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Understanding College Students with Physical Disabilities Kimberly L. Hardner Kutztown University/Millersville University

#### Abstract

The purpose of this qualitative research study was to explore what it means to be a college student with a physical disability. The visibility of a physical disability a is distinct characteristic, even within the disability community, which often results in discrimination, oppression, and marginalization that influence both the identity and experiences of the individual. Through the research method of Photovoice, important considerations related to the identity and experiences of college students with physical disabilities were revealed in this study including: visibility (of a physical disability which leads to stigma and stereotypes); independence (ability to do things for oneself); membership in a university organization; support from the disability community; limited college options; money; insurance; power and control; mood; and, faculty awareness. In addition to the empowerment of participants in the creation of social changes as a result of this study, the findings of this study can also be utilized to shape current practices and policies in social work, and higher education and leadership, to improve access and inclusion of college students with physical disabilities.

*Keywords:* college students with physical disabilities, Critical Race Theory, Intersectionality, Self-Efficacy Theory, Universal Design, social work, higher education, access and inclusion, Photovoice, empowerment, social change

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# Understanding College Students with Physical Disabilities Chapter 1: Introduction and Problem Statement Introduction

As a particularly vulnerable population on university campuses, students with physical disabilities deserve attention, support, and advocacy from university leaders, faculty, and staff. Affording students with physical disabilities the same opportunities for inclusion and success within higher education aligns with social justice, one of the core values of the social work profession (NASW, 2008). Access to postsecondary opportunities should be equally available to all individuals, regardless of race, ethnicity, gender, sexual orientation, and in this argument, physical ability (Espinoza, 2007). This qualitative study, through the research method of Photovoice, provided insight into what it means to be a college student with a physical disability. The overarching qualitative research question of this study was: What does it mean to be a college student with a physical disability? In order to answer this question, two sub-questions were posed to each participant:

- 1. How do you describe your identity as a college student?
- 2. How has your physical disability influenced your experiences (academic and social) in college?

The findings of this study suggest that in relation to one's identity as a college student with physical disabilities, the themes of visibility, independence, membership within a university organization, and support from the disability community are paramount to one's success. These four themes influence a sense of security in relation to students' identity, which in turn, impacts their academic and social experiences in college. In relation to one's experiences, limited college options, money, insurance, power and control, mood, and, faculty awareness were found to be

significant factors that influence students' academic and social experiences in college, contributing to students' belief in their ability to succeed in college and further contributing to their overall sense of identity as a college student. Overall, the findings of this study suggest a relationship between the identity and experiences among students with physical disabilities, which influence students' belief in their ability to succeed, known as self-efficacy.

This chapter provides an introduction to this research study by exploring the problem statement, the purpose of the study, as well as the background of the problem. Additionally, an overview of each chapter is presented, followed by the implications of the findings of this study in relation to social work, and higher education and leadership.

## **Purpose of Study**

The overall aim of the study was to understand what it means to be a college student with a physical disability, through the exploration of participants' identity and experiences. This knowledge has the potential to shape practices and policies to promote and improve inclusion of individuals with disabilities in higher education. Understanding vulnerable populations, such as college students with physical disabilities, can provide significant contributions toward both leadership and education within the field of social work. Evidence that higher education "promotes the expansion of other capabilities" (Terzi, 2007, p. 759) underscores the demand for continued advocacy with and on behalf of individuals with disabilities. This need is further amplified by the reality that higher educational institutions are not adequately prepared to address the recruitment and retention of students with disabilities (Hong, Haefner, & Slekar, 2011). Qualitative research provides an opportunity for the voices of college students with physical disabilities to be heard, exposing the discrimination and challenges of current laws, policies, and practices in higher education, while simultaneously shedding light on the strengths

and capabilities of such students. Although literature exists on students with disabilities, in general, very few studies have considered the identity and experiences of college students with physical disabilities.

