper conducted a systematic analysis of research from 1985 to 2000 dealing with services provided at the postsecondary level. The researchers found 46% of the articles did not discuss program modifications, while 35% did allow for part time schedules. In addition, 23% of the articles mentioned the allowance of a longer time to complete the program. Furthermore, 19% of the articles recommended priority registration and perhaps most importantly, 65% of the articles recommended testing accommodations.

Despite the documented benefit to students with disabilities who access disability-related accommodations, a substantial percentage of students decide not to access such services. Research conducted by Wagner, Newman, Cameto, Garza, and Levine (2005) revealed a student with a disability was less likely to access support services if he was not familiar with the campus's disability support services.

Reasons for not accessing services vary. According to Wagner et al. (2005), some students believed their learning disability was *cured*, and did not feel they needed academic support services. Similarly, Norton (1997) indicated mixed comfort levels of students with learning disabilities to discuss disability-related issues, and to request

accommodations. Sixty percent of the students indicated they were comfortable, while 25% stated they were uncomfortable. In addition, 11% stated their disclosure depended on the class and perceptions of their professors.

Marshak et al. (2010) indicated many college students did not use college disability services and accommodations. In an effort to understand the reasons for such decisions, Marshak et al. (2010) interviewed sixteen college students with disabilities who chose to forego accommodations. Reasons provided by these students included a desire to redefine their personal identity, to avoid social stigma and negative peer and faculty reactions, difficulty in explaining their disability-related needs, and being disappointed with the utility of accommodations received.

As a culmination of the literature on disability related stigma, the concept of passing, and the decision to conceal or disclose a hidden disability, my research focus is to understand the meanings and interpretations college students who do not request accommodations assign to their lived experiences. Therefore, my research question is “What meanings and interpretations do college students who don’t request accommodations assign to their lived experiences?” In addition, I seek to understand the strategies and/or techniques used by college students to negotiate their identity and environment in higher education.

Chapter 3: Theoretical Framework and Methodology

This chapter will discuss: (a) paradigms, (b) the nature of qualitative research, (c) the methodology of phenomenology, (d) culturally responsive methodology, (e) lived experiences and hermeneutics, (f) recruitment of participants, (g) the data collection process, (h) the data analysis process, and (i) processes used to ensure trustworthiness.

Paradigms, also referred to as “methodological and philosophical persuasions” (Schwandt, 1994, p. 118) in human and social sciences, help researchers to “understand phenomena” (Creswell, 1998, p. 1). Blumer (1954) regarded these persuasions as concepts that provide suggestions on which direction to look and not a description of what to see. In addition, paradigms defined a “basic belief system or worldview that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways” (Guba & Lincoln, 1994, p. 105).

Interpretivism is the paradigm that guides this research study. Comprised of multiple layers, interpretivism draws ideas from hermeneutics, the phenomenology of Schultz (Thévenaz, 1962), the *Verstehen* (Weber, 1968) tradition, and critiques of positivism (Schwandt, 1994). Interpretivism argues against the idea that social science and natural science share the same aims and methods. The goal of natural science is to provide a scientific explanation, whereas grasping an understanding of the meaning of a social phenomenon is the goal of social science inquiry.

For the purpose of this study, the term *interpretivism* will denote qualitative research, while *objectivism* will refer to quantitative research. Sufficient literature exists to describe aspects of various paradigms, including interpretivism, which can yield equally credible data (Blumer, 1954; Burrell & Morgan, 1979; Creswell, 1994; Ferguson & Ferguson, 1995; Fisher & Stenner, 2011; Guba & Lincoln, 1994; Hesse-Biber &

Leavy, 2006; Holliday, 2007; Schwandt, 1994; Skrtic, 1995; Sleeter, 1995; Tomlinson, 1995).

Unlike the objectivist paradigm, the interpretive paradigm does not “presuppose the existence of an objective and lawful reality independent of the mind” (Paul, Kleinhammer-Tramill, & Fowler, 2009, p. 6). In direct contrast to the objectivist paradigm that is linear in its approach, the interpretivist paradigm employs an understanding that is holistic in nature (Bogdan & Biklen, 2007; Eisner, 1991; Ferguson & Ferguson, 1995; Merriam, 2009). Hence, according to Ferguson and Ferguson (1995, p. 112), the goal of interpretive research is to “describe, interpret, and understand.”

Key features of interpretive research include, expressive language, field focus, and attending to participants (Eisner, 1991), inductive methodology (Merriam, 2009), researcher as key instrument and process (Bogdan & Biklen, 2007), and the value of telling stories (Ferguson & Ferguson, 1995). To elaborate, stories are told to interpret one’s life, and it is through “*the telling*” of stories the speaker and the listener become implicit collaborators in giving meaning to the story being told (Ferguson & Ferguson, 1995, p. 105).

The Nature of Qualitative Research

Within the interpretivist paradigm, qualitative research is but one of several methodologies for gathering and analyzing information about the world (Ferguson & Ferguson, 1995). In qualitative research “meaning is socially constructed by individuals in interactions with their world” (Merriam & Associates, 2002, p. 3). Qualitative researchers assume that individuals have multiple constructions and interpretations of reality. Reality is created and socially constructed. Qualitative researchers set out to

examine how individuals construct knowledge, experience their world, and make meaning of those experiences. In contrast, the objective, quantitative researcher assumes there is a single, fixed and measurable phenomenon. In addition, the qualitative research method seeks to describe themes and interpret the meanings assigned to events, experiences and emotions. The product of the qualitative method is a *rich and thick* description of the experiences and interpretations of the research participants (Merriam & Associates, 2002).

I selected the *interpretive* perspective as my guiding paradigm.

Epistemologically, interpretive researchers believe that different meanings and analyses of social interactions derive because individuals have different interpretations and perspectives of the same experience or event. Bogdan and Biklen (2007) described participant perspective as one of the key features of qualitative research. Hence, in an interpretive qualitative study, as many perspectives as there are participants will be available for analysis.

Phenomenology

Phenomenology refers to the “philosophical, epistemological and methodological perspectives that attempt to explore and interpret the essence of the phenomena that structure our conscious experience” (Smith & Fowler, 2009, p.163). With this approach, there is no separation between subject and object. The “reality of an object is only perceived within the meaning of the experiences of an individual” (Creswell, 1998, p. 59). Neither the human subject nor the human world is the focus of phenomenology, rather the meaning of this interaction or lived experience is the focus. Describing this

essence from the perspective of those who experience it is the defining characteristic of phenomenological research (Merriam & Associates, 2002).

In a phenomenological study, people describe the meaning of their lived experience of a phenomenon; the *object* of human experience (Van Manen, 1990). A composite description of the essence of the phenomenon develops as the phenomenologist collects data from the people who experienced the phenomenon. Phenomenologists believe these experiences are interpreted in multiple ways and are committed to understanding the person's perspectives of their experiences.

The Weberian tradition emphasizes the interpretive understanding of human interaction. Within this tradition, the personal level of understanding and motives behind people's actions is what Max Weber (1968) calls *verstehen*, a desired goal of the phenomenologist (Taylor & Bogdan, 1998). It is through the interactions with others that phenomenologists believe multiple ways of interpreting experiences are available to people (Bogdan & Biklen, 2007).

It is not the goal of phenomenology to reduce the experience of a phenomenon to an abstract law; rather it is concerned with assigned meanings of lived experiences and how such experiences are transformed into consciousness. In order to achieve this goal, the researcher must go directly to the phenomena and explore the understanding of the individuals who have lived experiences related to the phenomena. On a daily basis, ordinary people have interactions in particular situations; it is the meaning of those events and interactions that phenomenologists attempt to understand (Bogdan & Biklen, 2007).

When used in the social sciences, the term phenomenology is concerned with the social actor's frame of reference (Taylor & Bogdan, 1998). The phenomenologist

assumes each participant will have an individual conscious experience; however, phenomenologists do not assume they know what these things mean to the people they are studying (Douglas, 1976). Smith and Fowler (2009) described the nature of conscious experience, intentionality of directed action, person in context, and situated human experience as the underlying principles specific to phenomenological inquiry.

It is through these insights that researchers have more opportunities to understand how participants experience their world. A brief discussion of consciousness is warranted since phenomenology is interested in the world of the human being. Revonsuo (2010) argued to “study consciousness is to study the fundamental nature of our personal existence” (p. xx). According to Van Manen (1990), “consciousness is the only access human beings have to the world” (p .9). In other words, just by being conscious, a relationship to the world is already established. The phenomenologist seeks to understand an experience which, at a given point, presents itself to the consciousness of their participant.

According to Van Manen (1990), the reflection is retrospective because the experience has already passed or has been lived through. In contrast to the idea of consciousness being solely retrospective, Revonsuo (2010) described a conscious being to have “internal psychological reality, a mental lie consisting of subjective experiences, with a stream of consciousness flowing within” (p. xx). This inner stream contains one’s subjective experiences, is present, and continuously reveals itself to us. Hence, consciousness is not restricted to retrospective thought. In this study, I define *consciousness* as a state of awareness that a person can experience, feel, sense, and assign meaning to their existence.

The purpose of this phenomenological study is to explore the meanings and interpretations college students who do not request accommodations assign to the strategies and/or techniques as they negotiate their identity and environment in higher education. Therefore, I seek to explore, understand, and interpret the lived experiences of participants meeting the stated criteria.

Scholars have stated that emotions, events, and experiences have meaning once an individual assigns meaning to it (Husserl, 1960; Merleau-Ponty, 1964; Van Manen, 1990). As college students who have decided not to request accommodations, engage in the rigors of higher education, student body and extracurricular activities, they may experience a wide range of emotions, thoughts, and interactions as they navigate higher education. Meaning is assigned to these experiences when the student reflects and interprets their own experiences. Although phenomenology is the guiding methodology of this study, I also employed essential principles from culturally responsive methodology (CRM) in my research because in order to access consciousness, one must develop relationships in culturally responsive ways (Berryman, SooHoo, & Nevin, 2013).

Culturally Responsive Methodology (CRM)

CRM is positioned with the traditions of critical theory and kaupapa Maori theory (Berryman et al. 2013). As with culturally responsive pedagogy, CRM values the cultural background and experience of individuals. In direct contrast to traditional Western research, CRM regards the participant's right to "initiate, contribute, critique, or evaluate research" (Berryman et al., p. 1). The inclusion of CRM in this phenomenological study is a logical step in that it challenges dehumanizing and devaluing paradigms in order to obtain culturally responsive research outcomes.

The scholarship of members belonging to *minoritized* groups, including indigenous, disabled, gay, and Latino, have informed CRM (Berryman et al., 2013). In CRM, a key component to human dignity and research is the establishment of respectful relationships with participants. A commonality among the mentioned minoritized groups is they have historically been subjected to a research tradition that has asserted its power to determine who is studied, who conducts the research and who defines the researched (Smith, 1988). Therefore, this study employs key principles of CRM and phenomenology to ensure rapport and relationships are established.

The philosophical roots of CRM are in *decolonizing methodology* (Smith, 1988). Decolonizing methodologies focuses on research practices on indigenous populations. The term *research* is linked to western European imperialism and colonialism and according to Smith (1988) is one of the *dirtiest* words in indigenous language. Accompanying this term, for indigenous groups, are thoughts and “bad memories” of being researched. Smith (1988) described twelve ways to be *researched* or colonized. They include, “having your genealogy and identity stolen, having cultural institutions and rituals patented by a non-indigenous or another indigenous person, and denial of global citizenship” (pp. 102). As a result of their experience with western European researchers, most indigenous people have a distrust of researchers (Smith, 2012). However, this distrust did not paralyze the indigenous people, rather it served to mobilize them to develop a field that was conceptualized and carried out by indigenous people working as researchers in indigenous communities (Smith, 2012). This assertion of the indigenous community is similar to the demonstrations of persons with disabilities during the disability rights movement (Bryan, 2006; Charlton, 1998; Linton, 1998; Longmore &

Umansky, 2001; Stroman, 2003). This movement was instrumental in generating social change for persons with disabilities who historically were excluded, isolated, and segregated from mainstream and as a result, this group claimed and exercised their right to access and be included in mainstream society (Longmore & Umansky, 2001).

In an effort to ensure cultural sensitivity, I sought to know my participants and their lived experience by allowing them an opportunity to share, to the extent they were comfortable, any aspect of their life, including but not limited to cultural, social and economic status and experience. I considered the participants of this study to be members of a group who are members of their own cultures (i.e., ethnic, religious, linguistic, geographic) but who have no discernable culture of disabilities. I acknowledge that these individuals have the potential to develop a culture of disability if given the opportunity to come together, share, and define themselves, as do other groups within the college community.

Examples of groups that have defined themselves and share a culture include, but are not limited to, student-organized clubs, such as M.E.C.H.A., Black Student Union (BSU), and Gay, Lesbian, Bisexual, and Tran-sexual (GLBT). As a result of their non-disclosure, research participants have not had the opportunity to build camaraderie, share and establish a cultural group. Therefore, I viewed my participants as a group that may struggle to *situate* themselves in terms of their identity (Asher, 2003).

The second CRM principle I employed was to consider how to bring relational and dialogical consciousness to the study. Specifically, I focused on open-mindedness, and how through reciprocity, this concept was conveyed. During all interviews, I used magnification and managed print material in my daily manner. During this study, I

managed the tensions of being an insider and an outsider as I focused on the participant and allowed my own experience to enter the conversation when it made sense and when it was helpful. However, four of the thirteen participants questioned or made mention of the nature of my visual impairment. Jacob stated, “While people may not notice you as having a disability, that is not the case for me, passing is not an option. There is no way for me to cover up my polio.” While I was interviewing Austin, he asked about my eyes because, according to him, I was “*looking cross-eyed*.” In contrast, the dialogue with Gwen and Amanda focused on the actual use and request of accommodations. I shared how I became aware of services and accommodations available to college students with disabilities and the factors that influenced my decision to disclose and request accommodations. I conveyed open-mindedness by realizing my reason for disclosing and using accommodations were specific to my individual perspective and experiences. As well, I expressed to the participants that disclosure decisions vary and are equally valid. I emphasized the intent of sharing my experience was not to influence their decision to request accommodations. Hence, I acknowledged that each participant had the right to make a conscious decision about what they consider best.

Although the remaining nine participants did not specifically mention or ask questions regarding my disability, we shared similarities among other aspects of our lived experiences. For example, Angela shared a heart-felt account of her experience in foster care: “Just when I would get comfortable with a counselor or therapist, my social worker would make a change and then I would have to meet and get to know another therapist. It is hard to open up and talk about all of your baggage to people you really don’t know.” Although I was never a foster child, I attempted to establish reciprocity through sharing

my experience as working with foster youth and foster parents for nine years. Through our dialogue, I affirmed that her emotions were similar to others and that the systemic problems plaguing the foster-care system are on the minds of Human and Social Services officials.

Regina was another participant who did not mention my disability; however, we had similar lived experiences. Regina's realization that she no longer considered herself as having a disability, led us to a conversation of how society socially constructs disability. Through this dialogue, I attempted to establish reciprocity as researcher and Regina (participant) listened to each other's experiences.

Philosophical Roots of Phenomenology

To avoid the risk of merely defining phenomenology, the historical account of its evolution and the relationship among various concepts is provided in this section. Today, many tools used in analysis in various areas of qualitative inquiry were shaped by Edmund Husserl (1859-1938) who is credited as being the originator of phenomenology, even though the term was previously used by Hegel (Farber, 1966). Writers such as Heidegger, Sartre, and Merleau-Ponty acknowledged Husserl as their philosophical influence and expanded on his views. However, it was Renè Descartes, whom Husserl credited as France's greatest thinker (Husserl, 1960; *Paris Lectures*, 1929) and who influenced his writings.

Husserl and other scholars proposed the need for an alternative to objective sciences for explaining the natural world (Husserl, 1970a). During Husserl's era, the discipline of psychology ruled supreme and conversations of *consciousness* were tied to psychology. Husserl's attempt to create a new direction for the analysis of consciousness

resulted in phenomenological analysis. Unlike the psychological analysis, the phenomenologist seeks the meaning assigned to experiences, interactions, events, and emotions of ordinary people in particular situations (Bogdan & Biklen, 2007). A saying commonly associated with Husserl is “back to the things themselves” which means that we must return to the original data or our consciousness (Kockelmans, 1994, p. x).

Phenomenology considers an individual’s conscious experiences as legitimate sources of knowledge and it assumes that each participant will have a specific experience with the phenomena.

Husserl’s search for the primary foundation of all knowledge further advanced as Heidegger addressed the need for a general theory of being (Thévenaz, 1962). Hence, ontologically, the foundation was apparent with Husserl but directly articulated by Heidegger (Thévenaz, 1962). As a result, Heidegger’s question became, “What is the meaning of being?” While the term *being* was evident prior to Heidegger, it had been indefinable (Thévenaz, 1962). Heidegger reasoned if difficulty resulted in attempting to answer this question, then the question was unclear. Primarily, Heidegger abandoned Husserl’s idea of consciousness and adopted a more ontological structure. An ontological assumption is what people believe and understand to be the case.

Next, the phenomenology of Sartre demonstrates the passage from phenomenology to existentialism as a continual progression from Husserl through Heidegger to Sartre (Thévenaz, 1962). Although Husserl did not state a position of existence in his writings, he ultimately “arrived at the consecration of the lived world” and the insertion of consciousness became more indestructible (Thévenaz, 1962, p. 67). As a result of Sartre ejecting everything from consciousness, the intentionality “all

consciousness is consciousness of something” carries a different sense than in the past (Thévenaz, 1962, p. 69). Lastly, the phenomenology of Merleau-Ponty, in its most basic ideology, is in contrast to Sartre. Merleau-Ponty argues that one’s existence is not reduced to the consciousness one has of existing (Thévenaz, 1962). Merleau-Ponty considered this no different than unconsciousness. Here, being present to the world equated to being present to oneself. Additionally, Merleau-Ponty defined *freedom* as the “negative aspect of our universal engagement in the world” (Thévenaz, 1962, p. 85). Although phenomenology informed my study, here I will discuss the critical elements of the *lived experience* and the role of hermeneutics.

Lived Experiences and Hermeneutics

Phenomenology begins and ends with lived experiences (Van Manen, 1990). In its most basic form, lived experiences involve a person’s immediate pre-reflective consciousness of life (Dilthey, 1985), it is experienced before one categorizes, conceptualizes, or reflects on it (Husserl, 1970b). Once experiences present themselves to one’s consciousness, they have the potential to become of interest to phenomenology. All we can “ever know must present itself to consciousness” (Van Manen, 1990, p. 9).

As an example of a lived experience, let’s consider the experience of a high school student with a disability as they complete the application for admission to college. With application in hand, or on the screen before them, the student contemplates how to answer the essay question asking them to describe any difficulties or challenges they have overcome. With this example, a phenomenologist would “transform the lived experience into a textual expression of its essence” (Van Manen, 1990, p. 36). This textual expression is achieved as the student reflects on and uses written or oral language

to assign meanings to the events, emotions, and experiences related to that particular phenomenon—answering the question. Specific to this study, six of the thirteen participants indicated they disclosed either a challenge or disability when they answered this question. In particular, Douglass stated,

Yes, I did share that I had Asperger's on my college application. I also talked about some of my accomplishments. But I wanted the college to know about my Asperger's because I was going to be living on campus and I had never shared a room with anyone. I am glad I disclosed that information because they made special arrangements for my roommate situation. Instead of having three other roommates, I only had one."

This phenomenological study questions the ways in which the participants experienced their world (e.g., higher education), and assigned meaning to those experiences. In addition, hermeneutics is the path the researcher travels to explore how we read, understand and handle text (Thiselton, 2009).

According to Gadamer (1976), "hermeneutics has its breaches in intersubjectivity. Its field of application is comprised of all those situations in which we encounter meanings that are not immediately understandable but require interpretive effort" (p. xii). When engaging in phenomenological research, the concept of hermeneutics and various levels of interpretations are of consideration (Gadamer, 1976; Van Manen, 1990). In this study, I used a recursive process in which my repeated layers of interpretations of interpretations assigned meaning. I continually checked and revisited my interpretations against the participant's interpretation, their interpretation against theory, and my interpretation against theory.

Participants

The total of thirteen participants consisted of three male and ten female college students. Age range for all participants was 18-44 with a mean age of 25 years. Fifty-three percent (n=7) of participants identified themselves as Caucasian, 15% (n=2) as BlackAfrican American, .08% (n=1 in each category) as Asian American, Korean American, and Hispanic from Central America, and .08 % (n=1) does not use racial categories to identify herself.

Of the thirteen participants, .08 % (n=1) was enrolled at a community college, 53% (n=7) were enrolled at the undergraduate level, and 38% (n=5) were enrolled at the graduate level (see Table 3.1). Participants provided various reasons for participation in this study. Austin shared the day I conducted snowball sampling in his class, “I was feeling like I could use an Adderall right now.” On the other hand, Lorraine considered her participation in this study as an opportunity to have a conversation and “tell my complicated life story.” Lastly, Douglass simply stated his reason to participate as being “glad to help out a fellow human being.”

Study participants comprised separate individuals who possibly shared similar experiences and interactions as they navigate higher education. I consider the university campus to be a community of different members, each having assigned roles. A community is a “social group of any size where members reside in a specific locality, share government, and often have a common cultural and historical heritage” (Dictionary.com). It was through the examination of these dynamics that a clear description of how students with learning challenges and disabilities negotiate the

environment, their identity, and factors related to their decision to request accommodations.

Table 3.1

<i>Description of Participants</i>					
Name	Sex / Age	College Level	Major	Disability/ Challenge	Race/ Ethnicity
Amanda	F / 29	Graduate	Education	Chronic Pain PTSD	“My preference is not to identify myself by race . . . If you ask me, I am just Amanda”
Angela	F / 19	Sophomore	Psychology	Attention Deficit Disorder	Hispanic from Central America
Austin	M / 21	Senior	Visual Arts (Film / Screen)	Attention Deficit Disorder	Caucasian
Bernice	F / 21	Senior	Psychology	Landau Kleffner Syndrome (Aphasia)	Caucasian
Candice	F / 22	4 th year Community College	Early Childhood Education	Dyslexia	African American
Douglass	M / 19	Sophomore	Liberal Arts with Pre-Med emphasis	Asperger’s	Caucasian
Gwen	F / 30	Graduate	Education	Severely Hearing Impaired	Korean American
Jacob	M/ 40	Graduate	Education	Physical Impairment	Black /African American/ Global citizen of the world
Lorraine	F / 20	Sophomore	Education (IES)	Attention Deficit Disorder & Eating Disorder	Caucasian
Pamela	F / 19	Freshman	Business Management / Marketing	None	Caucasian
Rachel	F / 24	Graduate / MA	Education	Learning Disability	Caucasian
Regina	F / 44	Graduate/ MAEd	Special Education	Learning Disability	Caucasian
Roberta	F / 18	Freshman	Education	Auditory Processing Deficit	Asian American

Recruitment of Participants

Participants were recruited from two private universities, with one being a non-Christian university (UA) and the other being a Christian university (UB). Both universities were located in the western region of the United States. Due to the unique characteristics of my participants and the small number of cases, Snowball Sampling was the purposeful sampling strategy used.

Each university utilized different strategies for the distribution of the invitation letter. With the permission of program administrators, UA permitted snowball sampling to occur in ten college courses taught by eight solicited professors. In each course, the purpose of the study was explained and the invitation letter was distributed to all students. During the sampling, extra copies of the invitation letter were available to all students with the encouragement to give the letter to friends, family members and anyone else who may meet the criteria to participate in this study. In contrast, UB administrator permitted five hundred letters to be placed in the on-campus mailboxes of students living in the dorms. No face-to-face interaction with students occurred during the recruitment of students from UB. Participants were recruited over a four-month period (October 2013 to January 2014). Potential participants initiated the communication, either by phone or email, to indicate their interest in volunteering as study participants.

Upon the receipt of initial communication, informing me of their interest, an agreed date and location for the first interview was determined. Interview dates, times and locations were determined as convenient for each participant.

Data Collection

Qualitative data was collected from participants who met the study criteria. Methods of data collection included field notes, researcher's reflective journal, and digital recordings of individual semi-structured interviews with thirteen participants, personal poems, narratives and documentation provided by the participants.

When obtaining informed consent, I ensured the participants were made aware of: (1) the fact they were participating in research, (2) the purpose of the research, (3) the procedures used during the research, (4) the risks and benefits of the research, (5) the voluntary nature of the research participation, (6) their right to stop the research at any time, (7) the procedures used to protect confidentiality, (8) their right to have all their questions answered at any time, (9) other information relevant to the participants, (10) what is required of them if they consent to participate, and (11) that refusal to participate or withdraw at any time would lead to no foreseeable consequences (American Sociological Association, 1999, p. 13).

Field Notes

My field notes were contained in a spiral bound notebook. I maintain field notes in order to have a repository of important and not-so-important data of my field research (Bailey, 2007). Having the notebook with me during all stages of the research was a practice I maintained. I was aware and observed how my field notes improved as I progressed through my research. Even when it seemed my field notes were vague, I trusted in the process and continued to write. Jotted notes posed no problems because they were elaborated into full sentences and the usefulness was not diminished.

Field note entries helped me decide particular aspects of the research to study. For example, while notes related to Angela's relationship with her boyfriend were considered, I chose to include comments related to abandonment and rejection in the analysis of data. As well, the writing of field notes enabled me to reflect on emotions that arose while some participants shared heart-wrenching accounts of their lived experiences. It was through such reflective notes that my reflective journal entries and field notes became a cohesive forum.

My field notes maintained the six types of materials outlined by Lofland (1971): (1) detailed description, (2) things previously forgotten, (3) analytic ideas and inferences, (4) personal feelings, (5) things to think about and do, and (6) reflective thoughts, including any unpredictable changes, ethical dilemmas, and adjustments in protocol. As well, a chronological log indicating time and location was maintained.

Interviews

As part of my data collection, I collected verbal data through semi-structured interviews because I wanted flexibility, while at the same time maintaining some structure within the parameters of each interview. A distinction between interviews and talk that occurs in everyday conversations is that questions asked by the researcher in an interview situation are to seek research-related information (Bailey, 2007).

A portable digital recording device was used to record semi-structured interviews. To ensure confidentiality, researcher assigned pseudonyms to all participants, with the exception of Douglass. Douglass shared the following reason for wanting this pseudonym,

I once gave my first name at a Starbucks and when they called, they said

‘Douglass.’ I thought that was so funny because that was not what I told them. So since then, I like to use Douglass as a pseudonym.

I stated the pseudonyms at the beginning of each recorded interview. Upon completion of each interview, digital recordings were saved to a password-protected computer. As a backup, interviews were downloaded and saved to a password-protected Dropbox located on line. Recordings from the portable digital recording device were deleted once downloaded and saved at two secure locations.

To accommodate the participants, the interview sessions were scheduled in advance and lasted between 60-90 minutes. In the event that participants needed more time to describe painful or emotional experiences, I embedded an additional hour on my schedule to ensure I or a participant would not feel pressured to leave the setting in preparation for the next participant. Locations for the interviews were mutually agreed upon to ensure the participants were comfortable and included lobby area of campus libraries, private study rooms in campus library, campus coffee shop, campus quad area, campus cafeteria patio area, and researcher’s home office.

As with good teaching, interviewers need to be aware of participants’ “energy level and nonverbal cues” (Seidman, 1998, p. 79). Since the interviews were conducted during the fall semester, I remained mindful that participants might experience stress due to class and workload. For example, when I contacted Austin for his second interview, he was extremely busy and on a tight timeline to complete a project related to his graduation requirements. Austin stated, “I am swamped right now. Can we talk at the end of the semester or over interterm?” As well, considering the point at which we were in the

semester and prior to each interview, I asked each participant how they were doing regarding their class load and course expectations. Although some participants were extremely busy, they looked forward to the scheduled interview. Bernice reported, “Yes, I am so busy, but I really was looking forward to our meeting.” As well, Lorraine, shared, “I felt like I needed to have this conversation with you. I have been so busy and this was something I looked forward to.”

To put my participants at ease, I provided an overview for the purpose of the study and went over the informed consent before starting the first interview. I was aware that participants might continue talking about research-related topics after the interview and the recording device stopped. This occurred after the first interview with Douglass. He discussed how he felt the pressure of getting all of his assignments done. Once Douglass left the interview setting, I took the required time and wrote notes of that dialogue before I left the premises.

I set out to follow Seidman’s (1998) Three Interview Series. This series, designed to conduct three interviews, each having one of the following focuses: focused life history, details of the experience, and reflection on the meaning of their experience. In addition, each interview had a set of general questions to guide the interview. The semi-structured nature of the interviews allowed the researcher the opportunity to ask follow-up or probing questions as needed. All participants addressed questions regarding *focused life history* and *detailed experience* during the first interview. Five of the participants (Austin, Candice, Gwen, Amanda, and Jacob) considered their participation as complete after the first interview. These participants were definite in their reasons for not requesting services. Although only one in-person interview was conducted, additional

contacts were made with them through email, text messages and phone calls to obtain additional information or clarification.

Data saturation varied between participants and was achieved by all participants.

Poems and Narratives

In addition to their interviews, Douglass and Regina offered their reflections in the form of poems and narratives. Regina shared three poems entitled, *Labeled*, *Education*, and *Continuous Variable*. As well, Regina shared a narrative entitled, *Visual Learning Frustration / E.G. On-line Digital Technology Course*. Here she openly explains the process by which she attempts to comprehend material presented in an on-line course.

Douglass, shared one poem entitled, *From the Dark*, and one narrative entitled, *Phoenix and Iron* in which he described his lived experiences in four eras ranging from a “miserable tormented youth with a heart full of hate, fear, and loathing” to now a “more mature adult with a complex, yet respectful relationship with his Creator.” Due to the clarity of the poems and narratives, minimal subjective interpretation was used in their analysis.

Data Analysis

In quantitative research, data analysis appears sequentially after data collection. However, in qualitative research, data analysis begins and continues during each stage of the research (Bailey, 2007). During the data analysis process, I focused my attention on analyzing the multiple sources of information collected. The data analysis process consisted of multiple systematic steps. Bailey (2007) described data analysis as, “the multipronged process of analysis requires that the researcher makes sense of the data:

break it down, study its components, investigate its importance, and interpret its meaning” (p. 125).

In contrast to quantitative data analysis, the analysis of qualitative data is of words (Bailey, 2007). Coding is the process I used to organize my data (the transcribed interviews, poems and narratives). To ensure effective management of data sources, digital recordings were saved onto a password-protected computer and on line. Flash drives, signed consent forms, and participant list with participants’ real names and pseudonyms were kept in locked file cabinet at the researcher’s residence.

During this phenomenological study, I continually returned to the essence of the experience to ensure the interpretation of the interpretations and meaning of the participants’ experience were accurately derived and reported. As a result of conducting phenomenological reduction, I acquired a greater understanding of the phenomena.

During the initial stages of data analysis, all aspects of data had equal value. It was through the process of horizontalization that I laid out all the data and treated them as having equal weight. This resulted in the identification of what I considered *general* and *specific* codes. General codes were codes that appeared for all participants. For example, the *family dynamics* referred to verbal data related to parental involvement, birth order, relationship with parents etc., while *current educational experience* referred to verbal text related specifically to their current experiences as a college student, including but not limited to schoolwork, social life, and relationships with professors.

In contrast, specific codes related to codes not relevant to all participants. Examples of specific codes included *awareness*, to indicate the point at which this participant became aware that his education was for him. *Busy work* was another code

specific to a participant who described his view of general education assignments. After coding the transcribed interviews from all participants, twenty general codes were developed. Further into my analysis, I clustered data into *families of interconnected codes*.

At the second level of analysis, I combined related general codes from all participants and used visuals to represent the relationship/connection between codes. This process resulted in six *families of interconnected codes*: (1) bullied, (2) advocacy, (3) definition of self, (4) participants perceived role of the family, (5) the journey to college, and (6) the college experience. First, the bullied family combined the *relationship* and *family dynamic* codes. *Advocacy*, the second family, analyzed the role of advocacy by combining *advocacy* and *realization* codes. Further analysis resulted in *identity* (a new code), to be formed. Several participants reported a sense of relief when identified or labeled. The acquired knowledge of their strengths and limitations provided a platform on which to self-advocate. The third family, *Definition of self*, allowed for further analysis of the new *identity* code. This family revealed the processes by which participants came to know strategies to achieve academic success and a realization that they are satisfied with who they are. Next, the *Participants' Perceived Role of the Family* combined and analyzed *educational history* and *family dynamics*. This analysis revealed four types of family relationships: supportive families, strained families, uninvolved parents, and families void of structure. The fifth family, *Journey to College*, joined *campus size* and *college admission*. Further analysis of these codes resulted in four paths related to the journey: reason for college, campus size, class size and transition paths. Lastly, the *College Experience* family analyzed *current educational experience*, *supportive*

professors, and *services*. An examination of these codes resulted in further analysis of *academic performance* and *accommodations and services*. To follow is a more detailed description of the *Bullied* family of interconnected codes.

Three participants (Douglass, Bernice, and Lorraine) described being bullied during their K-12 education. Although Lorraine shared being bullied by a family member, she stated, “In my home state, sarcasm was a way of life. So at a young age, I wasn’t able to tell the difference between sarcasm and bullying.” On the other hand, Bernice and Douglass described specific accounts of being bullied by peers, with both describing their peer relationships as “I did not have a lot of friends” and “I realized that I did not have great friends.” Douglass described the account when he “attacked” a student who had bullied him for years. In contrast, Bernice did not retaliate against her peers. A solemn expression graced Bernice’s face as she recalled:

Kids would make fun of me. . . . I drooled a lot as the result of the seizures and kids in public would make fun of me because of that...in eighth grade I was bullied by my best friend who turned her back on me. I was bullied the entire summer between middle and high school. She would call me on the phone and always tell me that she was going to kick my butt when she saw me.

Additionally, Douglass and Bernice described the dynamics of their family as strong and supportive. Douglass described his family as “a great support system.” As well, Bernice described her parents as being “big supporters” of her. Another similarity between Douglass and Bernice is that they both attend a Christian university. The resulting implications are: (1) the K-12 system must ensure a safe and inclusive environment

accepting of difference, and (2) the experience of having a disability and bullying in K-12 may create a hesitation to disclose or request accommodations in higher education.

I continued my analysis by looking across the six families of interconnected codes; an emergence of tensions from opposing views resulted. I further examined the data from opposing perspectives and constructed a synthesis of textual and structural descriptions of the phenomena of study. This synthesis resulted in the development of the metaphor, *Stuck Between a Rock and a Hard Place*, with three focus areas: (1) negotiating environment, (2) negotiating disabled identity and (3) negotiating nondisabled identity (Low, 1996).

Ethical Consideration

During my entire study, I was mindful of the manner in which I communicated with each participant by being attentive to the narrative. I allowed each participant to express their feelings and describe their experiences of being a college student who has not requested accommodations. Due to the fact that some aspects of the lived experience were traumatic, I was mindful of and sensitive to the participants' well-being including physical or psychological state during the entire interview.

Trustworthiness

The overarching evaluative standard for field research is trustworthiness (Guba & Lincoln, 1994). As a researcher, I want the reader to know this study is worth their attention. Therefore, in my attempt to ensure trustworthiness, I used recursive analysis as I conducted, analyzed, interpreted, and presented data. Through recursive analysis, I believe the reader is likely to trust the results. As well, to ensure the reader can

determine how I came to my conclusion, I took efforts to explain the recursive processes and procedures used to analyze the data and to draw my conclusions.

To convey believability and accuracy, I ensured the reader that “recounting the research context and the relations the researcher had with the people in that context” was completed (Ferguson & Ferguson, 2000, p. 183). Given that relationships occur between researchers and participants, it was an important factor for the researcher to know the participant well enough (i.e., having built respect and rapport through reciprocity) to believe they will say what they really want, feel and believe to be true (Berryman et. al., 2013; Ferguson & Ferguson, 2000). I demonstrated how knowledge and meaning was constructed as a result of this interaction. My description of how I came to know the participants promotes trustworthiness.

Chapter 4: Who Occupies the Space Between a Rock and a Hard Place?

The metaphor, *Stuck Between a Rock and a Hard Place*, seemed best to express the participants' lived experiences. Here, the tensions are illustrated within a continuum ranging from *incompatible options* (the rock) and *competing perspectives* (the hard place) (Ferguson, personal communication), while the space in between represents the tensions characterized by their lived experiences. Specifically, participants described non-static tensions as they negotiated their disabled and nondisabled identity and environment as documented by research. For example, Prowse (2009) interviewed college students who declared themselves as disabled when in fact they reluctantly submitted to the institution's labeling system. Samuels (2003) described the tension of being able to pass as nondisabled and his internal turmoil as he considers this ability as a privilege. As well, I continue to experience the non-static tension.

Every five years, I am required to submit an eligibility application for para-transit.⁷ During the second semester of my doctoral studies, an application for renewal was submitted, followed by a required in-person eligibility assessment. The eligibility specialist determined that I was "not disabled enough." Although I use fixed route buses, para-transit is a major part of my transportation and independence. I experience anxiety every time I receive mail from the local transportation authority.

The college students in this study find themselves stuck between a rock and hard place as they make their journey through higher education. Of course, different students find themselves stuck in different ways and for different reasons.

⁷ Para-transit provides public transportation for people with disabilities. The frequency of usage is determined by a professional, using standardized and objective (observation) instruments. Usually associated with local transit authority.

The thirteen participants candidly shared their educational history, family dynamics, descriptions of their learning limitations, and college experiences. In this chapter, I introduce each participant by describing seven spaces between a rock and the hard place that characterize study participants' experiences. Some study participants find themselves occupying more than one space but I will begin their introduction with the most dominate one.

These spaces include:

1. Which identity will I wear?: Reaping the benefits of a disabled identity
2. No Documentation + No Cash = No Accommodations
3. Thanks mom and dad: Not bothered by what others think of me
4. Will the real me please stand up: Knowing myself without medication
5. Trusting others & accepting advice
6. I'm OK in a Not OK system
7. Maybe next time: Making choices I can live with

To follow, participants' individual voices will illustrate tensions between incompatible options and competing perspectives (Ferguson, personal communication) as they describe their lived experiences.

Which identity will I wear? Reaping the benefits of a disabled identity

Some college students may need services and/or accommodations in order to be successful. Although services provided to students with disabilities vary across universities (Hunter et al., 2014), research shows that college students who avail themselves of services and accommodations offered through ODS perform better academically (Trammell & Hathaway, 2007; Troiano, Liefeld, & Trachtenberg, 2010).

Candice, the one participant occupying this space, acknowledges the benefit of receiving priority registration.

Candice, a 22-year old female majoring in Early Childhood Education (ECE) at a community college, clearly stated reasons she decided to enroll into community college:

I did not want to spend money or time to take the SAT or ACT in order to get into college. Community colleges were the only schools where you could go without having those scores. [Today, some universities are test optional.]⁸ My older sister took those test and went straight to a four-year university right after high school. My parents were supportive of me going to community college. They wanted me to be at a place where I could be successful.

As is often stated by the youngest or middle child in a family, Candice openly shared her experience of “being in the shadow” of her big sister.

Before I learned that I was an ‘artsy’ person, I used to compare myself to my older sister who was good academically. Although my parents never compared us, I felt like my best was never good enough. I tried my hardest, but my grades were never as good as hers.

The act of comparing herself to others extended to the classroom. Candice recalled feelings of inadequacy during primary grades when reading aloud:

I remember being in special education in the first grade. I was in speech. I was in speech for two years. I had problems pronouncing a lot of my sounds, so I had

⁸ Today, some 300 out of the roughly 3,000 colleges and universities make SAT and ACT test submission optional. He [Bill Hiss] found that there was virtually no difference in grades and graduation rates between test submitters and non-test submitters. Those who did not submit scores had cumulative grade rates just five one-hundredths of a GPA point lower than submitters, and graduation rates just six-tenths of one percent less. Hiss concludes if the non-test submitters had good grades in high school, they are almost certain to do fine in college. *Citation: NPR, February 18, 2014 Morning Edition.*

speech to help me. It took me a while to learn all of my phonics. I was nervous to read aloud.

When the teacher would have us do popcorn reading, I was so afraid that I would mispronounce words that I would count the number of students ahead of me and then figure out what part of the reading I would read aloud. While the kids in front of me were reading, I would practice the part I would read. So that meant that I was not hearing or learning what the other children were reading. I was only worried about being able to pronounce the words.

Candice recalled having to work on her phonics at home as well. Candice described her mother as very involved in her education. The following recollection brought a smile to her face:

My mother thought the speech [therapy] I was getting at school was not enough so she purchased the *Hooked on Phonics* program and worked with me at home. I had to wake up one-half hour earlier each day so she could review my phonics before she went to work. [Smiling] She made me a cup of hot cocoa each morning because I hated waking up early. The extra time working on my phonics paid off in the long run.

Candice described another time when her mother made a decision regarding her education and did what she felt was best:

When I was in the sixth grade, my mother pulled me out of school and home schooled me because she thought that I was not going to be ready for middle school if I stayed at the school I was at. She went to the Home School department

in our district and used their curriculum. I hated being home schooled but she did what she felt she had to do to get me ready for middle school.

Candice's experience in middle school proved to be a turning point in her perception of herself as a student. Candice shared the events leading to the knowledge that she was an *artsy* student:

In middle school, I learned that I was an arts person. I was the sports photographer for the yearbook and for the first time I felt and saw I was good at something. I started taking photos and loved it. My parents bought me a camera and I continued to learn more about photography. Being an artsy person only got better in high school.

Although Candice was doing well, her mother noticed how she often struggled with reading and reading comprehension.

My mother, who knows a lot about special education, told me that she was concerned about my reading. She took me to a place where I was tested for a learning disability. I remember that I had to go back a few times in order to complete the entire test. After all of the test, they told me that I had dyslexia. At the same time, I was told that I was good at number sequencing. The label of being dyslexic did not impact me. I just knew that I would have to do things a little different in order to learn. I did not have an IEP but I did have a 504 Plan. Even though the lady told me that I had a learning disability, I did not feel like I was disabled.

Receiving accommodations in high school was uneventful. Candice recalled never having a problem getting what she needed:

I just worked out my accommodations with my teachers. If I needed more time on a test or to complete an assignment, we worked it out. Starting in the tenth grade, I really didn't even need those accommodations because I was put into the Digital Arts program. This was a program where 'artsy' students could use the visual arts to complete history and language arts assignments. This was great. My grades picked up because using digital art was my strong point. I did good in this program. I was in this program until I graduated from high school.

Once in college, at the suggestion of her mother, Candice disclosed her dyslexia to the ODS and requested accommodations.

Once I got to college, I did get services here and there...I sign up and complete the paperwork with ODS so I can get priority registration. For the past two years, I haven't needed the services that I am approved for. Priority registration is really the only benefit.

Candice's identity as nondisabled continued during her college enrollment. She candidly shared the tension she experiences as she negotiates two identities.

I don't even feel like I am disabled. But in order for me to get priority registration I have to sign the paper and say I am disabled. Having priority registration allows me to know what classes and what professors I will have so I can contact them and get the information about assignments so I can get prepared by getting reading material earlier. Sometimes I can get the book on my Kindle and start reading way before the semester begins. . .it is like I have two identities. I have to use my identity as disabled in order to get priority registration, and the other identity is a student without a disability doing just fine in her classes.

Candice recalled receiving accommodations in her first year of college and believes they helped to learn valuable strategies:

I think I learned helpful strategies from the services offered by ODS and what my mother suggested. Through the services, I learned different ways to get to the lecture material. For example, I record my lectures and take very detailed notes. I don't like requesting a note-taker because basically, the professor asks for a volunteer in class and just anyone can raise their hand. The professor does not even know if that person can even take good notes. I prefer my own notes.

Candice is selective to whom she discloses.

No, I don't disclose. I feel like if I don't need accommodations, they don't need to know that information. I don't feel I need to share it with everybody. I share it on a need-to-know basis. Like I said earlier, I disclose to ODS because I need priority registration.

Candice manages the accommodations herself and is currently experiencing academic success without requesting accommodations from ODS.

I am satisfied with where I am academically. I feel like I am doing good in my classes and I have strategies that I am now using and they are working. I am an honor student in college. I am part of the Honor Society Kappa Phi Beta, a honor society for community college students.

Candice proudly spoke of her recent employment and future goals.