#### **Background of Problem**

Understanding the challenges experienced by college students with physical disabilities can be further appreciated by exploring important terms; applying a social work framework; and, reviewing current literature, to develop a strong theoretical framework which can be used to further analyze the problem. A social work framework, such as Ecosystems Model, provides a comprehensive assessment of individuals with physical disabilities, which incorporates the political, historical, social, economic, and cultural dimensions that influence this minority group. Current literature on college students with disabilities, although more general in nature, provides a solid foundation to build upon but demonstrates the need for literature that is more specific to the unique experiences of college students with physical disabilities. The Ecosystems Model along with current literature, assisted in the development of a theoretical framework for this study, which incorporated Critical Race Theory (CRT), Intersectionality, and Self-Efficacy Theory to expose social injustices that can be utilized to create social change.

## **Definition of Terms**

The Americans with Disabilities Act of 1990 "prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, State and local government services, public accommodations, commercial facilities, and transportation" (U.S. Government, n.d.). After challenges to the original definition of a disability the ADA Amendments Act of 2008 established a broad, yet more clear

three-prong definition of disability as: (1) a physical or mental impairment that substantially limits one or more major life activities; (2) a record (or past history) of such an impairment; or (3) being regarded as having a disability (U.S. Government, n.d.).
This new definition was established to prevent further scrutiny from the Supreme Court, which previously resulted in unfavorable findings toward individuals with disabilities (Final Rule Implementing the ADA Amendments Act of 2008, n.d.). The ADA does not provide a list of diagnoses that qualify under the law, but only guidelines for a physical impairment. Physical limitations refer to conditions that "limit major life activities such as seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, and working" (ADA Questions and Answers, 2009). College students with physical disabilities may have an impairment that impacts one or several of the ADA's identified life activities.

## **Social Work Framework**

Ecological Systems Theory, known more commonly as Ecosystems Theory, exemplifies the need to understand the person-in-environment, as individuals are influenced by their immediate and extended environments (Rogers, 2013). This multi-dimensional framework takes into consideration the reciprocal relationships between various systems and structures in society that influence a person or group of individuals (Morales, Sheafor, & Scott, 2012). The application of Ecosystems Theory provides guidance for a comprehensive assessment that incorporates elements of the political, social, economic, and cultural dimensions of society providing insight into societal "attitudes, perceptions, and prejudices" (Enwereji, 2016, p. 410) which influence post-secondary students with physical disabilities (Shrogen, Wehmeyer, Palmer, Soukup, Little, Garner, & Lawrence, 2007).

## **Political Dimensions**

The political dimensions of a social problem consider the laws, policies, and power differentials that exist in society (Rogers, 2013). Rules and regulations, whether implicit or explicit, ultimately define the values, rights, resources, and opportunities available to community members. The political lens of social work practice takes into consideration issues of social justice, which is defined as providing all individuals with "equal economic, political, and social rights and opportunities" (NASW, n.d.). By exploring the history of disability in the United States and disability laws with respect to education, one can gain insight into the trials and tribulations experienced by college students with physical disabilities and determine a more effective strategy to transform the current policies and laws to prevent discrimination and promote success in higher education.

Historical influences. Incorporating a person-in-environment framework provides a more thorough understanding of the political implications of living with a disability. After World War I, and the return of many wounded and disabled soldiers, Americans began viewing physical disabilities as less of an individual problem, and funding was provided to help war veterans (Morales et al, 2012). Almost a century later, despite the advances in perception and understanding, the stigma that persists with respect to physical disabilities continues to be debilitating (Nario-Redmond, Noel, & Fern, 2013). Policies and laws promoting equality, which resulted from the Civil Rights Act and the Feminist Movement of the 1960's, encouraged the persistence of those engaged in the Disability Rights Movement (Roessler, Hennessey, & Rumrill, 2007; Segal & Jacobs, 2013). The most prominent disability rights law is the Americans with Disabilities Act of 1990, which promotes the equality of individuals with disabilities in housing, education, the workplace, and the public in general (Lombardi, Gerdes, & Murray, 2011).