This past summer, I was hired as a full-time Preschool Teacher. I completed enough ECE units to qualify for this position. I really enjoy my job. I will

continue to earn ECE Permits and eventually earn a Bachelor's degree in Child Development and a Master's in Social Work.

Unlike Candice, Angela did not have a supportive mother as she completed her K-12 education.

No Documentation + No Cash = No Accommodations

This space has two occupants, Bernice and Angela I will only introduce Angela here. Bernice, unlike Angela, did not have an IEP in high school and effectively utilized self-advocacy skills to successfully complete high school. Students whom the university has deemed ineligible to receive accommodations due the lack of acceptable disability documentation occupy this space. One such occupant is Angela, a 20-year-old female Hispanic from Central America. At the time of this study, Angela was a sophomore majoring in psychology. It was because of adversities and a genuine level of compassion that prompted Angela to participate in this study.

If I can help someone by telling my story, I want to. . . I want to help people. I know what it feels like to struggle. I know what it feels like when no one cares...if I take the time to care about your education and to talk about how I suck at school and explain why, maybe someone who is struggling reads it or sees it, will understand to and in that way, I am helping them.

Of all the study participants, Angela was the only one who classified herself as a *foster youth*. From birth, Angela did not live with her birth mother, which resulted in her childhood and adolescent years being spent in the foster care system. Angela indicated that there are aspects of her life that “*suck*.”

It seems like while being in foster care I was always in some type of therapy. I have had therapy since I was little; it was a routine for me. It takes me a while for me to open up to a therapist and for them to really get to know my heart. There was one therapist that I had for three years. She was really good and by the time we got to trauma therapy, I was very comfortable with her. She knew a lot about me and I was ready to open up but the government or Child Services terminated services with her. . . . So I never really learned to develop relationships.

Throughout our conversations, Angela solemnly described herself as having

Bad test anxiety. . . . I grew up and had a lot of behavioral problems. . . . I am an introvert. . . . I have Attention-Deficit Disorder (ADD) and was on medication as a kid. . . . I have a learning disability and that really sucks.

Although Angela considered five years of being in one foster home as stable, she painfully described the overall, adverse, long-lasting impact of being in foster care.

Foster care really tore up my life. I am socially awkward because of foster care. I can hold conversations with people really good, but relationship building has been the hardest thing to deal with because people walk away from me.

While in foster care, Angela and her brothers were assessed for and identified as having ADD. The difficult recollections of having elementary school teachers who did not take the time to work with Angela, but rather kicked her out of class were heartfelt.

I have never been a good student. I had low grades and was put into ESL. . . . I was so worried about what was going on at home and in my life, I acted out in class and tried to get attention in other ways. . . . I felt rejected when the teachers kicked me out of class.

Angela demonstrated insight into the value of caring teachers through her reflections of her third grade teacher.

In the third grade, I had a great teacher who cared about me more than just a student. Her care and acceptance of me triggered a spark in me and I wanted to do better in school. I had no behavior problems during my third grade year. . . . If the teacher told me to sit down, I sat down. I think this was because this teacher really cared for me and my basic needs were being met.

According to Angela, adjusting to high school proved challenging until she found places into which she could fit.

High school was actually difficult for me to fit in. I just felt like there was no place for me until I joined the volleyball team. Because of volleyball, I had a motivation to get good grades.

Throughout her education, Angela felt she was judged for being a foster youth. However, through Associated Students Body (ASB), she found acceptance and solace in joining a club.

One of my teachers was the advisor for the Christian club. He invited me to attend one of their meetings. . . . When I walked into the club, not only did it help me give my life to the Lord, there was a good solid foundation where I did not feel judged or mistreated. Being a foster youth did not matter here. . . . I joined in my junior year, and I became the president of the club in my senior year.

Angela described one event as the most memorable event during her entire school years. Sharing this experience was accompanied with a smile that brightened her entire face.

When I was a junior in high school, I got a 100% on a test and my teacher posted it on the board. Never in my life had I seen my work on the board for other students to look at as an example. That really made me feel proud of myself.

Later in the interview, I asked if that fond memory helps her get through times that are academically challenging. Angela calmly said, “No, it only happened that one time and it probably won’t happen again.”

While Angela was adjusting to her junior year of high school, her home life was in transition. Angela’s social worker thought it would be good for her to live with her birth mother in Valentine City. However, Angela’s experience was different from what her social worker envisioned.

I thought being with my birth mom was going to grow me, but it was actually crippling me, hindering my walk. I did not want to be stuck at home. It was the first time I ever lived with my birth mother and did not like it. I figured the only way out was college. . . . I wasn’t even sure I wanted to go to college. Since I did not like living with my birth mother, I knew college was my way out.

Angela was candid in sharing the experiences of her personal and educational life. However, of the events she discussed, Angela described the manner in which she processes and makes meaning of these events in the following manner: “I just let it go. I don’t make meaning of it. I just suppress it.”

With the hopes of playing volleyball, Angela applied at several state universities and was not admitted to any due to a low GPA. Although being accepted at UB came as a shock, Angela shared her thoughts about being enrolled at a smaller university.

Even though I applied to state universities, I really don't hear good things about them. It's like you are just a body in a classroom. I just couldn't do that. I need for the professor to know that I am there. I need them to know that I exist. I need them to know that I do struggle and I need them to know my name.

Angela shared that while being on a smaller campus, the fear that she often experiences was not automatically eliminated.

Some people just don't think I can do it. Some people put me down. I would rather put myself down than anyone else because that way I don't feel like I am failing. Failing is one of my biggest fears.

Due to bureaucratic red tape, Angela's educational records remain tied up in the foster care system and the university will not provide services or accommodations without this documentation. Although ODS at the postsecondary level can utilize Summary of Performance (SOP) and other documentation requirements for high school students entering college (Shaw, 2012), the university at which Angela was enrolled does not assess students. Therefore, to obtain documentation, Angela would be required to pay for an outside assessment. Angela indicated that she does not have the financial resources to pay for such assessments. Therefore, she is a sophomore and not been assessed for a learning disability or ADD.

I don't get services here because I don't have copies of the paperwork I had as a foster youth. Without that they [the university] can't help me with what I struggle with. . . . Not getting accommodations made me want to begin to think about getting away from accommodations all together. But I really never realized how much I need them.

Without the provisions of accommodations from the campus, Angela is stuck between a rock and a hard place. She continues to struggle in her classes and is diligent in her efforts to seek assistance and successfully complete fall semester.

Every day I question why I am here. I don't get good grades. . . . Since I don't get accommodations, I utilize my professor's office hours. I also use tutoring for English and I attend study sessions offered by my professors and Research Assistants.

Through the despair, an articulation of hope was conveyed by Angela.

This semester is going to be different. I came into this semester with a strong head on my shoulders and I am going to do whatever it takes to get 'Bs' or 'Cs' in all of my classes. It has been a big struggle and I have had to change some of my study habits. Even though they won't accommodate me, my professors are gracious. They know me and they know that I struggle. . . . They don't accommodate me like they do the other students and in a way I am glad. I am happy because in a way, I want to feel like everyone else.

Angela described the professors in psychology (her major) as being gracious, caring and supportive.

My professors talk to me a lot. Sometimes before a test, my professors would tell me that I am worth it and that my grade is just a number. They encourage me by saying that I am far more capable of than what my grade is. Just having them tell me that sometimes really helps a lot.

During her second interview, Angela shared an experience with a psychology professor that meant a lot to her.

Usually I am down, super down. Today is a great day because I got prayer from one of my professors. This professor has been walking with me through my college journey and he has seen me struggle a lot. I got to cry a little today. I hardly ever cry.

Angela acknowledges accommodations would be beneficial to her academic performance, she admits not really wanting them.

I do think it would change significantly if I got some kind of help. But the other question would be would I want it? And the answer to that question is I would not want the help...I already accept that a 'C' may be my best. . . . I am capable of so much more in my mind. My teachers can see it, but I don't think I can ever average out of a 'C.'

It is my interpretation that Angela does not want to seek out formalized accommodations (i.e., requesting services from ODS). I shared the following hypothetical scenario with Angela: If a professor was willing to accommodate your test anxiety by allowing you to provide verbal responses to essay questions instead of written responses, would you accept that? Without hesitation, Angela replied, "Absolutely. That would probably solve all of my problems."

Angela described the following realizations:

Looking back, I personally don't think I had ADD, I just needed attention. . . . I am done using my baggage as an excuse. . . . I realize that I cannot be like everyone else. . . . When it comes to school, I have performance anxiety. . . . I already do accept that a 'C' may be my best. I know that I am capable of much

more in my mind, my teachers can see it, but I don't think I will ever average out of a C.'

Angela was hopeful when sharing her expectations for the future: "In five years I want to have my Ph.D. and having a good job working with foster youth. I want to give back and have really good relationships during this time."

Despite the challenges of her early years, Angela cheerfully expressed a sense of pride. With a huge smile, Angela described how she proved the foster care system wrong.

I had something in me. I graduated from high school and proved the system wrong. The system that says foster youth don't graduate from high school. Even being in college proved the system wrong. To me that is the biggest accomplishment in my life this far.

Through a follow-up communication via email, Angela informed me of how her fall semester ended and described her current semester:

My fall semester ended the only way it could end. I got 'Cs' in most of my classes. I am just glad I passed. I did get one 'B' which I am super happy about. I am satisfied to an extent of what I can be. This semester is a bit hard because I am not doing any of my major classes and haven't worked with these teachers before.

Some don't really have any grace and expect you to get it like everyone else.

In contrast to Angela, Bernice and Douglass considered supportive families as factors leading to their sense of self and academic achievement.

Thanks Mom and Dad: Not Bothered by What Others Think of Me

Occupying this space are Bernice and Douglass. Their introductions illustrate the role of supportive families as they went through challenging experiences and came out as

achievers with a sense of self. Bernice is a 21-year old female in her senior year, majoring in psychology, while Douglass is a 19-year-old male in his sophomore year majoring in Liberal Arts with a Pre-Med concentration.

Douglass and Bernice are both the youngest of three children and credit their families as being major supports in the midst of less-than-ideal prognosis.

Bernice proudly stated:

My parents are big supports of me. My mom really understands. To my mom, I am fascinating. She is a speech therapist and can understand what I went through. My dad is really good with it. . . . My parents thought I was going to die. They never thought I would go to college, live on my own or get married. They thought that they were going to have to take care of me for the rest of their lives. Being the youngest, I naturally got more attention, but my parents did not make me feel like I was any different from anyone else. I appreciate them for that.

Similarly, Douglass described his family as a major support system throughout his education

my family was there for me. They always were and always would be. They are a good support system. . . . When I was diagnosed at age four, they told my mother that she needed to be prepared for the possibility that I might not ever graduate from high school and that broke her heart. . . . I proved them wrong, I had one of the highest STAR testing scores in the state and now I am in college.

Until the age of six, Bernice described herself as being an above-average student. However, due to a high fever during her childhood, Bernice lost all language and comprehension. Upon initial observation, school personnel thought Bernice was autistic.

With the expertise of Bernice's mother and other professionals, she was diagnosed with Landau Kleffner Syndrome,^{9]} a seizure disorder.

I lost all my language and comprehension for one to two years. I lost all language at once and then slowly began to regain it. So, I completed the first and second grade without language or comprehension. . . . Even though I had no language, my parents told me how important it was for me to communicate what I needed and wanted. From that, I learned that I had a voice. When I got to the third grade that is when I started regaining my language and comprehension. I forgot everything I had learned to that point. I had learning issues from the third grade to high school.

Unlike Bernice who received accommodations soon after her diagnosis, Douglass was diagnosed with Asperger's Syndrome¹⁰ at the age of four and did not receive any accommodations until high school. This vast difference was due to Bernice's parents being knowledgeable of accommodations, while Douglass's parents were uninformed until a major incident occurred in his eighth grade year.

Douglass's life journey is eloquently recorded in his narrative entitled *Phoenix and Iron*. He identifies four specific eras in which he describes himself. In his early years,

⁹ A childhood disorder characterized by the gradual or sudden loss of the ability to understand and use spoken language. All children with LKS have abnormal electrical brain waves that can be documented by an [electroencephalogram](#) (EEG), a recording of the electric activity of the brain. Approximately 80 percent of the children with LKS have one or more [epileptic seizures](#) that usually occur at night. *Citation:* http://www.medicinenet.com/landau-kleffner_syndrome/article.htm#what_is_landau-kleffner_syndrome

¹⁰ Asperger syndrome is an autism spectrum disorder (ASD) considered to be on the "high functioning" end of the spectrum. Affected children and adults have difficulty with social interactions and exhibit a restricted range of interests and/or repetitive behaviors. *Citation:* <http://www.autismspeaks.org/what-autism/asperger-syndrome>

he describes himself as “a miserable, tormented youth with a heart full of hate, fear, and loathing.”

Elementary school was spent being bullied. By the time I got to middle school, this life of torment had shaped me into a pitiful creature. I was nearly bullied to death. I thought no one loved me. I thought no one cared. I had no friends, why go out? I hated life and I hated myself. I wanted my life to end and in a way it did.

There was a vast difference between the elementary years of Douglass and Bernice.

While Douglass was bullied, Bernice was accepted by her classmates, but did not like the attention she received due to having a full time one-on-one aide. Bernice subsequently received undesired attention.

I had an aide with me during the day and I hated it because of the attention I got. Even though I could not communicate, I really wanted to be with my friends and I did not want the aide with me. . . . I never wanted to be that unique student who got the special attention. . . . I only had the IEP up until about the 7th grade. After my work was age appropriate, I went on a 504 Plan.

Bernice’s parents were instrumental in her valuing the importance of self-advocacy, which was demonstrated during high school.

I decided to talk to my teachers and tell them where I have been and tell them that I may need more help on certain things. I asked them if they would be able to assist me. I would seek out help even though I didn’t have an IEP. My advocacy was successful. I generally was allowed to take longer on tests or anything else. Early on in my life, I learned that regardless to what others think, I know what I need to do to be successful.”

When asked about the development of what seemed to be a natural ability to self-advocate, Bernice stated.

I think my self-efficacy came from both my parents and self-taught. My mom and dad taught me early on that it is important to communicate the best way possible . . . any way possible . . . or any way I can to let others know what I need and want.

For Douglass, the pressure of continued bullying came to a head in middle school

In middle school, there was continued harassment at the hands of those around me. Nearly everyone who talked to me would insult, harass, or annoy me. I would get picked on a lot and I did not deserve it. It was in middle school when things went extremely bad. I was bullied to the point of severe depression and I had suicidal thoughts during middle school. They had to remove the strings out of my sweatshirt because I tried to strangle myself.

Solemnly, Douglass described a horrible fight with the boy who continually bullied him “One day without mercy, I snapped and attacked him. It was horrible.”

As a result of Douglass attacking this boy, the police were called. After some discussion, the police wanted to know why Douglass was not receiving some type of special education. This question prompted the school to offer social skills training to Douglass.

After the fight, the police were called because the boy I attacked wanted to file a restraining order against me. That was when the school realized they had royally messed up by not informing my parents of the social skills training that was

available. My parents were furious at the time because this program had been available all along and no one ever offered it to us.

Once in high school, Douglass's experiences were completely different from those in elementary and middle school. Douglass described himself during this era as "a euphoric passionate adolescent with a heart overflowing with love." The difference in Douglass's description of himself was the result of him accepting Jesus Christ: "When I found Christ, it was like a complete change. Some people describe the change as being replaced by a different person. It was like I was reborn, like a Phoenix."¹¹

Douglass shared good memories of high school:

In high school I remember just hanging out and talking to people. Just nice memories. When I found Christ, I learned that I could forgive the people who hurt me. I forgave all of the people who hurt me and were mean to me. I realized not everyone hated me nor did everyone want to hurt me.

Douglas proudly proclaimed the benefits of receiving social skills training:

The social skills training is what has allowed me to go to college. I can now look students here in the eye and have conversations with them. (Smiling) Because of what I received when I was younger, I am able to look you in the eye right now.

Douglass and Bernice purposefully sought admittance into smaller universities. Douglass shared,

¹¹ A phoenix is a mythical bird that is a fire spirit with a colorful plumage and a tail of gold and scarlet (or purple, blue, and green according to some legends). It has a 500- to 1000-year life cycle, near the end of which it builds itself a nest of twigs that then ignites; both nest and bird burn fiercely and are reduced to ashes, from which a new, young phoenix or phoenix egg arises, reborn anew to live again. *Citation:* https://www.princeton.edu/~achaney/tmve/wiki100k/docs/Phoenix_%28mythology%29.html

I wanted to be a student on a small campus where the professors care about me.

At a state university, professors can have hundreds of students; here the professors know your name. I can go to anyone here and tell them that I am having a problem.”

In his college admission essay, Douglass disclosed that he had Asperger’s. Since he was going to live in the dorms and had never shared a room with anyone, he wanted campus administrators to be aware. To facilitate Douglass’s transition, he had only one roommate during his freshman year. Disclosing also had a negative consequence:

My first roommate also had a social disorder. I don’t think he had any social skills training. He really did not do anything to cope with it. And looking back, I think they did that more for his benefit rather than mine. I think they put him in there because they probably thought I would be more accepting of him.

Bernice shared similar reasons for selecting a small college:

This is a small campus and they are very understanding. I don’t know if the professors at larger universities are as gracious, nice, or understanding. A part of why I succeed is because my professors are so helpful. They go the extra mile and help me understand.

Entering college, Douglass arrived having accomplished much. For example, Douglass described how he earned Eagle Scout.¹²

Because I developed so drastically and quickly [in social skills training], I also started helping other kids like me. This actually helped me out with my Eagle Project. In Boy Scouts, you have to do a community service or leadership project.

¹² Eagle Scout is the highest advancement rank in Boy Scouting. Citation: <http://www.scouting.org/About/FactSheets/EagleScouts.aspx>

. . . I did one in which I created a teaching tool to help kids like me to recognize facial expressions...I got a Distinguished Consumer Awards from the Speech & Hearing Association for my progression. I said a couple of speeches and I went to a couple of conferences.

Bernice entered college equipped with a balanced sense of who she was. She credits her upbringing for this.

My parents did not treat me differently because of my seizures. I still had to do what was expected and required of me. I played sports, even though they were worried about me. They did not want me to feel different from anyone. They didn't do the pity thing, and they weren't mean either.

Currently, neither Douglass nor Bernice use accommodations. Similar to Angela, when Bernice requested accommodations, the ODS required documentation from her high school. Because Bernice did not have an IEP in high school, she did not have documentation deemed "appropriate" by the university. The 504 Plan was not considered. It was at that point Bernice decided not to get outside testing and begin her college journey without any formal accommodations. Bernice recalls:

From that point, I just decided that I would try harder. That meant that I would have to study that much harder. I actually feel more prideful...more proud of myself for sticking to my guns and not getting accommodations. I knew that I would work harder than everyone else.

Bernice's hard work paid off.

I needed to put more effort into my work than I thought I needed to. I surprise myself. This semester I have all As.' I have been working my butt off. This

semester, I took a lot of putting forth my best work. I am applying to graduate school and I hope this helps me get a good GPA. . . . I have spent a lot of time and my fiancé wonders when I will make time for him.

On the contrary, school has always come easy to Douglass.

I have always gotten good grades. . . . I can get 100% in each of my classes if I really try. I have gotten used to just coasting by. I never had to put much effort to get an A.' I know I could succeed at a top-notch medical school if I REALLY put forth the effort . . . I am not used to doing this because I am used to all of my classes being very easy.

Bernice gave the following as reason why she does not request accommodations:

Looking back I saw where I came from and I say 'WOW' I did all of that without accommodations . . . I got tutoring my freshman year. Other than that, the professors were supportive . . . Because I attend a private school, I already get enough help and attention . . . those services would take more of my time and won't be useful . . . It would hinder me to rely on other people to do the work for me . . . I believe that if I work hard enough at it, I will get it.

In addition to applying more effort to her schoolwork, Bernice credits supportive professors as part of the reason for her postsecondary academic success.

After I bombed a test, I asked my professor if there was a way he could meet with me to help me understand. For the rest of the semester, he met with me every Friday, reviewed my work and answered questions. It helped tremendously. It was like I had a private class session with my professor. . . I was raised to believe that you need to work hard to get what you want.

In addition to their current academic success, Bernice and Douglass have clear senses of identity. Given that Bernice's learning limitations are non-observable, she distinguishes between others who are shocked to learn all she went through and those that just don't have an understanding of her impairment.

A person's lack of understanding of the extent of my impairment does not affect me. If a person chooses not to believe I have an impairment, I respect their choice. I explain the history of my disorder to others, and how it still affects me to this day in school, work, and my daily life. When I give them my explanation and what I went through, people are usually really shocked to see how successful I am now. From my explanation, people can choose if they want to believe me or not.

Bernice took effort to ensure that I understood that she does not exert energy into trying to convince others that she has impairment; however, she takes pleasure in educating others who are interested in learning more about her impairment. The self-advocating nature of Bernice continued throughout her college years.

I told a Psych professor and I sent him some links describing what and how I learn. He was so excited to learn this information. He was so interested that I ended up sending him links to helpful websites that helped me. It is cool to have people to understand and interact with me on that level.

Bernice's future goals include becoming a school psychologist. At the time of this interview, she had applied to graduate school for fall 2014 admission. At the time this chapter was written, Bernice notified me via email stating, "I just got an email for an interview on March 17 at Coastal University."

It was not until Bernice was an adult that she expressed a sense of relief related to her academic challenges.

Seeing video clips of myself during the time I had no language and comprehension helped me to understand the degree of my seizure disorder and loss of language. It helped me to understand who I am. I understand why I struggle the way I struggle. For me, these experiences have made me who I am. I am grateful for my parents. I am grateful for supportive teachers. I am proud of myself. What I went through has become one of my strengths.

Although Douglass has not requested accommodations, he does not consider them a form of dependency. Douglass shared the following:

In my opinion, I consider accommodations as a support system. I realize that everyone, regardless to what they are doing needs a support system. I think the entire economy is a support system for a person. Some people may need more support than others. Either way, it is OK.

Douglass offered to share a poem he believed would help me to understand how he became the man he is today.

This poem was part of a series. The first one I ever wrote was before the fight and it was about being in the dark. The second poem was the same one but it was reworded because it was after the fight. The poem you have was written after my writing skills improved, From the Dark, I wrote that last year.