**Disability laws and education.** In primary and secondary school, students with disabilities are protected by educational laws, either under the Individuals with Disabilities Education Act (IDEA), which enforces access to primary and secondary education for students with disabilities designed to meet their specific needs; or, Section 504 of the Rehabilitation Act of 1973, more commonly known as Section 504 (Hamblet, 2009). IDEA requires the development of an Individualized Education Plan (IEP) for students with learning disabilities, intellectual disabilities, and hearing or visual impairments (Hamblet, 2009). The IEP must be reviewed for students on a yearly basis with a team of professionals. In contrast, Section 504 Plans are developed to address the specific needs of students with physical impairments, behavioral issues, and chronic health problems (Hadley, 2011).

Education laws, such as IDEA, no longer apply to students with disabilities after graduation from high school (Adams & Hayes, 2011). Only anti-discrimination laws, such as the ADA and Section 504, can be enforced in post-secondary institutions; although, such laws only require minimal provisions to be compliant (Hamblet, 2009). While 504 Plans can be requested in post-secondary education, it is important to note that 504 Plans from high school expire upon graduation, thus, a new plan must be initiated by the student in order to be developed (Hamblet, 2009). This can create an additional challenge for students with physical disabilities who may be accustomed to high levels of support and accommodations stemming from a plan initiated by professionals in primary and secondary school (Hadley, 2011).

## **Social Dimensions**

The social dimensions of disability provide and explanation and description of the reciprocal relationship that exists among individuals, organizations, and community (Rogers, 2013). A social lens allows one to view the "isms" (e.g. racism, sexism, ageism, and ableism)

that infiltrate society and the impact of such atrocities on an individual's ability to achieve their desired goals in life (Milner, Myers, & O'Byrne, 2015). Social workers consider relationships with others as a source of strength and support, and essential to life satisfaction, given that all persons are a part of a larger community. It is only natural, that one must consider the implications of the social lens with respect to disability, and more specifically, the social model of disability, which heeds the notion of disability as a concept constructed by human beings to categorize and determine who is or is not worthy of power (Ferguson & Nusbaum, 2012).

**Social model of disability.** Disability is a socially constructed concept that has changed throughout history to align with current political, economic, and cultural ideals (Ferguson & Nusbaum, 2012). In the United States, individualism is favored over collectivism, and as a result, social policies have been written to reflect values of individualism, leaving persons with physical disabilities often at a disadvantage (Duffy & Dik, 2009). Activists through the Disability Rights Movement sought to change this construction by shifting the focus of disability from a problem of the individual to a deficit in society, known as the social model of disability (Ferguson & Nusbaum, 2012). A social model of disability requires one to consider not only individuals who have disabilities, but also those who do not have disabilities (Liasidou, 2014). Social constructivist theory suggests that the meaning of disability and the assumptions that accompany it are constructed by the majority, in this case, those who do not have disabilities (Morales et al, 2012). The social model of disability suggests that in order to understand a person's view, the context in which that person interacts with the world must be taken into consideration (Ferguson & Nusbaum, 2012).

Understanding the social model of disability requires the delineation between the biological aspects of a person's disability and the barriers that prevent full inclusion in society

(Nario-Redmond, 2010). In contrast, the medical model of disability utilizes a biological deficit perspective by focusing on the individual's illness, disease, or impairment which does not align with the social work perspective (Pingry O'Neill et al, 2012). The medical model, a popular perspective until the 1970's when the Disability Rights Movement began to take form, proposes that disability is an individual problem requiring the individual to adapt to society, rather than considering adaptions that society can make to be more accessible (Dunn & Andrews, 2015).

Using a social model, one can begin to understand how stigma, which develops from the negative attitudes of those who experience the privilege of being able-bodied can be more harmful than the actual limitations of the person's disability (Nario-Redmond, 2010; Wang & Dovidio, 2011). Unfortunately, for many individuals with disabilities, the advances in policies and laws that promote equality have failed to transform the rigid social barriers that prevent true inclusion in society (Cory, White, & Stuckey, 2010). Incorporating a socially constructed framework of the concept of disability provides an opportunity for all members of a community, not just those who have a disability, to take an active role in dismantling the barriers that preclude inclusivity (Nario-Redmond et al, 2013). Gaining insight into the day to day trials and tribulations of college students with physical disabilities will provide other campus community members with opportunities to become allies in the efforts to address the needs of marginalized and oppressed students.

**Stigma theory.** Ervin Goffman's Stigma Theory creates a framework that conceptualizes the challenges individuals with disabilities face in society (Rogers, 2013). Goffman posited that society establishes norms of appearance, character, and behavior that are deemed to be acceptable (Pryor, Reeder, & Monroe, 2011). If an individual's appearance, character, or behavior does not fit within that realm of normalcy, such individuals are marginalized and

treated as if they are less of a person (Rogers, 2013). The overt and subliminal messages of inadequacy that permeate various aspects of one's environment create barriers to inclusion, further reaffirming the social construction of stigma (Nario-Redmond et al, 2013). Consequently, those who experience stigma may begin to internalize what society regards as shortcomings, which becomes embedded in their identity (Campbell, 2008). Normification, the concept of concealing or suppressing an aspect of oneself in an attempt to conform to society's expectations is rarely an option for an individual with physical disabilities, making stigma unavoidable (Adams & Proctor, 2010). Through examination of the everyday experiences of college students with physical disabilities, campus communities can develop more insight into the impact of stigma on students as well as student strengths that potentially combat stigma and stereotypes.

## **Economic Dimensions**

An individual's contribution toward greater society and sense of independence a staple value in American society, therefore it is impossible to overlook the economic dimensions of disability. American society deems optimal work performance and productivity as attributes of only those who are able-bodied (Duffy & Dik, 2009). Individuals with physical disabilities are viewed as incapable, less productive, and therefore, less economically worthy of employment opportunities (Barnard-Brak et al, 2016). Social exchange theory, the economic model of disability, as well as the market model of disability assist in the explanations of various economic perspectives that either promote or hinder the economic well-being of individuals with physical disabilities.

**Social exchange theory.** Higher education is viewed as a principle mean toward upward mobility, given that employability and financial security are dependent upon educational

attainment (Tevis & Griffen, 2014). Most major life choices require a cost-benefit analysis, the very foundation of Social Exchange Theory. Individuals are more willing to invest their time, energy, and money on items and services that will likely generate monetary, material, or emotional benefits (Rogers, 2013). An investment in a college education should yield long-term benefits of job stability and financial security; yet, the reality of the current economy combined with disability stigma leaves a bleak outlook on the promises of higher education for students with physical disabilities (Barnard-Brak et al, 2010; Sachs & Schreuer, 2011).

**Economic model of disability.** The economic model of disability stems from the medical model of disability and focuses on the individual's impairment and limitations (Fisher & Goodley, 2007). As such, the economic model defines disability as a person's inability to work or perform job tasks in the same manner as a person without a disability (Barmard-Brak, David, Tate, & Sulak, 2009). From an economic perspective, this model proposes that individuals with disabilities are either incapable of work or less productive in their efforts due to their limitations, resulting in a loss of monetary compensation for the individual, the employer, and society (Roessler et al, 2007).