From the Dark

I hid my face
from the World that always harms

I turned my Heart into stone
No kind words from Anyone,
no compassion Anywhere

Fear Anger and Hurt
in a Void, alone
Even the Stars were black
and cold

So I let my Heart harden
This was all I had known,
Constant Suffering
In the Sin of my Hate

Then a Snap, a Break
A Storm of Ice,
Fire, and flood

Tears in my eyes and
Anger in my empty Heart
Why did this have to be my fate
betrayed by my own blood

Hours alone and afraid
nursing wounds like an animal Hurt
my tears Burned

A shimmer of Light,
Dawn
All is calm, peaceful, serene, right

Open eyes, and open arms
my Heart and Soul opened
toward the Sun

Lifted from Despair
by Angels of Sunshine and Gold

I learned to see
the Light that had always
been there

I had been too blind to see

The vast Love
that is my Family

Through my Despair

they had been there

for me

Hate can't break or bind me

The Chains that I made

no longer bind me

I am no longer Afraid to share

I am safe from the Dark

From the Hate and Cold

Saved by God

Saved by Grace

I live in the Light

God please guide me,

so I can help free,

help deliver others,

From the Dark

Douglass's personal philosophy summarizes his self-identity at the time of our interview.

Every raindrop raises the sea... I don't want to think my greatest contribution to society has already happened... I don't want to be that 40 year old man still talking about that one great thing I did in high school that helped people... It is one thing after the next... It's not a thing about overcoming challenges, but once

you have done something great, don't stop there. Don't ride that success forever.

Once you have done something great, celebrate it and then do another great thing.

Of the participants, Douglass was the only one to briefly mention the benefit of medication prescribed to help his attention. In contrast, Lorraine shared a different account.

Will the real Me please stand up: Knowing myself without medication

Occupying this space are Lorraine and Austin. Lorraine is a 20-year-old female sophomore majoring in Education and identified as having Attention-Deficit Hyperactivity Disorder (ADHD) and an eating disorder. Austin is a 21-year-old male senior majoring in Film/Screenwriting. Austin, never identified as having ADD or ADHD, describes himself as having all of the traits for ADD. Because Lorraine describes her life story as "*complicated*," her introduction is first.

Upon our initial introduction for our first interview, I observed that Lorraine was physically jittery. As Lorraine stood in front of me, she extended her slender hand that was shaking and clammy. She then quickly approached the seat, while nervously brushing her hair away from her face with her right hand; she loudly placed her items on the table and sat down. As I sat down across from Lorraine, I asked her if she was okay, and if she felt up to the interview. Lorraine replied,

I am on a two-week trial of medication. At first I felt like it was going to benefit me, but today, is a very different day. I feel the side effects. I just wanted to see if the medications really worked or not. I have heard the debates... It's like I don't sleep a lot and I have a lot more nervousness. This isn't normal. I generally have a lot of energy, but now I feel a lot of anxiety.

Lorraine has an older brother who, during the time Lorraine described as being in an “unstable household,” was in college. During her adolescence, Lorraine would compare herself to her brother.

He went out on his own and is now very successful. He is earning his Masters in Bio Chem from XYZ University. It is so extreme, I think that is why I have always compared myself to my brother. I would ask why I wasn’t as smart as him.

To give her a sense of self, Lorraine looked inward and proudly ascribed the following traits. Lorraine stated, “I would just say that I am more social, a social butterfly, I was more sociable and I liked to talk.”

Unfortunately, the traits that Lorraine indicated as being instrumental in identifying who she was as an individual became part of the reason she was initially put on medication.

Until I moved here, the way I was, was OK. All of these came up and now I am being medicated for those reasons. And I now think, is that a problem? Do I need to be medicated or is that just who I am? My treatment team thinks I have ADHD. They believe the eating disorder is related to having ADHD because of its impulsive nature.

Lorraine spent her early years in the northeastern portion of the United States (U.S.). In high school her family moved to the southwestern region of the U.S. Lorraine described the differences between the states.

I am from a small community of all Caucasians. We all did the same thing. ...And now I am thrown into this new school where there is such diversity and a great line between wealth and poor. It was very racially diverse.

Prior to her move, Lorraine described being treated for an eating disorder.

I believe it was around my freshman year when I was treated for an eating disorder that I have had for five years. The eating disorder was my coping mechanism through the instability of high school. Because I went to camp and did all these other things, I was always too busy to take the time to actually control it [the eating disorder]. Since I am just seeking out and getting help for the eating disorder, I am getting exposed to everything. All of my distress happened between eight grade and now. And it keeps on happening.

Lorraine's over-commitment to school organizations proved detrimental during her freshman year of college.

I was a mess, during my freshman year. I was very active in the Greek and sorority life on campus. I basically overcommitted. I made myself busy with all of these things. I realized that I didn't even have time to take care of myself. When I had to leave the sorority, I told one person about my eating disorder. To this day, I don't know if she told others because when I see them around campus, they just kind of smile...I am actually glad to be out of that life. . . . I think it is basically corrupt.

Lorraine was appreciative to have psychological services available to her. "I started going to the counseling because I said to myself that I really need help. I also liked it because I could do it without anyone knowing about it."

Lorraine used the psychological services on campus to receive counseling. Because she was over the age of 18, she could get the services without her parents'

knowledge. Lorraine lied to her parents about the reason she was getting counseling from the psychological services department.

When I talked with my parents, I would just tell them that I was seeing a counselor because I needed someone to talk to regarding my stressful school life. I would make excuses as to why I was there. I never told them the real reason and how I was struggling with the eating disorder.

As a result of working with a nutritionist, Lorraine had no other choice but to inform her parents of the truth about her eating disorder.

The nutritionist told me that I was to the point where I would have to eventually tell someone because she said I was an extreme case. She tried to work with me but it got to the point where I just needed to admit it. When I finally told my mother, she was very angry with me because I had lied for so long...I portrayed a really well-adjusted social butterfly.

At the time of our interview, Lorraine had been in treatment that summer.

This summer I had to go into treatment. I had to find a treatment center. My parents really didn't want me to go into treatment. They wanted to know if I had that big of a problem. They said if I just stopped doing some of the stressful activities and live with my mom... I would be OK. They said I needed to de-stress.

The nature of the eating disorder had an adverse impact on Lorraine's academic life.

I now have C+'s for the first time now. I feel awful. I feel dumb. I never had a C+, ever. I had straight As through my freshman year...a 4.0. And now I am on

medication that is supposed to be helping me. And I am asking, what is going on with my life.

The afternoon of our first interview, Lorraine had an appointment with her psychiatrist. When she returned for the second interview, she proudly described how she stood up to the psychiatrist and told him she did not like being on the medication.

I had a lot more motivation to stand up to him and tell him that I did not want to be on medication anymore...I realized that I really didn't know Lorraine without being medicated or without an eating disorder.

During our second interview, Lorraine described her plan for getting off medication altogether.

Right now, I am only staying on Prozac. Because I am going to England, I will talk about getting off of Prozac as soon as I get back. Since it is a new environment, I don't know how I am going to react. After talking with the psychiatrist, I felt like this was the first time I made the decision to get off the medication without hearing it from my mother...I wanted to know who the non-medicated Lorraine is.

Towards the end of the second interview, Lorraine stated,

[Smiling] I am realizing how much happier I am. Noticing that and being able to take a breath and saying 'this is who I am and I am OK with that.' I told the psychiatrist I don't want to think about the side effects and be careful about mixing this and that. I don't want that factor in my life anymore.

Approximately six weeks after Lorraine returned from England, I sent a follow-up email asking about her trip to England. I asked if she had completely stopped taking medications.

Europe went well. However, coping with my eating disorder was a lot more difficult being that far from home. I struggled a lot more being out of a routine and lack of exercise and sunshine. I had to keep reassuring myself that I had to expect these emotions and learn to cope once again. I got irritated and upset a lot easier. I felt the need to relapse and I was not happy to have to cope with my disorder once again. Overall, it did open my eyes that this disorder isn't just something I can sweep under the rug. And even today, feeling so close to recovery, I still deal with it on a daily basis. The medication was a mess over my trip. My doctor did not realize that I would run out of Prozac so quickly during the trip. I had to cut down the dose in order to make them last. I am sure this did not help with my desired relapse. I went three days without any medication and I had to reassure myself that everything will be okay. It wasn't a good time.

Lorraine's desire to get off of medication has been postponed.

I did want to get off of Prozac when returning from my trip, but we decided that I should just maintain at 40 mg of Prozac for a few more months. I am not really sure what would happen if I do eventually get off Prozac. Right now, I am just glad to be stable again. So I decided it was just fine sticking with the 40 mg.

In contrast to Lorraine, Austin was never identified as having ADD. Austin decided to participate in this study because, "On the day you came into our classroom and explained your research, I was feeling like I could use an Adderall. It was just one of those days."

However, he describes himself as having characteristics associated with ADD.

Now that I am in my career phase of being a film-maker, I need to sit down and focus more and that doesn't come easy to me because my mind is always racing so my progress ends up going a little slower. Sometimes, I am in class and things get hazy. When that happens, I would do anything to stimulate my attention and focus, but I wouldn't really be present. I am impulsive and I often speak before I think...I go from here to there and then from there to here. It is hard for me to sit down and do one thing. I have often thought that I might have some form of ADD.

Even though Austin decided against taking medication, he did make some changes recommended by his doctor. Austin shared, "So I talked to a doctor and we talked about changing my diet, exercising more and having a better schedule. This worked for a little bit but then I fell off of it again."

Austin described growing up in a home where there was no structure as being a contributor to why he is currently struggling with finding structure. "I was basically allowed to do whatever I wanted to. Now, I need structure in my life in order to get through this part of my education and it is a bit difficult."

Austin's K-12 experience was characterized by a lack of effort.

I really didn't care. I just went to school and got the grade. I did not put much effort into it at all. I basically flew below the radar. My teachers either really like me or barely knew me. . . . My grades were one A,' three 'Bs,' and one 'C.'

Austin expressed his belief that his film/screen colleagues share similar traits, which he considers an asset.

I work in the film school. I think there are many artists like me and they work with it. I think that is partially why I did not take the medicine. I know that it benefits me in some factors. I often see interviews of professionals in the field who say they have ADD or traits similar to ADD.

As a senior in college, Austin decided to see a specialist regarding the possibility of being prescribed medication for symptoms associated with ADD.

I was thinking about taking Adderall...I considered it but I was iffy because I feel like your natural state or individual limitation might propel you to achieve what you can accomplish. This year, I have been trying to develop better work habits... I have a hunger for something outside of my own thoughts.

Even though Austin consulted a specialist, requesting accommodations will never be an option for Austin.

I consider this my own kind of thing. I do fine enough. I never really had to struggle. . . . Only when I did not put my full effort into my work. I think my uniqueness benefits me in my field of study. That is why I won't take medication or request accommodations.

Aside from developing structure, Austin does not consider his academic performance to be an issue. He has come to accept that this is who he is and he is OK with it. However, he and his parents do not agree when it comes to grades.

It is not an issue for me. However, it is an issue for my parents or someone who is concerned about what types of grades I am getting. Grades are not going to affect my career. To my father, an 'A' means that you really focused and a 'C' means

you didn't do anything. I bet you I have retained more information as a 'C' student than an 'A' student who crammed.

Towards the end of the interview, Austin provided the following summary:

I acknowledge that my challenges are unique to me and I don't consider them to be a disability. It is something that I will have to deal with. And knowing that I may have it [ADD] makes it easier to deal with. I feel like I just need to keep going. My philosophy is that your limitations are probably things you should try to overcome and that will make you a stronger individual.

In five years, Austin declared, "I hope to be preparing to make my first movie."

Trusting Others and Accepting Advice

This space is occupied by Amanda, a 29-year old female graduate student; and Jacob, a 40-year old male graduate student, both majoring in Education. Amanda and Jacob have physical impairments and recently decided to request accommodations.

Jacob was born with polio and unequivocally shared,

I have never felt ashamed of being disabled. I have always lived with my impairment. I don't know any other way. I think my mother was a very religious person... She told me that I was going to be OK. As long as you have faith and believe in it. She did have high expectations...She sent me to school and I had to fight through it.

Jacob took time to describe the nature of polio and the extent of his impairment.

Polio was/is a dreadful disease. Maybe even worse than AIDS today. What we have with polio is that our muscles are affected in a big way. We have very little muscle to begin with and we have to be sensible enough to manage it because

over time, as you age and around 50 or 60 years you begin to deteriorate. It doesn't happen to everybody or as rapidly as it may happen in other. One of the problems with losing muscles is going down and up stairs. In my case, I don't have a lot of muscles in my legs, it means that my muscles in my shoulders are very good but I have learned that if I don't save them, I can lose them.

According to Jacob, his current condition is an improvement from past time in his life.

There was a time in my life when I was probably worse off. I used two braces and I had a corset. I have had to go through serious physical rehabilitation including surgeries to get me to this point that I am at now.

Attending school outside of the US, Jacob had to endure challenges.

Most of the people with polio stayed in a residential home where the children stayed and went to school. My mother decided not to send me there. Some places had elevators, but most of them were not working because we had daily blackout issues. The elevators did not work so I hardly ever used them...I think of the context of my country, they were only learning about polio.

Jacob earned his teaching credential and Master's in the US. Throughout those programs, he did not request accommodations.

At _____ University, where I got my teaching credential and Masters, I never requested any accommodations because most, if not all of their classrooms were held on the first floor level of in buildings that had elevators.”

According to Jacob,

I have never really officially requested service. I do know that on a few occasions, I have requested classroom changes...But I usually did not ask for

accommodations...I think it is because I have always climbed stairs with no problems and over the years, I have always managed. But since I have gotten the polio study, I am realizing that as I get older, I need to do some things differently. Although Jacob never requested accommodations, he did disclose his impairment on all of his college applications.

I always disclose. I have never hidden it nor have I ever even thought about not disclosing or not mentioning it...I have always used some type of brace or crutch. So passing has never been an option for me.

Jacob's recent study of post-polio survivors have led him to consider why he never requested for accommodation and asked valuable questions.

No. I have never signed up. A lot of the research I am doing and [studying about disability] has made me think more about why polio survivors, it's just not me, don't ask for accommodations when probably we should. Even with the issue of time, I have been thinking about polio survivors who are so significantly disabled that they would need extra time if they were taking classes.

Jacob shared possible insight into the reasons polio survivors may not request accommodations or seek help.

Perhaps, we have been so taught independence that we don't often think we need extra time. When you think about it, the typical polio-survivor, even in my case, the reality is that I do things differently...Why I don't ask for accommodations is maybe something I need to do.

As a result of his research, Jacob consulted his doctor and accepted his advice.

I recently had myself tested for post-polio syndrome and I am still fine, thank God. But it is one of those things you have to be cautious of. When I went to the polio center for my evaluation, the doctor said to me ‘Jacob, polio survivors your age are very stubborn. When we tell them they need to save their muscles, they think they will have their muscles forever. Although in some cases, you have quite a few who will not end up with post-polio. Don’t do that to yourself, take my advice, use elevator, take breaks and rest when you walk a lot.’ So I have been advised to use elevators and request for an accommodation if there is no elevator. Ask for accommodations, it’s OK. You want to get into a position that if you are still alive at 60 or 70 years of age, you want to stay as independent...Now, whenever I can, I do ask for accommodations.

In stark contrast to Jacob, Amanda acquired a physical impairment during college, “I have been in pain since 2008. At that time, I was working full time as a teacher and I was also getting my Masters.”

Amanda’s reasons for not requesting accommodations were clearly due to a lack of knowledge.

I never even knew that was a possibility...When I was working on my Masters, I wasn’t thinking about getting services, I was thinking about walking again, how to make the pain go away and how to get back to work. I wasn’t really prioritizing school... I also thought that it wouldn’t count as a disability. I just did not have any context in which to think otherwise.

After receiving advice from a fellow student, Amanda was still not convinced that accommodations were suitable for her.

I was just unaware of the fact it could help and how it could help. A fellow student told me that I should request accommodations and I told her that she was crazy. I was thinking what can they do? My professors are already really great and understanding.

It wasn't until Amanda's situation took a turn for the worse that she decided to seek accommodations.

At first it was just my back problem...through the whole process, I wasn't really looking for help to make it easier. Then I started having bad anxiety attacks and depression and all of that made the back problem worse. Then I stopped being able to keep up with my commitments at school...I felt that if I couldn't get myself going again, I was going to let down a lot of people...including myself...but I did not know what else to do.

Additional stress and continued advice resulted in Amanda seeking accommodations.

So this semester was really tough and when my fellow student told me to go get disability support services it was a point where she had already seen me have a breakdown...I am usually the one who says, 'Things are going to work out' but this time I was the one saying, 'I don't think I am going to make it.' Now that I have been working with a psychologist that I got through this process of requesting disability services, I have PTSD which triggered the depression and anxiety. All of those things make my back problems worse. The worst thing you can do is add stress.'

Amanda had a suspicion that she had anxiety or PTSD, “I suspected that I did. I think I had it long term but I guess since I never had anyone around me to tell me to go see someone about that.”

Making the decision to request accommodations proved challenging.

I also felt more anxious in terms of applying for services. I wasn’t sure how they [parents] were going to react...I was surprised...they both just wanted me to get what I needed from the school. If I could get something to help me, that is what they wanted...I just want help doing what everybody else needs to do.

Amanda has since worked with ODS and is in the process of receiving accommodations.

They asked [on the form] space to keep things so I don’t have to carry things around, the ability to sit on a yoga ball and to get textbooks in electronic format. The problem was really last semester when I could not focus and I could not do my work. I fell behind and I felt really uncomfortable asking for support with that...I trust a lot of the people who have lead me to this place and the ODS staff has been amazing.

Amanda further explained how having an ODS staff professional to talk to was very helpful.

They follow up with me to make sure I found somebody and that person follows up with me. Now realize that I probably vented to him in the emails more than he ever wanted to know or needed to know. But I guess I thought that was the only person I thought was going to hear me and understand me. It’s a lesson...sometimes you say things to people who don’t need to hear it but they are the only people who are willing to listen at the time.

Amanda admits that school itself does not add additional stress, but her anxiety comes from other sources.

This program is like my point of sanity...the work is difficult but my anxiety comes around not feeling like the quality of my work is reflective in what I am trying to convey...I am so insecure about my work and that brings me a lot of anxiety.

Amanda expressed respect for the university as well as those who gave her advice.

I also respect the institution...I have had really good interactions with this institution so I kind of feel comfortable about giving this personal information and asking for help. If I did not feel that way, then I would probably not ask. It would be a different story.

While Jacob and Amanda had no critique of the system, occupants in the next space identified components in the systems worthy of attention.

I'm OK in a Not OK System

Occupying this space are participants who are academically satisfied with themselves. However, the following occupants have critiques of higher education. Regina, a 44-year old female pursuing a Master's degree in Education, described her attending a public high school as a welcomed change.

Before high school, I got a choice to go to public school. I jumped at the chance because I went to a Lutheran school from K-8 and I did not like it. . . . In high school, I tested into the lowest math...I took algebra and probably passed with a 'D-.'

Regina graduated from high school, attended a community college, and tested into basic algebra. Regina described her frustrations. “Over the period of a couple of years, I could not pass math. I was frustrated...In between dropping math and not taking math, I opted for an abroad study trip to England.

Changing of her major was problematic for Regina’s parents.

I changed my major from business, which was my parents’ idea, to speech communication. The change of my major did not go over well with my parents...My mother reacted in anger and told me that since I changed my major, they were cutting me off. I was told if I wanted to continue in school, it would be on me...I dropped out of school...before then, I did four years of college and earned ‘A’s in just about everything and could not pass math.

Regina’s challenges in math did not hinder her desire to continue college.

I did go back to school, I went to a community college to take Art classes... but I took enough art classes that I finally got to a point that I wanted to go back to what I called ‘academic school’...I still had that nagging feeling of wondering why I could not pass math.

What could have been a devastating turn of events, Regina used it to her advantage.

“When I just returned to the academic part of school, I was laid off...I took all of my profit sharing and invested it in me...I did not work. I just went to school.”

Regina candidly described the events leading to her being assessed for a learning disability. Regina was eventually assessed at a community college.

Nine years ago, I decided to see if I had a learning disability. A friend of mine suggested that maybe there was a reason I could not do math...I went to the ODS

at the community college...The fourth appointment is when I learned I had a learning disability in perceptual organization.

For the first time, there seemed to be an explanation of why Regina could not pass math.

I asked her if that is why math was such a challenge, she said it could very well be the reason. I did not know it then, but as I reflect on how hearing that label changed my life. I have changed everything for the past nine years until this semester.

Although she accepted the label at that time, it wasn't until recently that Regina realized the impact that label had on her. Regina's realizations uncover aspects of higher education needed attention.

For the last three weeks, I suddenly realized that no one ever asked me how I felt about the label. I was 35 and no one asked how that made me feel. I felt like ADA gave me services and accommodations, but how do I feel? How do I feel that now I am going to leave class to take a test because I need more time? I'm segregated in order to take the test. Nobody asked me how it affected my sense of self-esteem. I believe that the person who did my assessment...knew more than I did. She had a title, she was the expert. I am just a student, what do I know?

Before Regina came to mentioned realization, she was introduced to a math teacher who later became a mentor and instrumental in her current academic success.

That teacher became my math mentor, the person who helped me figure out how to get through school. I have known Darlene for nine years. I told her that 'you are a visual teacher and I am not a visual learner and I want to learn' she said 'OK, I am in.' She and I developed a system for how I learned.

Regina described how this professor saw something in her that she did not see at that time. This professor met Regina where she was academically and focused on her strengths. Regina credits this professor as being a major part of her success.

She told me that as far as she was concerned, I did not have a learning disability.

She told me that my brain learns in a different way and it was her job to figure out how...She helped me develop a note-taking system using different color ink and recording the instructions. She spent many hours working with me. I would take notes, read and reread them and then follow the instructions to complete my work.

While at the community college, Regina utilized her newly learned note-taking skills to benefit other students.

I became a note-taker for students with learning disabilities and visual impairments. I had a lot of review in math because some of my students were in math classes and I was taking notes for them. I was grateful for the note-taking techniques I learned.

While enrolled in college, Regina also gained self-advocacy skills which were nurtured by the ODS staff.

The ODS staff really talked a lot about advocacy...For me, the skills of self-advocacy came from my advisor in community college.