In the college classroom, faculty who subscribe to this model fail to demonstrate a belief in the capabilities of students with physical disabilities to succeed academically. Such pessimistic faculty attitudes can lead to unfair grading practices and unsupportive relationships with students. On a larger scale, faculty who model such negative behaviors serve only to reinforce the belief for other campus community members that students with physical disabilities are less capable and less worthy of higher education. The economic model, although prominent in mainstream society, does not align with the social work perspective as it demonstrates a

mentality that perpetuates negative stereotypes and reflects lack of empathy and insight toward individuals outside of the dominant group (Ferguson & Nusbaum, 2012).

Market model of disability. In contrast, the market model of disability promotes individual expression of disability with a focus on investing in programs and services that support and empower individuals through economic opportunities (Enwereji, 2016). The market model of disability views individuals with disabilities along with their natural support systems (immediate family, friends, extended family) as major investors and consumers in the economic market (Enwereji, 2016). As such, the law of supply and demand will create a culture that naturally becomes not only more accepting, but more proactive toward social justice issues that impact individuals with disabilities (Liasidou, 2014). Providing opportunities for students with physical disabilities to not only access, but succeed in higher education will allow all students, faculty, and administrators to: 1. develop positive concepts of individuals with physical disabilities; 2. engage in more meaningful relationships with individuals with physical disabilities; 3. model positive interactions with individuals with disabilities to members outside of the campus community; and, 4. become more engaged in advocacy efforts with and on behalf of individuals with physical disabilities. Furthermore, colleges that implement the market model of disability can gain recognition for establishing new standards of diversity and inclusion.

## **Cultural Dimensions**

Culture refers to customs, behaviors, beliefs, and values of a group of individuals who share a commonality (Morales et al, 2012). Individuals with disabilities experience a sense of cohesion with one another, based on their shared experiences of having a condition that renders them "disabled" by society (Salsgiver, 2015). The cultural dimensions of disability are important to consider, as individuals with a multitude of disabilities encounter and interact with their

environment in a much different manner than a person without a disability. The experiences of individuals with disabilities are often reflective of marginalization and oppression brought on by able-bodied members of society who are in the majority, generating yet another source of commonality to solidify the status of persons with disabilities as a minority group (Salsgiver, 2015).

**Minority Model of Disability.** During the mid-20<sup>th</sup> century, the recognition of discrimination and oppression generated a source of shared identity for individuals with disabilities (Morales et al, 2012). A minority model approach can be utilized to understand: 1. how groups with shared identity are viewed in society; and, 2. the lack of power and control experienced by minority groups in comparison to the majority (Anastasiou, & Kauffman, 2013). As a minority group, individuals with disabilities have been treated unfairly, excluded from aspects of society, extended less freedom, and given fewer opportunities for self-determination than those of the majority who are able-bodied (Beckett, 2015). The minority model of disability emphasizes the discrimination experienced by minority groups at the systemic level, transferring the ownership of the problem and the solution to society (Morales et al, 2012).

At the college level, it is imperative to develop a deeper understanding of how students with physical disabilities are viewed by able-bodied peers, staff, faculty, and administration. As a minority group, college students with physical disabilities experience a lack of power and control in comparison to their able-bodied peers. Clarifying the perceptions of students with physical disabilities is essential in order to determine campus policies and practices that require re-evaluation to eliminate discrimination. Although it is certainly necessary to engage college students with physical disabilities in discussions on discrimination, the minority model of disability insists on the participation of all members of society in the quest for a solution.

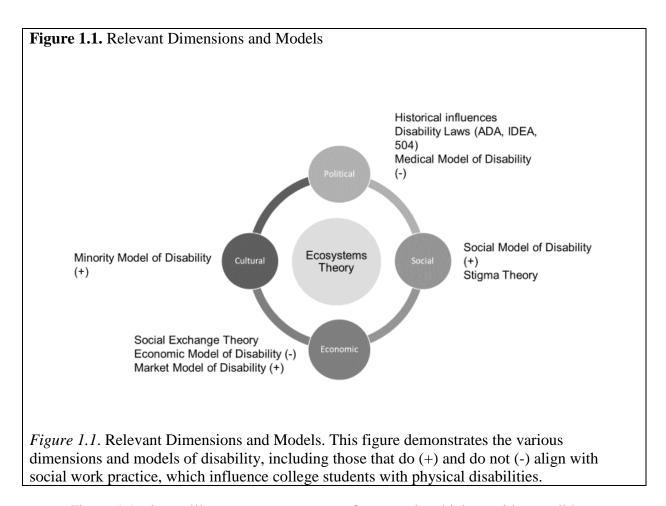


Figure 1.1, above, illustrates an ecosystems framework, which provides a solid foundation for social work research to explore the everyday experiences of college students with physical disabilities, by taking into consideration the political, social, economic, and cultural dimensions of this social problem. Individuals with physical disabilities are a particularly vulnerable population given their history of being mistreated and undervalued. Despite the efforts of the Disability Rights Movement that began decades ago, ignorance, stigma, and discrimination continue to persist through policies and practices grounded in the outdated and insensitive medical and economic models of disability. Rewriting policies grounded in the social and minority models of disability that challenge the status quo demonstrates the acknowledgement and commitment of all citizens as active participants in the efforts for a more inclusive society, which can become reaffirmed over the course of time through the market model of disability.

## **Synopsis of Chapters**

In addition to the Ecological Perspective that provides insight into the background of the barriers experienced by college students with physical disabilities, current disability literature in higher education must also be considered. Chapter 2: Literature Review, will explore the emerging themes from existing literature which demonstrate that: identity; self-advocacy; student skills; inclusion; family support; accessibility; accommodations; and, faculty perception and relationships are inherent to academic success in higher education. While this study validated the significance of each of these themes, more importantly, this study illuminated distinct themes exclusive to students with physical disabilities.

Chapter 3: Theoretical Framework, explicates three important theories: Critical Race Theory (CRT), Intersectionality, and Self-Efficacy Theory which offer a sound theoretical framework for the study of college students with physical disabilities. Implementing an antioppressive disability agenda, as previously suggested, requires an understanding of the existing social, political, and educational agenda that places individuals with physical disabilities in an inferior status in comparison to individuals who are able-bodied. By combining CRT, Intersectionality, and Self-Efficacy Theory as a framework, along with the method of Photovoice, this study was able to create counter-narratives from participants that can be utilized to combat oppression and discrimination experienced by college students with physical disabilities. The elements of this theoretical framework align not only with the research method of Photovoice, but also with the community-based participatory action research.

Chapter 4: Methodology, explores the research design of this study. Given the deficits in current literature specific to college students with physical disabilities, a transcendental phenomenological qualitative research design was chosen to explore the identity and experiences among participants of this study. Current literature is limited in relation to identity and experiences specific to college students with physical disabilities. Existing literature on disability and higher education is focused either on disabilities in general, or more recently on invisible disabilities (learning disabilities, ADHD, anxiety, etc.). Photovoice, a qualitative research method grounded in community-based participatory action research and known for increasing advocacy efforts to address social injustice issues was implemented.

The sample consisted of 8 college students, all of whom identified as having a mobility impairment. Participants ranged in age from eighteen to twenty-eight years. This study was conducted at a state university in northeastern United States, known for their exemplary services to students with physical disabilities. Despite the proactive efforts of the university, students with physical disabilities continue to experience discrimination on an individual and systemic level that impacts their experience as college students. Using Photovoice, participants were asked to take photographs that depicted both strengths and concerns related to the influence of their physical disability on their identity and experiences as college students. Within a focus group interview, participants shared their photographs and personal stories, engaged in dialogue about the phenomenon in question, and, explored themes that resulted from the focus group.