Although Regina was appreciative of test taking accommodations, she clearly stated her dislike of being isolated and strongly criticized the system.

I think whenever you take a student out of the class, for whatever reason, there is that line that states that you are different...The person who sits in the back may not notice that you are not there for the exam, but the person you sit next to will

notice...They will wonder where in the hell I was...I tell them that I take my exam somewhere else.

Persistence during her enrollment in community college paid off. Regina eventually passed all required math classes and transferred to a university. Regina proudly said, “I probably retook and reread thousands of math problems, quizzes and exams. Because of that, I was able to transfer and attend a university and in two years, I got my degree.”

Although Regina used test-taking accommodations in community college, she opted against the use of that accommodation at the university level. She completed the ODS paperwork in order to get the benefits of priority registration. “There were 35,000 students and I had to use whatever I could to make sure I got the classes to get out of there in two years. So many students.”

While Regina had strong, uneventful relationships with professors at the community college, she described a different response from a professor at the university.

There was a professor who used the words ‘you people’ when I asked her to sign my forms to get accommodations. The moment it came out of her mouth, you knew she regretted it. She was fully tenured and she was not going to retract it...That was not a good experience.

Regina shared lasting memories of the day she was identified and told she had a learning disability.

The day my ODS advisor told me that I had LD, she showed me on a graph where I stacked up. I don’t think she was malicious in doing this, but that was just her way of thinking and the way she had been trained. I believed the person who did

my assessment. I believed she knew more than I did, she had a title, she was an expert. I was just a student.

Regina uses the writing of poems as a method of communicating and creative outlet.

I write for me. If someone reads it and likes it and has a reaction, that's great. I don't write unless I purposefully say that I am going to sit down and write about this segment of my life. For example, I wrote to my online professor to explain how the online format is not working for me.

Referring to Regina's self-realization is an excellent way to synthesize her interview.

I would say that it is self-realization that I learn differently, my brain works differently, and that is perfectly OK, but it wasn't OK back then. You know what I think now? I don't even have a learning disability of perceptual organization. I come from a perspective that there are many different ways to learn. And mine is the way I learn once I started letting go of that labeling process, there is a lot of freedom in just knowing that I learn this way and that I am OK with it.

Two of Regina's poems follow.

Labeled

Test scores determined a LD in Perceptual Organization.

What if the test scores were wrong?

What if they only represented a fraction of truth?

A slice of a fraction,

½ of a lie,

I a whole person?

How was that missed?
This inner question
Persists.
Accommodations felt like separation
Visual you are different
Tests taken elsewhere set me apart
I didn't want to be separate
But needed quiet and more time
Produced Deficit feeling
DSPS advisor watching
Through a closely guarded lens
I was so much more than a graph representing LD test scores.

Continuous Variable

Documented evidence
For once there is no documented evidence
No test scores
No scatter plots or bar graphs
To measure me against another
No standard deviation away from the mean
My choice to define
My choice to explain
Just what it means to be me

I claim my own self now
I am my own Qualitative variable
I am $n-1$ degrees of freedom
The students t-Distribution
I am my own measure of central tendency
Not defined by anyone
But by me
My own Bell Shaped Curve

The second occupant in this space is Gwen, a 30-year-old female graduate student who describes herself as being severely hearing impaired. Gwen described the nature of her hearing impairment.

If you look at my audiogram, I would be considered severely hard of hearing. My dad says I am pretty much deaf. The reason I do so well is because of my lip reading skills. I take my hearing aid out, I can barely hear at all. Even with overhead announcements. I can sense that there is something but I can't understand it. I have no hearing in my right ear and I have only 10% hearing in my left ear. I have a hearing aid in my left ear.

Gwen described her educational history as kind of "weird."

In elementary school there was one school that had a special program, kind of like inclusive setting. Here there was a blend of deaf, hard of hearing and hearing students that could sign. For the first couple of years of elementary school, I was in that program. Then I got moved to another elementary school where I was completely mainstreamed and then I got pulled back into that program.

Gwen's desire to remain in one school was greater than the desire to continue receiving accommodations.

I just wanted to stay at one school. So I did not have any accommodations...I did fine because my mom was a high school counselor. She made sure my teachers knew to help support me. I did not have any accommodations in middle or high school.

Entering college, Gwen was not aware of available accommodations for students with hearing impairments.

When I started my undergraduate work, I did not even know there were accommodations available. The first year, I did not have any accommodations whatsoever. It was a small home town university and the classrooms were much smaller. I then went to another university in another state...a much larger school. My mom went with me and she noticed that I was having more difficulties in these larger classrooms.

The atmosphere at the new college was such that there was none to limited communication between students and professors. Rather, the ODS played a major role in the communication with professors in order to obtain accommodations.

I really did not talk to them. The Disability Services offices talked directly with the professors. The ODS just notified them and then I had to get a piece of paper and have them sign it, other than that, there was no communication whatsoever.

Note-taking was one accommodation Gwen used. Even though Gwen was grateful for the accommodations, there were adverse aspects to the manner in which note-takers were 'hired.'

So at this school, I was able to get accommodations...mainly in the form of a note-taker. This accommodation was problematic for me because I am a very detailed note-taker. I capture everything, words and every idea. Their note-taking style was more subjective. They wrote down what they thought was important and did not write down what they thought was irrelevant. The notes were handwritten, because that is how it was at the time and so they could not capture everything either. Professors would just ask for a volunteer in the class and give them paper with like a carbon under it so I could get a copy of the notes at the end of class.

Even though Gwen was dissatisfied with some aspects of higher education, she expressed the benefit of having ODS staff with impairments

What I really liked...the person who worked in the ODS was blind. There was that sense of understanding that you may not get from an abled bodied person or someone who has not had a lot of exposure to disability.

As Gwen continued to struggle with receiving problematic note-taking accommodation, a friend made Gwen aware of an alternative to the traditional note-taking.

I had a friend who was doing the transcribing services. I had never seen this before. So after being in a class with her, I ended up going to ODS and inquiring about it...So for the last couple of years of my undergrad work, I had a transcriber in my classroom because the note-takers were not sufficient enough. Boy, it was nice.

Yes, they [the transcriptionists] are more detailed.

The knowledge of alternate methods for note-taking proved beneficial for Gwen. Some professors openly shared they were not concerned with the type of note-taking services she received, they told her to get whatever she needed.

During my Master's, I had a court reporter; I had captioning and real time transcriptioning. I primarily got those services because my professors for sociology and most professors for my other undergraduate classes were not really wanting to deal with accommodations. They were like, just get whatever accommodations you need. However, the professors in the sociology department became advocates for me. They told me other things I could be doing.

Steps taken by the department and faculty were beneficial to other students as well as Gwen.

They went ahead and got things closed captioned. I never had to bring them a slip of paper to sign. They took the initiative. I often think about how just closed captioning benefits so many other students and not just those that are hard of hearing or deaf. Think about the students that are learning English or those who are visual learners.

During her Master's program, Gwen recalled her feelings when academic departments were not aware of how to handle accommodation requests.

In my Master's program, my department did not know how to handle it or deal with it. So in that case, it was easier for ODS to deal with the professors. Even then there was some resistance and it was a very uncomfortable feeling for me. My major was sociology and I thought there would be less resistance from these professors."

Gwen's successful completion of a statistics course directed her thoughts to the idea of classroom supports.

I did have a statistic class...but statistics does not translate well...Because of the nature of the class, my professor wrote on the board a lot and talked while he wrote on the board. Therefore, I could not read his lips in order to get the lecture...I asked him several times not to talk while facing the board. I know it was hard for him because he was writing all of the time...But fortunately I knew what my rights...So I ended up negotiating that I did not have to show up to class as long as I turned in my assignments and studied from the textbook.

Gwen described the university's rationale and stern encouragement to use transcribers rather than providing her a sign language interpreter.

Interpreters actually cost more than a transcriber so the ODS tried to push people towards getting transcribers. It was the more economical option. There was politics about that. I could have used an interpreter but they really wanted me to use the most economical option. I guess it just comes down to money.

Gwen described a time when, due to departmental circumstances, she was not permitted to record lectures.

I can say for one of the incidents, it was circumstances that were going on in my program at the time. There were a lot of lawsuits going on so they really did not want anyone recording what was going on in their classroom. I think they were worried about having stuff on tape being used against them. Even though they had a contract saying that I could not do that...that did not reassure them. Even though I understood the circumstances, it was not good for me.

Gwen shared her opinion of how some professors think about disability.

I think it was how they understood or interpreted disability. I think it is just more about who they think or deserves and has the right to be in a graduate program. So it is a whole weeding out process.

Currently, Gwen is not using accommodations and credits the cohort model for support.

I have it available but I have not used them, I haven't needed to. For the most part, I think I am doing good because of the cohort model. I have a strong relationship with my cohort members. They help me out so if I don't understand something, they do a good job to make sure I get what I need...Otherwise, I have not had any issues.

Gwen has taken an active role to bring disability awareness to her campus.

Part of me wants to say that they just don't know. For example, right now on my job here on campus, I am trying to get more increased awareness about disability and providing accommodations. When I talk with them about films...I ask why can't they just all be closed-captioned for everyone. That would be a pure utopia. The reaction was that they never really thought about it. And then their response to that was that they said, they never had any complaints. I then responded by saying that if we create an environment in which we don't talk about it then how is it creating a safe place for them to talk about it or even bring it up to you. It is kind of awkward for something that is in my face every day to realize they don't know.

Gwen is committed to the idea of Universal Design in higher education.

It is interesting because most people think that accommodations only have a narrow view...accommodations are only helping this many people. Whereas with closed captioning, considering there is an increasing number of international students who appreciate the closed captioning. This helps them keep up. It is harder for them to process fast enough than just read it...I think in terms of regulations, yes, higher education has gotten there. But in terms of thinking more creatively, I don't think so. I have been reading about Universal Design and Architectural Design Theory most accessibility issues were fulfilled by the use of a checklist. There was no thought about more creative uses of space to accommodate sinks, toilets etc. It would make more room. if we did this...There is no room for discussion or creativity.

In summary, Gwen explained her thoughts regarding campus size vs. class size.

I don't need it [accommodations] now. Some people would argue that it is the size of the university that makes a difference, but it is really not. I think as long as you have the support within your classroom, you can get by. We need to take a closer look at the university classroom...I am surprised that this university is not as progressive.

The occupants in the next space did not find areas for improvement within the system, rather, they made choices and often sacrifices to earn desired positions within the system.

Maybe next time: Making choices I can live with

This space has three occupants, Pamela, Rachel, and Roberta, all of whom have described making sacrifices to earn their desired position with regard to their academic

standing. Pamela, a 19-year-old freshman majoring in Business Management, shares her earliest memories. “I have always been interested in going to school...Even before I was old enough to go to school, I grabbed my backpack...and I walked right out the door.”

In the third grade, Pamela learned the benefit of working hard.

She [the teacher] gave out money with her picture on it and if we did certain things, we got money and the money could be used to go to the Surprise Box. You had to have a certain amount of money in order to go to the Box...That always pushed me to do really good.

Pamela vividly described how the desire to be like the “smart” kids influenced her academic performance.

I was hanging out with really bright students. I always wanted to be like that. In the 3rd grade, my teacher gave us an advanced packet of math to complete over the winter break. I really wanted to do it. I really tried to focus and I did not do any of it. But there was this kid who came back to school with it all done and most of it was correct. He was really bright and I always looked up to kids like that...I wanted to be that kid. I would tell my parents that I wanted to be in certain math classes...where all the smart kids are.

In middle school, Pamela’s goal of being in class with “smart” kids became a reality.

So I took the normal math class in the 6th grade and then I talked to my dad and teacher and told them that I really wanted to be in the harder math class because that is where the smart kids are. So the summer after my 6th grade year, one of my teachers sent home a Pre-Algebra book for me to do. If I had gone through the material, read it and completed the homework assignments, she would put me in

the higher level math class. So over the summer, I did that. I did all of the homework assignments. Because I did this over the summer, I skipped Pre-Algebra. That is finally when I got bumped up to the ‘smart’ kids’ classes.

When asked from where the concept of “smart kid” came, Pamela identified two sources.

I think it was the tone of the school and my dad always pushing me to do better. I think it was also the kids I hung out with because they were always smarter than me. I would also want to do what they were doing. They were always reading and I wanted to read too. I didn’t like to read, but I wanted to read that type of book. They were always at different and higher reading levels than I was. I always wanted to be where they were at so I could compete...My dad always encouraged me to get good grades and study hard and to push yourself to be the best you can be. It was something I wanted to do because I saw my friends do it. I wanted to be like that too.

Although Pamela described math as being her most challenging subject, her continued effort and sacrifices paid off when she enrolled in college.

Math has always been one of my weakest subjects. I have a problem with second guessing myself and having confidence in my abilities. So it was something I struggled with but I was always seeking extra help from my teachers during lunch or after school...I worked really hard...math has always been something that I have struggled with. In my freshman year of high school, I was in Geometry. I really liked my teacher, but I still struggled.

When asked about her decision to attend college in spite of her learning difficulties,

Even though I struggled in upper division math, I never pulled myself out and put myself into the normal math or general math education. I have always been the upper division for my age. It was something that I kept telling myself, 'You got to do it...keep doing it, it's good for you' It's me; I know I needed to go to college. I worked all my life to get good grades knowing that I was going to college...I am not in a math class now [in college] because my ACT scores were high enough to exempt me for taking any math classes.

Pamela's past academic accomplishments came at the following cost.

Of course I had to learn time management when there were times I wanted to hang out with friends but still had homework to do. When there were times I wanted to go out I just made sure I got all my work done ahead of time so that I could.

The second occupant in this space is Rachel, a 24 year-old female pursuing a Master's degree in Education. In the first part of our interview, Rachel described the account of her early diagnosis.

I was formally diagnosed with a developmental reading disability. I never heard the word dyslexia as a label for me. I also have ADD, not the hyperactive part. I was never on medication and I never went to an outside source for it...The school diagnosed me. I had to see a psychologist.

By high school, Rachel had a better understanding of her limitations and the manner in which she processed information.

In high school, I just barely got by. I had RSP as a study period. I loved my RSP teacher...She was one of the best advocates I ever had. She told me that I was the

type of student who could go to a school like UCLA. They are not looking for students who can do everything and memorize all. She said they are looking for kids who can comprehend and then create something. I could do that. I was smart; I could put it in and make sense out of it. I just needed more time to comprehend it.

Growing up, Rachel's passion for horses was nurtured by her parents. Rachel learned confidence and other valuable lessons from working with horses.

You fall off, there are no excuses, and you just get back on. It is hard for everyone. That is one thing I learned. It's hard for everyone, so stop complaining and just go. That is a hard approach if someone is really young, but I was at an age where I was ready to hear that. And that carried with/stayed with me through education.

Rachel explained the lack of parental involvement during her K-12 years as being due to her parents' full-time employment. However, in college Rachel was able to witness parental involvement in action. Contact with her boyfriend's parents subsequently had an impact on her education.

Both of their children were at universities. Education was really pushed on them and I felt that. I felt like they were judging me when I got the bad grade during my first semester. I didn't like that. I had never had that type of judgment before. I think that is what pushed me. I started taking science classes. I kept the straight 'As' as long as they gave me extra time on my test. I was nominated Chemistry student of the year by my chemistry professor and for the American Chemical Society. I earned an award and some money. I got scholarships for my grades.

Rachel indicated her enrollment into community college was beneficial to her.

It was at community college that I really found myself academically...The teachers I had were great. Teachers could see if they gave me extra time, I was that 'A' student. After my first semester at JC, I was an 'A' student. I had high honors. I just figured it out.

Rachel transferred to a four-year university with the goal of becoming a veterinarian. However, it was the earning of a "B" at the university level that changed her goal and perspective.

I ended up getting a 'B' in my biology class my first semester at the university. I remember feeling that I no longer had to try for my straight 'A' any longer.

Because of that one 'B,' I stayed an A/B student during my time at the university.

Another realization accompanied Rachel's acceptance of being an A/B student.

That was still good [the A/B grade average] because I had hard classes, they were all science classes. I realized I did not need the accommodations. It was a hassle to ask the professor, emailing them all of this stuff.

Rachel furthered explained her reasons for not requesting accommodations.

So then I thought, if I don't have to be the straight 'A' student, I don't need the accommodations. I was OK with being a 'B' student. No one was going to judge a 'B' student. When I realized I didn't want to go to Vet school, I stopped pushing myself hard. I didn't have to be perfect, I didn't have to be perfect on a test, and I just had to do well. Then I decided, I just wanted to do the test with everyone else. It was proving to myself that I did not heed the accommodations. I ended up graduating from university and now I am here.

Rachel stated, “I felt a lot smarter. I wasn’t getting as good of a grade but I knew I could take an exam and work not as hard as the other kids and I would still do better than them” to describe how she felt when she was not receiving accommodations.

Rachel described acquired strategies she attributes to her academic success.

I did not have to study that long. I could cram study. I could stay up all night long, study the material and then take the test. If I could read through my notes a few times and then organize them in my head, I was golden and I knew that. So after the test, I would say that was so easy. It was just about myself making the connections faster. Here, I never requested. It is my first semester and I feel there is no need. In the past, I needed extra time and I don’t need that now. I have organization problems and other things that I have learned how to handle. I have also learned that you just have to get things done. Even if it is at the last minute...just get it done. That is what has kept me going through.

Stating with confidence, Rachel stated that she would be successful as long as she worked hard.

I don’t think I would ask for accommodations because I feel as though if I was able to do well in those science classes, without accommodations, I should have no problems in this credential program...Those classes were hard for several people, but not to me as long as I put the time into it. That makes me think if I can do that, then I should be able to do this program...I put in all of the work.

The last occupant in this space is Roberta, a 19-year-old female freshman majoring in Education. Roberta described herself as, “Always been hard on herself...Now, I get

“A’s.” I am very difficult on myself. . . Yes, school has always been hard for me. When I was young, school was very hard for me.”

Roberta solemnly recalled an incident in the fifth grade that remained a reason she continued to work so hard and remained critical of her academic efforts.

When I was in the 5th grade, my mom wanted me to get tested. She told my teacher ‘I see Roberta working really hard and her hard work is not being reflected in her grades. When my mother told my teacher that she wanted me to be tested for a learning disability, my teacher said ‘She doesn’t need to be tested; she just needs to work harder.’ So my mother accepted what my teacher said. So I just kept on working hard and found myself always being hard on myself.

This pattern continued for the next five years, at which time Roberta described as the most positive and memorable event in school occurred.

When my sophomore history teacher came to me and told me, ‘I know that you work hard and try hard and your tests are not showing what you really know.’ She then told me that she thought I might have a learning disability.

Being identified as having a learning disability was accompanied with a sense of relief.

It felt good to know that the difficulties I was having were because of a learning disability. I was so hard on myself all that time. I worked my ass off and it was good to know why I had struggled so much.

Roberta considered the many hours spent studying in school as the most negative aspect of school.

The most negative experience I had in school...studying a lot for tests and always working hard on my schoolwork...Studying so hard...I was hard on myself because I was told that I was not trying hard enough.

Roberta's current maintaining of an "A" average does come at the cost of her social life. She explained, "I put my school in front of my social life. But I still have a good social life. I have a lot of friends that support me."

Fall 2014 was Roberta's first semester in college. She is not currently using accommodations and has not disclosed her learning disability to anyone. She shared, "No, I have not told anyone. I just kind of work it out myself." She clearly stated her reasons for not requesting accommodations, "I really didn't think having the accommodations would make a difference in my grades from going from 'B's' to 'A's'...right now I don't have all 'A's' I am in the high 80s and low 90s."

In addition to Roberta's continued academic efforts, she described support systems that are of benefit to her. Roberta stated, "I use the support systems that are available to all students, I get tutoring. I just make it work."

While each participant's introduction described a variety of lived experiences, one commonality persisted. Each space was characterized by *tensions* along a continuum ranging from incompatible options to competing perspectives (Ferguson, Personal Communication. Chapter Five will examine, more closely the tensions illustrated in the space between a rock and a hard place.

Chapter 5: Examining the Spaces Between the Rock and a Hard Place

This chapter explores the reasons participants do not request accommodations. In addition, I will discuss my initial assumption and the use of the term *acceptance*, the concept of *individual response to disability*, the rise of disability studies and its relation to the social construction of disability, negotiating identities, and opportunity cost. In addition, the conclusion of this chapter provides a detailed discussion of recommendations and the value of this study.

When I began this research, I had a clear understanding of my position as both an insider and an outsider. As a doctoral student with a disability (insider position) who has always requested accommodations (outsider position), I sought to learn, understand, and interpret the lived experiences of college students who do not request accommodations. I began the study with the assumption that participants would report stigmatization as a primary reason for not requesting accommodations. However, it was not long before I realized participants shared similar experiences, with few related to stigma. While several identified existing tensions as they journeyed through higher education, I interpreted other reasons as directly related to the participant's acceptance of their impairment. The stories and reasons for not requesting accommodations varied. Reasons for not requesting accommodations included (a) being unaware that their impairment would qualify for accommodations, (b) the student accepted his/her individual learning style and did not consider themselves disabled, (c) acceptance of being a "B" or "C" student, (d) viewing the process of requesting accommodations as too much of a hassle, and (e) a belief that their unique traits were beneficial to their academic and future career.

Being unaware of services available and impairments considered eligible were among Amanda's and Gwen's reasons for not requesting accommodations. Research

conducted by Cawthon and Cole (2010) revealed that, while a need for greater awareness of available resources existed, participants had general knowledge of their disability and used same services as in high school. I think entering postsecondary education with the same general knowledge of disability and awareness of services may be problematic for some students. The rigor of postsecondary education might require the student to use additional or new accommodations than what they received during high school. Gaining an awareness of various services and accommodations prior to entering college may prevent potentially detrimental delays once enrolled in college courses.

Amanda was not aware her chronic pain would qualify as a disability, sharing, “I guess I did not think about it and I also thought that it would not count as a disability...Not like being in a wheelchair.” The fact that Amanda compared herself to a wheelchair user supports and draws attention to the construction of normalcy (Davis, 1995). Davis (1995) shifts focus from the construction of disability to the construction of normalcy as, “a feature of a certain kind of society” (p. 24). Here, the concept of a normal body (e.g., not being in a wheelchair) was the standard by which Amanda measured her degree of normalcy.

In a slightly different situation, Gwen entered college well aware of her hearing loss; however, she was not aware of available services and accommodations.

I did not have any accommodations in Jr. High or High School...*When I started my undergraduate work, I did not even know there were accommodations available,” The first year, I did not have any accommodations whatsoever.*

During her second year, Gwen’s initial use of accommodations became problematic.

I had note-taking services. This was a problem because the professor would just ask for a volunteer in class to take notes on carbon-like paper. This did not work because most of the students did not take very detailed notes. I am a detailed note-taker and the notes they took were subjective, they included what they thought was important.

This situation was not a detriment to Gwen's educational performance. Informed of transcription services as an alternate accommodation for note-taking, she advocated for herself and requested transcription services, from which she benefited for the duration of her undergraduate studies.

Another reason given for not requesting accommodations included reports by participants that they accepted their individual learning styles and were "OK" with a "B" or "C" grade. Regina and Rachel took this approach, with Regina sharing:

I would say that it is self-realization that I learn differently, my brain works differently and I am perfectly OK... I come from a perspective that there are many different ways to learn. And mine is the way I learn once I started letting go of that labeling process. there is a lot of freedom in just knowing that I learn this way.

In fact, self-realization was one of four integrative self- determination themes of an academic identity development model explored by Anctil, Ishikawa, and Scott (2008). Similarly, illustrated in their study, "participants appeared to have a mature understanding of their own individual strengths and weaknesses and possessed an accompanying intrinsic motivation to complete tasks, which resulted in high levels of self-awareness and self-realization" (p. 171).

A change in career paths prompted Rachel to reconsider the efforts placed into being a straight “A” student. During the interview, Rachel described the stress of maintaining a nearly perfect GPA, “I wanted to go to Vet school, so I had to keep up my grades. It is very competitive.” Rachel further recalled,

I ended up getting a ‘B’ in my biology class my first semester at the university. I remember feeling that I no longer had to try for my straight ‘A’ any longer...I wasn’t going to become a veterinarian, so I did not need straight ‘As.’ Because of that one ‘B’ I stayed an ‘A/B’ student during my time at the university.

Some participants reported receiving accommodations at one point, and later deciding against requesting them. Three participants described the process as “a hassle.” Rachel described her experience at the university as,

When I was at the university it was such a hassle...Submit paperwork to ODS and then they would send me the stuff that needed to be sent to the professors. I then had to meet with the professors because they had to sign something...It was too much to get the extra time.

Although Angela did not describe reasons for not receiving accommodations as a hassle, I consider her predicament relevant to this discussion: “I can’t get services here because I don’t have copies of the paperwork I had as a foster youth [I considered this a hassle]...I would have to get outside testing [a second hassle]...I don’t have the money.”

Bernice considered the amount of time required to request accommodations a determining factor for not requesting them. “Those services would take more of my time and not be as useful. I would have to spend time on getting those services...I could use

that time studying.” An encounter with a professor complicated Regina’s experience of requesting accommodations.

When I went to her office for her to sign the paperwork...she looked at me and said, ‘You people’...That was an ‘Oh crap’ moment...I never had that happen.

She signed the paperwork and then she asked me if I had more questions...I left her office thinking to myself, what just happened?

Regina’s encounter illustrates a continual barrier to higher education. Denhart (2008) investigated barriers to higher education experienced by college students, finding a source of barriers came from external social causes, such as faculty perceptions leading to misunderstanding of students, and being reluctant to request accommodations for fear of stigmatization. Cook, Rumrill, and Tankersley (2009) investigated professors’ willingness to provide accommodations. The priorities and understanding of 307 faculty members revealed issues and willingness to provide accommodations were neither highly important nor being addressed satisfactorily. In contrast, the study results indicated disability etiquette and accommodation policies viewed as highly important and addressed satisfactorily.

Certainly, the above illustration is not applicable to all faculty members. Mytkowicz and Goss (2012) attributed mentoring relationships with faculty members with positive outcomes of successful participation in programs. Regina provided evidence of this in her description of a math professor who mentored her during her enrollment in community college (see Chapter 4).

Although a study where 14 undergraduates identified as either LD or ADHD believed participation in support programs contributed to their outcome (Mytkowicz &

Goss, 2012), Roberta believed otherwise. She is satisfied with her current grades and does not consider accommodations a benefit. “I really don’t think having the accommodations would make a difference in my grades from ‘B’ to ‘A.’”

Lastly, another reason given for not requesting accommodations was the belief that a participant’s traits are beneficial to them and their future career. Austin’s personal philosophy contributes to his reasons for not requesting accommodations.

Your limitations are probably things you should try to overcome and that will make you a stronger individual. It is something that I just have to deal with...I personally don’t care about grades...because grades are not going to affect my career. I think the traits I have helps me as a film-maker/screenwriter.

Here, I need to explain the use of the term *acceptance*. I decided to use this term in the discussion of the previous assumption because that was my interpretation of the participant’s experience. However, I had to question my assumption when I later learned *acceptance* was one of three terms (*adjustments*, *adaptations*, and *acceptance*) that pathologize the experience of a disability, meaning a disability is automatically assumed to be an undesirable state (Smart, 2001). Knowing the disability experience has not been an undesirable state for me and some participants, I reconsidered my use of this term.

Originally, I assumed before entering or at some point during college, participants appeared to *accept* their disability. Now, instead of *acceptance*, I align my assumption with Livneh and Antonak (1997) who explained a range of *responses* that occur as participants cope with their disability. The phrase, *the individual’s response to disability* (Livneh & Antonak, 1997) best describe how participants coped with their disability and was the reason for its use. In general, the responses to disability are divided into three

categories: (1) cognitive, (2) behavioral, and (3) affective. Because a person's response may involve more than one category, there is no implication one's response is limited to a single category (Livneh & Antonak, 1997). To illustrate, Lorraine's cognitive response (thinking she could handle her scheduled commitments) led to a behavioral response (engaging in eating disorder behaviors). Lorraine, diagnosed with an eating disorder and ADD, described how over the past five years, she demonstrated a variety of responses as she coped with her disability.

I just kept it a secret for a few years...My parents thought I was fine. Even up until this past summer, I was engaging in behaviors of my eating disorder...I overcommitted myself and just kept busy. I thought I could handle it.

According to Smart (2001), cognitive means "thinking or how one chooses to view or think about the disability" (p. 230). A redefinition of reality versus ignoring or denying is an example of a good or positive cognitive response. For example, when Candice was identified as dyslexic, she stated, "I knew I would have to do things differently." In addition to her cognitive response, Candice's behavioral response (time management skills) are instrumental to her academic success.

Getting priority registration helps me to get information about book and assignments early. I send emails to the professors and ask for a copy of the syllabus so I can see if there is any outside reading...By the time the semester begins, I have all of my material and sometimes, I have already read the first few chapters.

Active mastery of a disability is a behavioral response (Smart, 2001). The mastery may include, but is not limited to, "compliance with treatment regimens, seeking out

social supports, or returning to work” (p. 230). For many people with disabilities, this response involves actively “fighting against the stigma and prejudice of society” (p. 230). For some study participants, this mastery came in various forms. Roberta described mastery as “working my way through it.” On the other hand, Douglass described mastery as “being enrolled in a rigorous academic program while coping with academics and college life.” Bernice characterized her mastery as a high point in her education, “I have all ‘As’...I am applying to graduate school.”

Lastly, the affective response describes “how the individual feels about the disability and how he or she manages emotions” (p. 230). Angela summed up her affective response to her disability in one sentence. “I have a learning disability and that really sucks.” In contrast, Jacob shared, “I have never been ashamed of my disability. Living with my disability is all I have ever known.” Although all participants, to varying degree, have an individual response to their disability, an examination of disability studies (DS) and the social model of disability may serve to help elucidate the negotiations of disabled and nondisabled identity in higher education.

Disability Studies

Disability Studies (DS), the academic wing of the disabled people’s movement (Thomas, 2004), embraces a shift in viewing disability as a *social pathology* rather than a *personal predicament* (Goodley, 2011). With the use of DS lenses, questions about societal forms of oppression arise. Within the medical model, disability is considered something to be fixed. Such ideology suggests the person is no more than their impairment (Charlton, 1998; Linton, 1998; Longmore, 2003).

DS represents multiple perspectives that include, but are not limited to, social constructionist, structural-functionalist; it also draws on the disciplines of critical theory, economics, and law (Taylor, 2006). Cory, White, and Stuckey (2010) assert disability studies theory is, “a synthesis of social constructionism and critical theory that places disability in the political realm, resisting notions of stigma, and asserting alliances with other groups excluded because of race, gender, class, or sexuality” (p. 29). The idea that disability is a social phenomenon is “one of the core ideas of DS” (Taylor, 2006, p. xiii). Distinctions between disability perspectives did not originate with DS (Taylor, 2006). Prior to the current use of medical and social models of disability, Mercer’s (1965) posed definitions of clinical¹³ perspective and social system¹⁴ perspectives influencing the “growing body of sociological literature diverging from the traditional treatment of deviance” (p. 18).

The social model provides an explanation of disability and its relation to the structural analysis of the social exclusion of disabled people (Gabel, 2006). To facilitate an understanding of the social model, a comparison to the medical model is helpful. Comparison points for discussion include (a) the location of the impairment or disability, (b) the central focus of treatment, and (c) the focus of prevention (Stroman, 2003). The first comparison point is the *location of impairment or disability*. The medical model locates the impairment in the individual as a result of birth defect, disease, or injury. The focus is not on the practices and policies of agencies and government. In contrast, the

¹³ A perspective in which mental retardation was viewed as pathological and located within an individual who was diagnosed by a trained professional using standardized instruments (Taylor, 2006).

¹⁴ A perspective in which mental retardation was a role played by individuals in a particular social system in which they participated (Taylor, 2006).

social model acknowledges the existence of impairment, but places attention on physical structures, social prejudices and discrimination (Stroman, 2003).

Study participant Regina candidly shared her experience about the day she received her diagnosis that located her deficits in her.

The day my ODS advisor told me that I had LD, she showed me on a graph where I stacked up. I don't think she was malicious in doing this, but that was just her way of thinking and the way she had been trained. I think my advisor had a deficit thinking perspective. I remember her telling me that she never had one of her students enter into a Master's program. She saw the deficit in me, not the system.

In a follow-up conversation, Candice described a similar account of a counselor's location of her dyslexia in her.

I used the Department of Rehabilitation for a couple of years. The last counselor I had did not believe I had the ability to become a preschool teacher. He pulled up some chart and said that because of my dyslexia, I would not be able to teach preschool. He told me if I had difficulties learning, I could not teach others to learn. I hated how he already had a negative view of what I would be able to accomplish...I just got a letter from him informing me that I need to contact him to receive services for next year. I decided today, that I am going to tell him to close my case. I really don't need the services and I really don't like that he thinks my dyslexia is stopping me from succeeding. I will tell him I was recently hired as a preschool teacher and that I am part of the honor society...That will shock him.

Although universities have reputations for being socially enlightened, universities can also play a role in undermining the social model of disability through the identification and documentation process (Prowse, 2009). Prowse (2009) argued, “A system [higher education] that is purportedly there to support disabled students is actually divisive and negative” (p. 90). Students requiring accommodations must identify themselves as disabled, whether they consider themselves disabled or not. Having to negotiate an identity with one they do not identify with is problematic (Low, 1996; Prowse, 2009). Over four decades ago, Dunn (1968) addressed the issue of adverse effects resulting from separate educational settings in the K-12 system. Although Prowse (2009) was speaking specifically about higher education, the binaries of *us/them* and *disabled/nondisabled* exist as a result of students completing exams at alternate times and/or locations. Regina described her feelings (affective response) about taking exams in separate locations.

Along the way I had to take all of my exams in ODS. It was good at the time, but I think whenever, you take a student out of the class...for whatever reason, there is that line that states that you are different. Even as an adult, it is that feeling of being less than. Because you are no longer a part of.

Likewise, Roberta described the pros and cons related to receiving accommodations. Specifically, the adverse reality of taking exams in alternate testing locations: Extra time on exams is really beneficial. But when I take tests in a quiet room, I am not able to ask the professor questions or get clarification on a question. If I was in the classroom with the other students, I would have that as an option.

The focus of treatment [intentional use of medical term] is the second comparison point and has changed over time. In earlier times, treatment mainly focused on some type of custodial care (Bucher & Schatzman, 1962; Perrow, 1963; Stroman, 2003), whereas current treatment options include eliminating or minimizing disability. One common misconception is that persons with disabilities would embrace the opportunity to eliminate a disability, if offered (Smart, 2001). None of the participants discussed the option of eliminating a disability; however, participants described various responses to coping with their disabilities.

As forms of treatment, Stroman (2003) suggests various method, such as medication or rehabilitation by a professional therapist. During the interviews, Lorraine provided a detailed account of her interactions with a psychiatrist and prescribed medications, “The psychiatrist thinks my ADD and eating disorder are related because they are both impulsive in nature... The medication is supposed to help me.”

Rather, the social model focuses on systemic change, including practices to eliminate the social construction of disability. For example, Gwen, described how closed-captioning provides equal access to videos and permits her to view the video with the entire class and participate in discussions related to them. When videos are not closed-captioned, students have to schedule separate times and locations, a divisive action, to view the video with no interaction or dialogue with classmates. This is a disadvantage for all students because it eliminates the opportunity for interaction and dialogue with classmates. Gwen shared,

In general, I think most people don’t understand the significance of the smallest action. For my professor to go out of her way to make sure the videos are closed

captioned, that simple action, means so much to me. That means I have one less thing I have to worry about.

The third comparison point is that of prevention. While the medical model focuses on identifying and stopping conditions that lead to individual impairment, the focus of the social model is on changing practices, attitudes, and physical structures that cause or worsen disability by undermining the independence of the person identified as impaired (Stroman, 2003). With advances in technology, identifying the genetic make-up of fetuses can serve as an avenue by which expectant parents can determine if they will give birth or abort the fetus. Several accounts and personal stories are available online (Our Bodies, Ourselves, 2014). In addition to the existing undermining perspectives of the social model, the location of impairment, treatment, and prevention has influenced the environments in which students with impairments negotiate their identity.

Negotiating Identities

People with disabilities have followed the path of other socially oppressed groups (e.g., women, ethnic, and sexual orientation) in an effort to fight for a more positive identity (Prowse, 2009). Given that, identity is a complex field and the term is used differently in various contexts (Shakespeare, 1996). An exhaustive exploration of identity is not possible here though, as mentioned in chapter two, the term identity parallels Stryker's (1980) who viewed identity from social and individual perspectives. From an individual perspective, identity is "contained in the meaning of the self—what it means to be who one is" (Burke et al., 2003, p. 1). A person learns these meanings from cultural knowledge and one's own experiences. An explanation of an "individual's role-related behavior" is the primary focus of identity theory, while the social identity theory seeks to

explain “group processes and intergroup relations” (Hogg, Terry, & White, 1995, p. 255). Being part of a group, either stigmatized or not, provides a framework for the establishment of meaning of one’s self.

Thomas (1982) described two ways to assimilate identity, “To become disabled is to be given a new identity, to receive a passport indicating membership of a separate tribe...[to] be born handicapped, is to have this identity assigned from the moment of discovery and diagnosis” (p. 39). Regardless of the method used to assimilate the meaning of identity, participants in one study valued their own disability experience (Olney & Brockelman, 2003).

During the interviews, tensions became apparent as participants described the process of identity negotiation. Low (1996) described students with disabilities as “engaged in two interconnected processes of identity negotiation in their lives on campus” (p. 240). As well, the conflicting discourse surrounding disability impedes the acquisition of an identity for a college student with a disability (Riddell & Weedon, 2013).

According to Davis (1961), the assignment of a label guides sociability, and students begin to negotiate a nondisabled identity in order to break away from the disabled identity. However, in an effort to learn about how people experience their disability, it is key to acknowledge that most people with disabilities consider their disability to be an integral part of their identity, not their sole identity or even most important (Higgins, 1980). For example, Roberta spent five years working extremely hard to show she was putting full effort into her schoolwork.

When my sophomore history teacher came to me and told me, ‘I know that you work hard and try hard and your tests are not showing what you really know.’ She then told me that she thought I might have a learning disability...It felt good to know that the difficulties I was having were because of a learning disability. I was so hard on myself all that time. I worked my ass off and it was good to know why I had struggled so much.

Another example is that of Candice, a community college student who acknowledges her disability as an integral part of her identity and only needs priority registration. Candice described the internal tensions (affective responses) as challenging and necessary.

Priority registration is really the only benefit. I don’t even feel like I am disabled. But in order for me to get priority registration I have to say I am disabled...It is like I have two identities.

Although numerous college students declare a disabled status, the assumption that all students with disabilities make or have the desire to make such a declaration is erroneous. In the case of study participants, several were clear that they were not willing to do so. Consider the tension of students who decide against the label and forego accommodations (cognitive response). For example, Austin shared that there was a point in every semester, at which he had to explain to his professors why assignments were late.

There is always a point in the semester when I send a long email to a professor explaining why assignments are late. I don’t explain me in general. The instructors will know that my emails make sense and that I know what I am doing.

Maybe they see that I am not completely negligent and that I am giving some sort of focus and the he does care. He has something else going on.

In addition to the negotiation of identity, some participants faced the reality of negotiating an environment filled with barriers. For the purposes of this study, environment refers to campus facilities and instructional material.

Jacob continues to navigate a campus where the majority of buildings and classrooms are inaccessible to people with physical impairments, limiting their access to lower level basements. Additionally, Amanda's accommodations included the option of sitting on a yoga ball and requesting textbooks in electronic format to reduce the weight of her backpack.

Opportunity Cost

College students continually confront decisions regarding time devoted to educational, social, and familial relationships. For some students, the future benefits of a decision (e.g. to earn a higher grade on an exam) outweigh the cost (e.g., not attending a social gathering). This is an example of the economic principle of *opportunity cost*, which refers to “the value of the best option not chosen in a choice between two or more mutually exclusive options” (Hooper, 2013, p. 1). Economist Friedrich von Wieser (1851-1926) was credited with developing the concept of opportunity cost. Wieser was interested in developing a “subjective theory of value that interprets costs based on utility rather than the determinants of supply and demand” (Hooper, 2013, p. 1). In this study, opportunity cost is essential to the discussion of the use of learning assistance programs. The “broad and sometime ambiguous” concept of learning assistance has many uses in higher education (Arendale, 2010, p. xi). Learning assistance programs are designed to

meet the academic needs of all students through provisions such as tutorial programs, workshops, computer-based learning modules, or drop-in learning centers.

Knowing institutions of higher education have ODS to address the academic needs of college students with disabilities, I question the effectiveness of services provided by learning assistance programs. All universities with which I have been affiliated had ODS and learning assistance programs in separate locations on campus and appeared to operate in isolation of one another. Therefore, some of my experiences have been unfavorable, placing me in situations in which I had to address opportunity cost. For example, during one semester, I used the tutoring learning assistance program (available to all students) for additional support in a statistics course. To my dismay, when I arrived to my first session, located in the tutoring center, I experienced difficulties reading my book due to poor lighting. The seating arrangement, designed with nondisabled students in mind, created an obstacle for students with visual impairments. The center housed cubicles with a shelf provided for students to place personal items. However, the location of the shelf prevented the dull and limited lighting from the overhead florescent bulb from benefiting my view of the material.

This experience illustrates how students choosing campus-wide learning assistance may experience the opportunity cost of foregoing the use of specialized items for students requiring Assistive Technology, adaptive furnishing, and/or high-wattage lighting. My decision was to continue this tutoring until appropriate lighting for the cubicle in which my tutoring occurred (opportunity cost) was provided. My other option was to request a tutor from the ODS, which required a one- to two-week waiting period. I was stuck between a rock and a hard place. I could not afford to wait that long. The sad

reality is that I struggled with seeing the material in the cubicle for about ten days. The ODS would not allow the tutor from the campus-wide tutoring center to work with me in their office because they did not hire her. Additionally, the tutoring center had to “find” an appropriate lamp without the assistance of the ODS. Hence, I based my decision on what was most beneficial. I decided to have a tutor in a dimly lit cubicle until adequate lighting was provided, instead of waiting for ODS to assign me to one of their tutors.

Although all participants expressed opportunity cost to some degree, some were more prevalent and stood out among others. Pamela recalled working hard and putting in additional time to master math and placement in a higher-level math class. Pamela said, “There were times when I wanted to hang out with my friends, I had to make sure I had my homework done before them...I had to learn time management skills.” Additionally, Pamela spent an entire summer completing math assignments with hopes she would skip a math level. Roberta clearly stated,

I sometimes had to give up time with friends. I did a lot of sports and after school activities and did not have to give these up. I think I had to work so much harder because of struggling in school and also fitting in the time. I refused to give up sports...I am a very active person...and I have athletics instead of just staying in and focusing all on my academics.

Bernice described how her decision to focus on academics had an impact on her relationship with her fiancé, “I feel sad when he asks me when will I have time for him. I tell him, my school is not going to last forever.” For some, the decision to attend college is an opportunity cost. This was the case for Angela.

Remember that no one in my family ever attended college...No one supported me. My brothers and my mother said I should not go to college...Because I chose college, I don't see them. I really wanted to go to college.

All study participants described some degree of opportunity cost; however, due to time restraints, additional questioning and further analysis will be conducted at a later date with the possibility of investigation for an additional study.

Conclusion: Are the stories the same?

I began this study with a narrative of being a student with a disability in higher education. I questioned if my story paralleled that of current students. From this study, I discovered similarities between my narrative and current students in *response to disability* and *opportunity cost*, while a difference in stories existed in *use of accommodations* and *relationship with faculty*.

One similarity between my narrative and that of study participants was our response to disability. A person's response to disability is not limited to a single response (Smart, 2001). At different times in the course of my education, I have demonstrated cognitive, behavioral, and affective responses to my visual impairment. Of the thirteen participants, all reported various responses to disability. One hundred percent (n=13) of participants described a *cognitive* and *behavioral* response to their disability, while 69% (n=9) described an *affective* response to their disability. Having less than 100% of the participants describe an *affective* response is not surprising. Giving the age range of participants for this study was 18-44, I suggest a percentage of the participants demonstrate a cognitive and behavioral response and have not yet demonstrated an affective response. This is not to suggest sequential responses occur. However, I am

suggesting the older participants had more time to respond than younger participants. A follow-up study of participants would prove beneficial in determining a correlation between a demonstration of affective response and age.

The concept of opportunity cost is the second similarity between my narrative and stories of the participants. As previously mentioned, all participants described opportunity cost to varying degrees. The variance among participants is equally sacrificial. Hence, a student opting to study rather than attend a family gathering can be equally sacrificial as the student who spends an entire summer completing assignments in an algebra text with the hopes of being placed in an advanced level of math. In contrast to my narrative, study participants told different stories of their *use of accommodations* and *relationship with faculty*.

After I learned AT skills and the availability of services for students with disabilities, I have requested accommodations at every level of my postsecondary education. None of the study participants requested accommodations throughout their entire postsecondary education. For example, 38% (n=5) requested accommodations at some point during their postsecondary education and have since decided not to request accommodations. In addition, 15% (n=2) earned bachelor degrees without accommodations and requested services at the graduate level (Table 5.1).

One participant (.08%) acknowledged accommodations as beneficial; however, has decided to not request accommodations because she desires to be treated like other students. Lastly, 38% (n=5) never requested accommodations. Of the five, Bernice and Austin successfully completed their program of study (Table 5.1). In post-interview emails, Bernice and Austin proudly shared their accomplishments. Bernice informed me

that she was accepted into a graduate program in psychology and will pursue her goal of becoming a school psychologist. Austin will graduate and begin the journey of becoming a filmmaker/screenwriter. Given that Bernice and Austin will graduate having never self-identified themselves to ODS, their perspective universities will report inaccurate and misleading graduation rates of students with disabilities who successfully completed postsecondary programs.

Table 5.1		
Use of Accommodations		
Number and names of participants	Percentage of participants	Accommodation status
n=5; Candice, Gwen, Rachel, Regina, and Roberta	38%	Requested services at one point during their postsecondary education and have since decided not to request accommodations.
n=2; Amanda and Jacob	15%	Completed undergraduate education without accommodations and have requested accommodations at the graduate level.
n=5; *Austin, *Bernice, Douglass, Lorraine, and Pamela	38%	Have never requested accommodations.

*Successful completion of program. Austin graduated with Bachelor's degree and Bernice was accepted into a graduate program

Recommendations

After hearing the participants' voices, I revisited the argument regarding graduation rates. To avoid continued inaccuracies and misleading graduation rates of college students with disabilities, I suggest an examination of the DS perspective in higher education and faculty and teaching practices in higher education, including Universal Design (UD).

DS Perspective in Higher Education

My first recommendation is that institutions of higher education adopt a DS perspective. DS examines social, cultural, political, and economic barriers that exist for individuals with impairments (Cory et al., 2010; Goodley, 2011; Linton, 1998). In order to engage higher education in conversations about disability and initiate a change in the way disability perceived, Gabel (2006) asserts the "challenge of evolving from a basic

theoretical agenda to an applied one” (p.179) may be one of the most difficult tasks for disability studies in education (DSE).

I suggest administrators of postsecondary institutions critically reexamine campus culture and services offered through ODS (Cory et al., 2010), including the documentation process required to receive services (Prowse, 2009). To ensure students receive the most beneficial accommodations, ODS should make efforts to ensure the insight of students is considered. In addition, the process by which faculty members are informed of accommodations should be streamlined to ensure students avoid delays in receiving accommodations.

Although I recommend administrators take an active role in implementing DS perspective in higher education, student groups at various universities have been instrumental in the implementation of the DS perspective. For example, student activists at Syracuse University (SU) demonstrate an excellent example of the power students have to inform change on a college campus (Cory et al., 2010). In the fall of 2001, students at SU formed the *Beyond Compliance Coordinating Committee* (BCCC) to address students’ frustrations related to obtaining appropriate services. Similar to study participant Gwen, one SU student had difficulties in obtaining a Sign Language Interpreter even though it was preferred by the student. ODS determined the provided accommodations were compliant. In addition, a student who was blind complained his books were not converted to e-text in adequate time for him to read for class, but the ODS argued they were compliant in their actions. Hence, the goal of the BCCC was to move administration “beyond this compliance ethos” (Cory et al., 2010, p. 30). While DS

permeated SU culture, students were encouraged to live what they learned (Cory et al., 2010). According to Corry et al. (2010),

The Disability Studies program at SU included, Master's and doctoral programs with concentrations in DS, a graduate Certificate in Advanced Studies (CAS) in DS, and a joint degree program in law and DS, which includes a law degree (J.D.) and a Master's and CAS in DS (p. 29).

One of the four aspects the BCCC wanted to change was “creating model accommodations exemplifying the university’s commitment to equality of opportunity for students with disabilities” (Cory et al., p. 30). The BCCC’s platform was not focused on a particular ODS staff member, rather on the need for low-tech and high-tech state-of-the-art accommodations which would contribute to course completion and achievement for students with disabilities (Cory et al., 2010). According to Cory et al, (2010), “disability studies is intimately tied to action” (p. 34). Cory et al. (2010) asserted systemic changes occurred as a result of BCCC’s persistent activism, meetings, and conversations with campus administrators regarding activities they considered discriminatory and oppressive.

The previous discussion was based solely on a university with a DS program. Are similar results possible for universities without DS programs? Given DS is a growing major/program in a large number of universities, an examination of how campuses without DS programs can acquire a DS perspective is warranted. I suggest university administrations and ODS develop a common purpose and goal to effectively meet the academic, social, emotional, and physical needs of college students with disabilities. For example, input regarding the most beneficial services and accommodations can be

solicited from students, allowing students to be an integral part of their education. In addition, students can be involved in reporting and addressing issues of inaccessible facilities, while allowing students' voices to be heard.

Equally important to implementing a DS perspective in higher education is an acknowledgment of the social construction of disability in higher education. Institutions of higher education construct disability when students have to assume a disabled identity and self-identify to ODS in order to obtain accommodations (Low, 1996; Prowse, 2009). Structural and environmental barriers are additional considerations of how disability is constructed. Reflecting on study participant Jacob, the inaccessible facilities constructed his disability, not his physical impairment (Barnes & Mercer, 2005; Prowse, 2009).

This example reminds me of action taken when a college administrators viewed complaints by physically- and visually-impaired students as unwarranted. Here, the Director of Diversity successfully encouraged campus administrators to navigate the campus in a wheelchair and blindfolded during multiple construction projects. The administrator's difficulties in navigating the campus served as a catalyst for gradual change. I suggest that regardless of the size and demographics of a university, students with disabilities should be valued for their input and diversity on campuses with a DS perspective (Cory et al., 2010).

Faculty and Teaching Practices: Universal Design

Originally a framework in the architectural field, Universal Design (UD) has been used in some postsecondary institutions to facilitate faculty training programs (Connell, Jones, Mace, Mueller, Mullick, & Ostroff, 2008; Lombardi, Murray & Gerdes, 2011). Lombardi et al. (2011) assert an underlying connection between disability

accommodations and UD. The principles of UD are meant to assist in the conceptualization and design of accessible environments for a wide range of learners (Lombardi et al. 2011). The seven principles of UD are (1) equitable use,¹⁵ (2) flexibility in use,¹⁶ (3) simple and intuitive use,¹⁷ (4) perceptible information,¹⁸ (5) tolerance of error,¹⁹ (6) low physical effort,²⁰ and (7) size and space for approach and use²¹(Center for Universal Design, North Carolina State University). These principles are instrumental for students to have full access to programs, services, and learning (Pliner & Johnson, 2004).

Considering faculty members generally possess expertise in certain subjects rather than effective pedagogical methods (Ouellett, 2004; Scott, McGuire, & Shaw, 2003), UD may be the mechanism by which faculty members can acquire an awareness, understanding and acceptance of accommodations and effective postsecondary instructional practices (Ouellett, 2004). Additionally, Pliner and Johnson (2004) assert changes in higher education are necessary and desirable. A reconfiguration would require shifts “in our educational practices that range from how we admit students, to the curriculum we teach, to pedagogical practices” (p. 105).

If institutions of higher education fail to follow the lead of society in facing the challenges of full integration, it will continue to operate in a cultural vacuum (Pliner & Johnson, 2004). Historically in the U.S., higher education was predominately available to

¹⁵ People with diverse abilities have equitable access to useful and marketable designs.

¹⁶ A wide range of individuals with various preferences and abilities are accommodated.

¹⁷ Regardless of the user’s experience, knowledge or language, the use of the design is easy to understand.

¹⁸ Regardless of ambient conditions or sensory abilities, the design should effectively communicate necessary information.

¹⁹ Hazards and unintentional actions should be minimized by the design.

²⁰ People should be able to use the design comfortably and with minimum fatigue.

²¹ Regardless of the user’s body size, mobility, or posture, the design should provide appropriate size and space for the user to approach, manipulate, use, and reach.

White male, heterosexual, able-bodied, Christians (Brickman & Lehrer, 1962; Brubacher & Rudy, 1968; Pliner & Johnson, 2004). According to Pliner & Johnson (2004), the consequence of this is our higher educational system has “perpetuated ways of being and knowing [epistemology and ontology] that disproportionately support and reward the aforementioned bodies” (p.106).

While literature documents an increase of students with disabilities into institutions of higher education (Leyser et. L., 2011; Olney et al., 2004; Raue & Lewis, 2011; Rehfuss & Quillin, 2005; Shackelford, 2009; Snyder et al., 2004; Wagner et al., 2003), no significant shift in culture or educational practices occurred (Pliner & Johnson, 2004). Therefore, the learning needs and experiences of newly enrolled diverse groups, including students with disabilities, were not addressed.

How might the principles of UD benefitted the study participants? The principle of *simple and intuitive use* would benefit Lorraine and Angela. Regardless of their current concentration level, experience and language, they would be able to access material in an understandable manner. In particular, being able to provide verbal responses to essay questions would provide an avenue for them to demonstrate their acquired knowledge. Additionally, the principle of *perceptible information* will benefit all participants. Here, regardless of the impairment or academic difficulties, necessary information is effectively communicated. Specifically, Regina’s material in an online course would be presented in a manner, such as audio, that is conducive to her particular learning style and would meet the needs of a student with a visual impairment.

The combined concepts of *low physical effort* and *size and space for approach and use* would benefit Jacob’s negotiation of the campus. Here, the design would allow

for Jacob to efficiently and comfortably manipulate, use, and access facilities. Lastly, the *tolerance of error* principle is applicable in various settings; however, I focus on this principle in lab settings. To minimize hazards and adverse consequences of accidental or unintended actions, ensuring laboratory settings for science courses have adequate space for movement, enlarged and clearly written labels, and varied heights of lab tables would be beneficial.

Value of Study

This phenomenological study addressed the misleading graduation data of college students with disabilities. This study documented literature to verify a percentage of college students with disabilities successfully complete postsecondary programs and are uncouned because they do not request accommodations. Two such examples are study participants, Bernice and Austin. In post-interview communications, Bernice informed me that she was accepted into a graduate program, while Austin earned his bachelor's degree and will pursue his filmmaking career. This study allowed the student's voice to be heard. As an outsider (i.e., a college student who requested accommodations), the goal of this study was to learn, describe, and interpret the lived experiences of college students who do not request accommodations. This was achieved by allowing participants to tell their stories.

The introductions to the participants, the examination of tensions within spaces occupied by each, and the examination of UD were specific to higher education. Any assumptions that these tensions are limited to educational settings would prove fallacious. Therefore, another value of this study and a logical progression is an examination of tensions experienced beyond education. Although I did not talk to older adults outside of

the educational context, I argue these *tensions* never go away. Even though people with disabilities experience more accessibility and less discrimination than 30 years ago, our society continues to be influenced by a narrative that is embedded in oppression. The concepts of *minority* and *majority* generally accompany the concept of oppression. Rather, for our purposes, the terms *subdominant* and *dominant* groups as described by Stroman (2003) are used.

Stroman's (2003) rationales for distinguishing these terms seemed most appropriate for this discussion. According to Stroman "a minority group is not always a numerical minority and thereby the so called majority is not always the majority" (p. 83). Stroman identified the second reason as the most important: "a key distinction between the two groups is a power differential that leads to unequal treatment" (p 84). Unequal treatment is evident in that Western society has not embraced social construction ideology. A central theme of DS is an examination of the dominant narrative. Such narrative creatively encapsulates principles of hegemony in a manner in which those who claim an understanding of the narrative may be influenced by it.

A consideration of the broader dominant narrative is also worthy of exploration. Why are athletes with Olympian levels of stamina and endurance relegated to display their talents in the shadow of the Olympics simply due to impairment? Have we passively accepted a narrative stating this subdominant group is better off "being with their own kind"? Or has the dominant narrative orchestrated a well-managed plan to schedule the Paralympics after the crowds and media have left, thereby lessening a perception of exclusion? Whatever the reason, we must be prepared to challenge the narrative.

A continued demonstration of the power differential between the dominant and subdominant groups is evident by the statistics related to the people with disabilities. According to the U.S. Census Bureau (2010), less than 41.1% of people with disabilities were employed, whereas 79.1% of nondisabled people were employed. In addition, people with disabilities typically earned less than the nondisabled population. The Census Bureau further examined income and determined that people without disabilities earned an average of \$763 (i.e. monthly salary) more than their disabled counterparts. Given their lower employment and earning rates, it is not surprising people with disabilities have higher rates of poverty. While 14.3% of the population (age 15-64) without disabilities lived in poverty, 28.6% with severe disabilities and 17.9% with non-severe disabilities lived in poverty (U.S. Census Bureau, 2010). I argue that as the amount of persons with disabilities increases (due to longer life-expectancy, increase of aging “baby-boomers,” and injured veterans), our society may experience a shift in our ways of being and knowing—a shift requiring society to confront the dominant narrative.

References

- Albrecht, G. L., Walker, V. G. & Levy, J. A. (1982). Social distance from the stigmatized. *Social Sciences & Medicine*, 16, 1319-1327.
- American Sociological Association (1999). Code of ethics and policies and procedures of the ASA committee on professional ethics. Washington, DC: Author.
- Americans with Disabilities Act of 1990.P.L.101-336.42 U.S.C. § 12101 et seq.
- Anctil, T. M., Ishikawa, M.E., & Scott, A.T. (2008). Academic identity development through self-determination: Successful college students with learning disabilities. *Career Development for Exceptional Individuals*, 31, 164-174.
- Ankeny, E. M.& Lehmann, J. P. (2010). Journey towards self-determination: Voices of students with disabilities who participated in a secondary transition program on a community college campus. *Remedial and Special Education*, 32, 279.
- Arendale, D. R. (2010). Access at the crossroads: Learning assistance in higher education. *ASHE Higher Education Report*, 35(6).United States: ASHE.
- Asher, N. (2003). Engaging difference: Towards a pedagogy of interbeing. *Teaching Education*, 1(3), 235-247.
- Bailey, C. A. (2007). *Guide to qualitative field research*. Thousand Oaks, CA: Pine Forge Press.
- Barnard-Brak, L., Lechtenberger, D. & Lan, W. Y. (2010). Accommodation strategies of college students with disabilities. *The Qualitative Report*, 15(2), 411-429.
- Barnes, C., & Mercer, G. (2005). *The social model of disability: Europe and the majority world*. Leeds: The Disability Press.

- Barreto, M., Ellemers, N. & Banal, S. (2006). Working undercover: Performance related self-confidence among members of a contextually devalued groups who try to pass. *European Journal of Social Psychology*, 36, 337-352.
- Berryman, M., SooHoo, S. & Nevin, A. (2013). *Culturally responsive methodology*. Bingley, West Yorkshire, England, UK: Emerald Group.
- Blackorby, J., & Wagner, M. (1996). Longitudinal postschool outcomes of youths with disabilities: Findings from the National Longitudinal Transition Study: *Exceptional Children*, 62, 399-413.
- Blumer, H. (1954). What is wrong with social theory? *American Sociological Review*, 19, 3-10.
- Bogdan, R. & Taylor, S. (1982). *Inside out: The social meaning of mental retardation*. Toronto, Ontario, Canada: University of Toronto Press.
- Bogdan, R., & Taylor, S. J. (1992). The social construction of humanness: Relationships with severely disabled people. In P. M. Ferguson, D. L. Ferguson & S. J. Taylor (Eds.), *Interpreting disability: A qualitative reader*, (pp. 275-294). New York, NY: Teachers College Press.
- Bogdan, R. C. & Biklen, S. K. (2007). *Qualitative research for education: An introduction to theory and methods*. Boston, MA: Pearson.
- Boster, D. H. (2013). "I made up my mind to act both deaf and dumb": Displays of disability and slave resistance in the Antebellum American South. In J.A. Brune

- & D. J. Wilson (Eds.), *Disability and passing: Blurring the lines of identity* (pp. 71-98). Philadelphia, PA: Temple University Press.
- Bowker, G. C. & Star, S. L. (1999). *Sorting things out: Classification and its consequences*. Cambridge, MA: MIT Press.
- Braithwaite, D. O. (1991). Just how much did that wheelchair cost? Management of privacy boundaries by persons with disabilities. *Western Journal of Speech Communication*, 55, 254-273.
- Brickman, W. W. & Lehrer, S. (1962). *A century of higher education: Classical citadel to collegiate colossus*. New York, NY: Society for the Advancement of Education.
- Brinckerhoff, L. C. (1994). Developing effective self-advocacy skills in college-bound students with learning disabilities. *Intervention in School and Clinic*, 29, 229-237.
- Brooks, J. & Lewis, M. (1976). Infants responses to strangers: Midget, adult, and children. *Child Development*, 47, 323-332.
- Brown, M. (2006). A geographer's metaphor and metonym in textual/sexual space. *Cultural Geographies*, 13, 313-339.
- Brubacher, J. S. & Rudy, W. (1968). *Higher education in transition: A history of American colleges and universities, 1636-1968*. New York, NY: Harper & Row.
- Brune, J. A. & Wilson, D. J. (2013). *Disability and passing*. Philadelphia, PA: Temple University Press.
- Bryan, W. V. (2006). *In search of freedom: How persons with disabilities have been disenfranchised from the mainstream of American society and how the search for freedom continues*. Springfield, IL: Charles C. Thomas.

- Bucher, R. & Schatzman, L. (1962). The logic of the state hospital. *Social Problems*, 9(4), 337-349.
- Burke, P. J., Owens, T. J., Serpe, R. T. & Thoits, P. A. (2003). *Advances in identity theory and research*. New York, NY: Kluwer Academic/Plenum.
- Burrell, G. & Morgan, G. (1979). *Sociological paradigms and organizational analysis*. London, England: Heinemann.
- Carey, A. C. (2013). The sociopolitical contexts of passing and intellectual disability. In J.A.
- Brune & D. J. Wilson (Eds.) *Disability and passing: Blurring the lines of identity* (pp. 142-166). Philadelphia, PA: Temple University Press.
- Cawthon, S. W. & Cole, E. V. (2010). Postsecondary students with disabilities who have a learning disability: Student perspectives on accommodation access and obstacles. *Journal of Postsecondary Education and Disability*, 23(2), 112-128.
- Center for Universal Design at North Carolina State University, Retrieved on March 22, 2014 from <http://www.ncsu.edu/ncsu/design/cud/>
- Chapman, C., Laird, J., Ifill, N. & Kewal-Ramani, A. (2011). Trends in high school dropout and completion rates in the United States: 1972-2009. Compendium Report. NCES 2012-006.
- Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley, CA: University of California Press.
- Chaudoir, S. R. & Fisher, J. D. (2010). The disclosure process model: Understanding disclosure decision-making and postdisclosure outcomes among people living with a concealable stigmatized identity. *Psychological Bulletin*, 136(2), 236-256.

- Coleman, L. M. (2006). Stigma: An enigma demystified. In L. J. Davis (Ed), *The disability reader* (pp. 141-152). New York, NY: Routledge.
- Connell, B. R., Jones, M., Mace, R., Mueller, J., Mullick, A. & Ostroff, E. (2008). The principles of Universal Design. Retrieved from <http://www.ncsu.edu/www/ncsu/design/sod5/cud/>
- Connor, D. J. & Gabel, S. L. (2010). Welcoming the unwelcome: Disability as diversity. In T. K. Chapman & N. Hobbel (Eds.), *Social justice pedagogy across the curriculum* (pp. 201-220). New York, NY: Routledge.
- Cook, L., Rumrill, P.D. & Tankersley, M. (2009). Priorities and understanding of faculty members regarding college students with disabilities. *International Journal of Teaching and Learning in Higher Education*, 21(1), 84-96.
- Corrigan, P. W., Kosyluk, K. A. & Rusch, N. (2013). Reducing self-stigma by coming out proud. *American Journal of Public Health*, 103(5), 794-800.
- Corrigan, P.W. & Rao, D. (2012). On the self-stigma of mental illness: Stages, disclosure, strategies for change. *Psychiatry*, 57(8), 464-469.
- Corrigan, P. W., Watson, A. & Barr, T. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Clinical and Social Psychology*, 25(9), 875-884.
- Cox, P. (2013). Passing as sane, or how to get people to sit next to you on the bus. In J.A Brune & D.J. Wilson (Eds.). *Disability and passing: Blurring the lines of identity* (pp. 99-110). Philadelphia, PA: Temple University Press.

- Cory, R. C., White, J. M. & Stuckey, Z. (2010). Using disability studies theory to change disability services: A case study in student activism. *Journal of Postsecondary Education and Disability*, 23(1), 28-36.
- Creswell, J. W. (1998). *Qualitative inquiry and research design*. Thousand Oaks, CA: Sage.
- Darling, R. B. (2013). *Disability and identity: Negotiating self in a changing society*. Boulder, CO: Lynne Rienner.
- Davidson, J. & Henderson, V. L. (2010). 'Coming out' on the spectrum: Autism identify and disclosure. *Social and Cultural Geography*, 11(2), 156-170.
- Davis, F. (1961). Deviance disavowal: The management of strained interaction by the visibly handicapped. *Social Problems*, 9, 120-132.
- Davis, L. J. (1995). *Enforcing normalcy: Disability, deafness, and the body*. Brooklyn, NY: Verso.
- deFur, S. H., Getzel, E. E. & Trossi, K. (1996). Making the postsecondary education match: A role for transition planning. *Journal of Vocational Rehabilitation*, 6, 231-241.
- Denhart, H. (2008). Deconstructing barriers: Perceptions of students labeled with learning disabilities in higher education. *Journal of Learning Disabilities*, 41(6), 483-497.
- Dictionary.com. (2014). Retrieved on Feb 11, 2014 from <http://dictionary.reference.com/>
- Dilthey, W. (1985). *Poetry and experience: Selected works, Vol 5*. Princeton, NJ: Princeton University Press.
- Douglas, J. (1976). *Investigative social research*. Beverly Hills, CA: Sage.

- Dunn, L. M. (1968). Special education for the mildly retarded: Is much of it justified? *Exceptional Children*, 35, 5-22.
- Eisner, E.W. (1991). *The enlightened eye: qualitative inquiry and the enhancement of educational practice*. New York, NY: Macmillan.
- Encarta Dictionary, North American Version. Accessible in Microsoft Office Word 2007.
- Erikson, E. H. (1964). Insight and responsibility. New York, NY: Norton.
- Erikson, E. H. (1968). Identity: Youth and crisis. New York, NY: Norton.
- Farber, M. (1966). *The aims of phenomenology: The motives, methods, and impact of Husserl's thoughts*. New York, NY: Harper & Row.
- Federal Register, (2013). Retrieved on March 13, 2014 from <https://www.federalregister.gov/index/pdf/2013/12.pdf>
- Ferguson, D. L. & Ferguson, P. M. (2000). Qualitative research in special education: Notes towards an open inquiry instead of a new orthodoxy? *Journal for the Advocacy of the Severely Handicapped*, 25(3), 180-185.
- Ferguson, P. M. & Ferguson, D. L. (1995). The interpretivist view of special education and disability: The value of telling stories. In T. M. Skrtic (Ed.), *Disability and democracy: Reconstructing (special) education for postmodernity* (pp. 104-121). New York, NY: Teachers College Press.
- Ferguson, P. M., Ferguson, D. L. & Taylor, S. J. (1992). *Interpreting disability: A qualitative reader*. New York, NY: Teachers College Press.
- Field, S., Sarver, M. D. & Shaw, S. F. (2003). Self-determination: The key to success in postsecondary education for students with learning disabilities. *Remedial and Special Education*, 24(6), 339-349.

- Fine, M. & Asch, A. (1988). *Women with disabilities: Essays in psychology, culture, and politics*. Philadelphia, PA: Temple University Press.
- Fisher, M. P. & Stenner, A. J. (2011). Integrating qualitative and quantitative research and approaches via the phenomenological method. *International Journal of Multiple Research*, 5(1), 89-103.
- Fresko, S. (2001). Disclosure of HIV status in the workplace. *Health and Social Work*, 26, 235- 244.
- Gabel, S. L. (2006). Applying disability theory in educational policy: NDRR's "New paradigm of disability" as a cautionary tale. In S. Danforth & S. Gabel (Eds.). *Vital questions in disability studies in education* (pp.179-200). New York: Peter Lang.
- Gadamer, H. G. (1976). *Philosophical hermeneutics*. Berkeley, CA: University of California Press.
- Getzel, E. E. (2008). *Addressing the persistence and retention of students with disabilities in higher education: Incorporating key strategies and supports on campus*. doi 10.1080/09362830802412216
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon & Schuster.
- Goodley, D. (2011). *Disability studies: An interdisciplinary introduction*. Los Angeles, CA: Sage.
- Green, S. E. (2007). Components of perceived stigma and perceptions of well-being among university students with and without disability experience. *Health Sociology Review*, 16, 328-340.

- Greenbaum, B., Graham, S. & Scales, W. (1995). Adults with learning disabilities: Educational and social experiences during college. *Exceptional Children*, 61, 460-471.
- Guba, E. G. & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.) *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.
- Harris, J. (2007). *Enhancing evolution: The ethical case for making better people*. Princeton, NJ: Princeton University Press.
- Hesse-Biber, S. N. & Leavy, P. (2006). *The practice of qualitative research*. Thousand Oaks, CA: Sage.
- Higgins, P. C. (1980). *Outsiders in a hearing world: A sociology of Deafness*. Newbury, CA: Sage.
- Hogg, M. A., Terry, D. J. & White, K. M. (1995). A tale of two theories: A critical comparison of identity theory with social identity theory. *Social Psychology Quarterly*, 58(4), 255-269.
- Holliday, A. (2007). *Doing and writing qualitative research*. London, England: Sage.
- Hooper, M. (2013). Opportunity cost. *Research Starter Topic*.
- Horn, L., Berkold, J. & Bobbitt, L. (1999). *Students with disabilities in postsecondary education: A profile of preparation, participation, and outcomes*. Washington, DC: U.S. Department of Education, National Center for Education Statistics.
- Hunter, D., Reid, D. P. & Nishimura, T. (2014). Postsecondary education for students with disabilities. In K. Storey, & D. Hunter (Eds.), *The road ahead: Transition to*

- adult life for persons with disabilities* (pp. 177-198). Amsterdam, Netherlands: IOS Press.
- Husserl, E. (1960). *Cartesian meditations: An introduction to phenomenology*. The Hague, Netherlands: Martinus Nijhoff.
- Husserl, E. (1970a). *The crisis of European sciences and transcendental phenomenology*. Pittsburg, PA: Duquesne University Press.
- Husserl, E. (1970b). *The idea of phenomenology*. The Hague, Netherlands: Martinus Nijhoff.
- Individuals with Disabilities Education Act of 1990, P.L. 101-476, 20 U.S.C. 1400 et seq. (1990).
- Individuals with Disabilities Education Act Amendments of 1997, P.L. 105-17, 20 U.S.C. §1400 et seq. (1997).
- Jaeger, P. T. & Bowman, C. A. (2006). *Understanding disability: Inclusion, access, diversity, and civil rights*. Westport, CT: Praeger.
- Kockelmans, J. J. (1994). *Edmund Husserl's Phenomenology*. West Lafayette, IN: Purdue University Press.
- Kotz, M. B. (1985). The morphology of evil. In *Poverty and policy in American history*. New York, NY: Academic Press.
- Kowalsky, R. & Fresko, B. (2002). Peer tutoring for college students with disabilities. *Higher Education Research & Development*, 21, 259-271.
- Leyser, Y., Greenberger, L., Sharoni, V. & Vogel, G. (2011). *International Journal of Special Education*, 26(1), 162-174.

- Lightner, K. L., Kipps-Vaughn, D., Schulte, T. & Trice, A. D. (2012). Reasons university students with a learning disability wait to seek disability services. *Journal of Postsecondary Education and Disability*, 25(2), 145-159.
- Lingsom, S. (2008). Invisible impairment: Dilemmas of concealment and disclosure. *Journal of Disability Research*, 10(1), 2-16.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York, NY: New York University Press.
- Livneh, H. & Antonak, R. F. (1997). *Psychological adaptation to chronic illness and disability*. Gaithersburg, MD: Aspen.
- Lofland, J. (1971). *Analyzing social settings*. Belmont, CA: Wadsworth.
- Lombardi, A. R., Murray, C., & Gerdes, H. (2011). College faculty and inclusive instruction: Self-reported attitudes and actions pertaining to Universal Design. *Journal of Diversity in Higher Education*, 4(4), 250-261.
- Longmore, P. (2003). *Why I burned my book and other essays on disability*. Philadelphia: Temple University Press.
- Longmore, P. K. & Umansky, L. (2001). *The new disability history: American perspectives*. New York, NY: New York University Press.
- Low, J. (1996). Negotiating identities, negotiating environments: An interpretation of the experiences of students with disabilities. *Disability & Society*, 11(2), 235-248.
- Marshak, L., Van Wieren, T., Ferrell, D. R., Swiss, L. & Dugan, C. (2010). Exploring barriers to college student use of disability services and accommodations. *Journal of Postsecondary Education and Disability*, 22(3), 156-174.

- Martin, J. E. & Marshall, L.H. (1995).ChoiceMaker: A comprehensive self-determination transition program. *Intervention in School and Clinic*, 30,147-156.
- Matthews, C. & Harrington, N. (2000).Invisible disability.In D. Braithwaite & T. Thompson (Eds.), *Handbook of communication and people with disabilities: Research and application*. Mahwah, NJ: Lawrence Erlbaum Associates.
- May, A. L. & Stone, C. A. (2010). Stereotypes of individuals with learning disabilities: Views of college students with and without learning disabilities. *Journal of Learning Disabilities*, 43, 483-499.
- McGuire, J. (2010). Promoting self-determination. In J. McDonnell & M. Hardman (Eds.), *Successful Transition Programs* (pp. 101-114). Los Angeles, CA: Sage.
- Mercer, J. R. (1965). Social system perspective and clinical perspective: Frames of reference for understanding career patterns of persons labeled as mentally retarded. *Social Problems*, 13(1), 18-34.
- Merleau-Ponty, J. (1964). *The primacy of perception: and other essays on phenomenological psychology, the philosophy of art*. Evanston, IL: Northwestern University Press.
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.
- Merriam, S. B. & Associates (2002).*Qualitative research in practice: Examples for discussion and analysis*. San Francisco, CA: Jossey-Bass.
- Mull, C., Sitlington, P. L. & Alper, S. (2001). Postsecondary education for students with learning disabilities: A synthesis of the literature. *Council for Exceptional Children*, 68(1), 97-118.

- Murray, C., Goldstein, D. D., Nourse, S. & Edgar, E. (2000). The postsecondary school attendance and completion rates of high school graduates with learning disabilities. *Learning Disabilities Research & Practice, 15*, 119-127.
- Mytkowicz, P. & Goss, D. (2012). Students' perceptions of a postsecondary LD/ADD support program. *Journal of Postsecondary Education and Disability, 25*(4), 345-361.
- National Center for Educational Statistics, NCES 2011-018. *Students with disabilities at degree granting postsecondary institutions*. U.S. Department of Education.
- National Center for Educational Statistics, NCES 2012-006. *Compendium Report*. U.S. Department of Education.
- National Council on Disability (2004). *Higher Education Act fact sheet*.
- Newman, L. (2005). Chapter 4: Changes in postsecondary education participation of youth with disabilities. *Journal of Vocational Special Needs Education, 27*(2), 30-38.
- Newman, L., Wagner, M., Cameto, R. & Knokey, A. M. (2009). *The post-high school outcomes of youth with disabilities up to 4-years after high school: A report from the National Longitudinal Transition Study-2 (NLTS-2)*. National Center for Special Education Research.
- Newman, L., Wagner, M., Cameto, R., Knokey, A-M. & Shaver, D. (2010). *Comparison across time of the outcomes of youths with disabilities up to 4 years after high school*. A report of findings from the National Longitudinal Transition Study (NLTS) and the National Longitudinal Transition Study-2 (NLTS-2) (NCSER, 2010-3008). Menlo Park, CA: SRI International.

- Norton, S. M. (1997). Examination accommodations for community college students with learning disabilities: How are they viewed by faculty and students? *Community College Journal of Research and Practice*, 21(1), 57-69.
- Office of Civil Rights (2005). U.S. Department of Education. www.ed.gov/ocr
- Oliver, M. (1993). Re-defining disability: Challenge to research. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.). *Disabling barriers-enabling environments* (pp. 61-67). London, England: Sage.
- Olney, M. F. & Brockelman, K. F. (2003). Out of the disability closet: Strategic use of perception management by select university students with disabilities. *Disability & Society*, 18(1), 35-50.
- Olney, M. F., Kennedy, J., Brockelman, K. & Newsom, M. A. (2004). Do you have a disability? A population-based test of acceptance, denial, and adjustment among students with disabilities in the U. S. *Journal of Rehabilitation*, 70, 4-9.
- Ouellett, M. L. (2004). Faculty development and universal instructional design, *Equity and Excellence in Education*, 37, 135-144.
- Our Bodies, Ourselves, March 20, 2014;
<http://www.ourbodiesourselves.org/book/childbirthexcerpt.asp?id=79&chapterID=20>)
- Paul, J., Kleinhammer-Tramill, J. & Fowler, K. (2009). *Qualitative research methods in special education*. Denver, CO: Love.
- Pennell, R. L. (2001). Self-determination and self-advocacy: Shifting the power. *Journal Of Disability Policy Studies*, 11(4), 223-227.

- Perrow, C. (1963). Structures of custodial care: An anthropological study of a state mental hospital. *American Journal of Sociology*, 69(3), 302-303.
- Persson, A. & Richards, W. (2008). From closet to heterotopias: A conceptual exploration of disclosure and passing among heterosexual living with HIV. *Culture, Health, and Sexuality*, 10(1), 73-86.
- Phelan, J. C., Link, B. G., Stueve, A. & Pescosolido, B. A. (2000). Public conceptions of mental illness in 1950 and 1996: What is mental illness and is it to be feared? *Journal of Health and Social Behavior*, 41(2), 188-207.
- Pliner, S. M. & Johnson, A.R. (2004). Historical, theoretical, and foundational principles of Universal Instructional Design in higher education. *Equity & Excellence in Education*, 37, 105-113.
- Prowse, S. (2009). Institutional construction of disabled students. *Journal of Higher Education*
- Pryor, J. B., Reeder, G. D. & Monroe, A. E. (2012). The infection of bad company: Stigma by association. *Journal of Personality and Social Psychology*, 102(2), 224-241.
- Quick, D., Lehman, J. & Deniston, T. (2003). Opening doors for students with disabilities on community college campuses: What have we learned? What do we still need to know. *Community College Journal of Research and Practice*, 27, 815-827.
- Raue, K. & Lewis, L. (2011). *Students with disabilities in degree-granting postsecondary institutions*. NCES 2011-018; U.S. Department of Education.
- Rehabilitation Act of 1973. P.L. 93-112. 29 U.S.C. § 794.
- Rehabilitation Act Amendments of 1992, § 2, 29 U.S.C. § 701.

- Rehfuss, M. C. & Quillin, A. B. (2005). Connecting students with non-observable disabilities to resources. *NACADA Journal*, 25(1), 47-50.
- Revonsuo, A. (2010). *Consciousness: The science of subjectivity*. Howe, East Sussex: Psychology Press.
- Riddell, S. & Weedon, E. (2012). Disabled students in higher education: Discourses of disability and the negotiation of identity. *International Journal of Educational Research*. [www.elsevier.com /locate/ijedures](http://www.elsevier.com/locate/ijedures).
- Safilio-Rothschild, C. (1970). *The sociology and social psychology of disability and rehabilitation*. New York, NY: Random House.
- Samuels, E. (2003). My body, my closet: Invisible disability and the limits of the coming-out disclosure. *GLQ: A Journal of lesbian and gay studies*, 9, 233-255.
- Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin & N. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 118-137). Thousand Oaks, CA: Sage.
- Scott, S. T., McGuire, J. M. & Shaw, S. F. (2003). Universal design of instruction: A new paradigm for adult instruction in postsecondary education. *Remedial and Special Education*, 24, 369-379. doi:10.1177/07419325030240060801
- Sedgwick, E. K. (1990). *The epistemology of the closet*. Berkeley, CA: University of California Press.
- Seidman, I. (1998). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York, NY: Teachers College Press.

- Shackelford, A. L. (2009). Documenting the needs of student veterans with disabilities: Intersection roadblocks, solutions, and legal realities. *Journal of Postsecondary Education and Disability*, 22(1), 36-42.
- Shakespeare, T. (1996). Disability, identity, and difference. In C. Barnes & G. Mercer (Eds.). *Exploring the divide*, (pp. 94-113). Leeds: The Disability Press.
- Shapiro, A. & Margolis, H. (1988). Changing negative peer attitudes towards students with learning disabilities. *Reading, Writing, and Learning Disabilities*, 4, 133-146.
- Shaw, S. F. (2012). Disability documentation: Using all the data. *Journal of Postsecondary Education and Disability*, 25(4), 277-282.
- Sigelman, C. & Singleton, L. C. (1986). Stigmatization in childhood: A survey of developmental trends and issues. In S. Ainlay, G. Becker, & L. M. Coleman (Eds.), *The dilemma of difference: A multicultural view of stigma*. New York, NY: Plenum.
- Skrtic, T. M. (1995). Power/knowledge and pragmatism: A postmodern view of the professions. In T. M. Skrtic (Ed.), *Disability and democracy: Reconstructing (special) education for postmodernity* (pp. 25-65). New York, NY: Teachers College Press.
- Sleeter, C. M. (1995). Radical structuralist perspectives on the creation and use of learning disabilities. In T. M. Skrtic (Ed.), *Disability and democracy: Reconstructing (special) education for postmodernity* (pp. 135-152). New York: Teachers College Press.
- Smart, J. (2001). *Disability, society, and the individual*. Austin, TX: ProEd.

- Smith, L. T. (1988). *Decolonizing methodologies: Research and indigenous people*. London, England: Zed Books.
- Smith, M. D. & Fowler, K. M. (2009). Phenomenological research. In J. Paul, J. Kleinhammer-Tramill, & K. Fowleer (Eds.), *Qualitative research methods in special education* (pp. 163-178). Denver, CO: Love.
- Snyder, T. D., Tan, A. G. & Hoffman, C. M. (2004). *Digest of education statistics 2003* (NCES 2005-025). Washington, DC: U.S. Department of Education, National Center for Educational Statistics.
- Sroufe, L. A. (1997). Wariness of strangers and the study of infant development. *Child Development*, 48, 731-746.
- Stroman, D. F. (2003). *The disability rights movement: From deinstitutionalization to self-determination*. Lanham, MD: University Press of America.
- Stryker, S. (1980). *Symbolic interactionism: A social structural version*. Menlo Park, CA: Benjamin Cummings.
- Stryker, S. & Burke, P. J. (2000). The past, present, and future of an identity theory. *Social Psychology Quarterly*, 63(4), 284-297.
- Taylor, S. J. (2006). Forward: Before it had a name: Exploring the historical roots of disability studies in education. In S. Danforth & S Gabel (Eds.), *Vital questions facing disability studies in education*, (pp. xiii-xxii). New York: Peter Lang.
- Taylor, S. J. & Bogdan, R. (1998). *Introduction to qualitative research methods: A guidebook and resource*. New York, NY: John Wiley & Sons.
- Thévenaz, P. (1962). *What is phenomenology? And other essays*. Chicago, IL: Quadrangle Books.

- Thiselton, A. C. (2009). *Hermeneutics: An introduction*. Grand Rapids, MI: William B. Eerdmans.
- Thomas, C. (2004). Developing the social relational in the social model of disability: A theoretical agenda. In C. Barnes & G. Mercer (Eds.). *Implementing the social model of disability: Theory and research* (pp. 32-47), Leeds: The Disability Press.
- Thomas, D. (1982). *The experience of handicap*. London: Methuen.
- Thurlow, M. L., Ysseldyke, J. E. & Silverstein, B. (1995). Testing accommodations for students with disabilities. *Remedial and Special Education*, 16, 260-270.
- Tomlinson, S. (1995). The radical structuralist view of special education and disability: Unpopular perspectives on their origins and development. In T. M. Skrtic (Ed.), *Disability and democracy: Reconstructing (special) education for postmodernity* (pp.122-134). New York, NY: Teachers College Press.
- Torres, V., Howard-Hamilton, M. F. & Cooper, D. L. (2003). *Identity development of diverse populations: Implications for teaching and administration in higher education*. Washington, DC: Wiley Periodicals.
- Towler, A. J. & Schneider, D. J. (2005). Distinctions among stigmatized groups. *Journal of Applied Social Psychology*, 35(1), 1-14.
- Trammell, J. (2009). Postsecondary students and disability stigma: Development of the postsecondary student survey of disability-related stigma (PSSDS). *Journal of Postsecondary Education and Disability*, 22(2), 106-116.
- Trammell, J. & Hathaway, M. (2007). Help-seeking patterns in college students with disabilities. *Journal of Postsecondary Education and Disability*, 20(1), 5-15.

- Troiano, P. F., Liefeld, J. A. & Trachtenberg, J. V. (2010). Academic support and college success for postsecondary students with learning disabilities. *Journal of College Reading and Learning*, 40(2), 35-44.
- United States Census Bureau. (2010). Americans with disabilities: Household Economic Studies. Economic and Statistics Administration.
- United States Department of Education (2009). <http://www.ed.gov/news/press-releases/new-data-us-department-education-2009-10-civil-rights-data-collection-show-conti>
- United States Department of Education; Office of Educational Research and Improvement, (1999). Students with disabilities in postsecondary education: A profile of preparation, participation, and outcomes. National Center for Education Statistics (NCES 1999-187).
- Van Manen, M. (1990). *Researching lived experience: Human sciences for an action sensitive pedagogy*. New York, NY: State University of New York Press.
- Vogel, D. L., Bitman, R. L., Hammer, J. H., & Wade, N. G. (2013). Is stigma internalized? The longitudinal impact of public stigma on self-stigma. *Journal of Counseling Psychology*, 60(2), 311-316.
- Vogel, S. A. & Adelman, P. B. (1992). The success of college students with learning disabilities: Factors related to educational attainment. *Journal of Learning Disabilities*, 25, 430-441.
- Vogel, S. A., Leyser, Y., Wyland, S. & Brulle, A. (1999). Students with learning disabilities in higher education: Faculty attitude and practices. *Learning Disabilities Research & Practice*, 14(3), 173-186.

- Wagner, M., Cameto, R. & Newman, L. (2003). *Youth with disabilities: A changing population*. Menlo Park, CA: SRI International.
- Wagner, M., Newman, L., Cameto, R., Garza, N. & Levine, P. (2005). After high school: A first look at the postschool experience of youth with disabilities. A report from the National Longitudinal Transition Study-2 (NLTS2). Retrieved from http://www.nlts2.org/reports/2005_04/nlts2_report_2005_04_complete.pdf
- Wahl, O. F. (1999). Mental health consumer experience of stigma. *Schizophrenia Bulletin*, 25(3), 467-478.
- Ward, K. (2003). *Faculty service roles and the scholarship of engagement*. San Francisco, CA: Jossey-Bass.
- Weber, M. (1968). *Economy and society*. New York, NY: Bedminster Press.
- Webster, D. D. (2004). Giving voice to students with disabilities who have successfully transitioned to college. *Career Development for Exceptional Individuals*, 27, 151-175.
- West, M. D., Kregel, J., Getzel, E. E., Zhu, M., Ipsen, S. M. & Martin, E. D. (1993). Beyond Section 504: Satisfaction and empowerment of students with disabilities in higher education. *Exceptional Children*, 59, 456-467.
- Wolfensberger, W. (1988). Common assets of mentally retarded people that are not commonly acknowledged. *Mental Retardation*, 26, 65-70.