In Chapter 5: Findings, the photographs shared by participants during the focus groups are explicated in relation to each of the research questions: 1. "How do you describe your identity as a college student?"; and, "How does your physical disability influence your experiences (academic and social) as a college student?". Remaining consistent with CBPAR

which aligns with the transcendental phenomenological approach of this study, participants' responses to the research questions are further explicated in this chapter by distinguishing between textural descriptions (experiences of participants) and structural descriptions (context of experiences). Each photograph and corresponding description shared in relation to the identity and experience of each participant provides a counter-narrative that can be used to illuminate strengths and combat social injustices experienced by college students with physical disabilities.

Chapter 6: Discussion and Implications will review the specific themes that emerged from this study, discuss limitations, and highlight the implications of the findings of this study. This qualitative research study revealed ten significant factors that are distinct to college students with physical disabilities, including: visibility; independence; membership in a university organization; support from the disability community; limited college options; money; health insurance; power and control; mood; and, faculty awareness within a disability friendly university. As a qualitative study intended to highlight an unexplored area of research, this study is limited with respect to generalizability as a result of focusing on a small number of participants. Additionally, all participants of this study attended the same university, which could demonstrate findings that are inconsistent among other disability friendly universities in the United States.

In conclusion, as part of the process of Photovoice, which emphasizes CBPAR, participants explored ways in which the photographs of this study can be utilized to create awareness lead to important social changes. Participants of this study have been empowered by the process of Photovoice and are planning to start a student organization on campus that can address the needs and challenges of students with physical disabilities on campus, while enhancing strengths through community support. Through this organization, participants will be

developing a training to enhance faculty awareness, improving awareness of children in the community, and establishing a support group on campus for students with physical disabilities.

## Significance of Study

While literature on disabilities in higher education provides a foundation for understanding what it means to be a college student with a disability, this study though the implementation of Photovoice provides an opportunity to fill the current gaps in literature and provide a unique and authentic perspective of what it means to be a college student with a physical disability. This study revealed that college students with physical disabilities are a distinct and vulnerable group, who deserve more attention in research, practice, and policies in education and leadership, as well as social work.

## **Problem Statement**

Opportunities for students with disabilities to attend post-secondary institutions have increased tremendously over the past two decades, however, the rates at which individuals with physical disabilities attend college have remained rather stagnant over the past half-century (Wagner, Newman, Cameto, Garza, & Levine, 2005). Forty-five percent of high school graduates with disabilities, both visible and non-visible seek postsecondary education, representing approximately 11% of students in four-year colleges and universities (Newman, Wagner, Cameto, & Knokey, 2009), yet, only 1% of college students identify as having a physical disability (U.S. Department of Education, 2014). Additionally, only 34% of students with physical disabilities graduate from college compared to students without disabilities at 58% (Newman, et al, 2009; Wang & Dovidio, 2011). Post-secondary educational opportunities lead to careers that promote financial security, increase levels of independence, and enhance the overall quality of one's life (Sachs & Schreuer, 2011). Access to upward mobility, self-determination,

and enhanced well-being should be regarded as fundamental opportunities for all members of society, not only those who experience the privilege of being able-bodied.

Despite the laws established to protect individuals with physical disabilities and promote inclusion, many individuals continue to face discrimination on an individual and systemic level (Getzel & Thoma, 2008). Although the Americans with Disabilities Act (ADA) is viewed by many as the most significant law for individuals with disabilities, the battle for equality and acceptance continues to require unrelenting vigilance and advocacy (Pingry O'Neill, Markward, & French, 2012). Students with physical disabilities experience unique challenges associated with their acclimation to the college experience, such as: accessibility issues when navigating the campus; developing a sense of belonging in and out of the classroom; and, establishing their personal and professional identity (Vaccaro & Daly-Cano, 2015).

It is not unheard of for colleges to reject students with physical disabilities requiring personal care aides as decisions to deny students under such conditions are deemed constitutional under the ADA law (Hamblet, 2009). In fact, colleges are not obligated to permit personal care aides even when the student is paying privately for such services, and only three colleges in the United States provide 24-hour attendant care to students with physical disabilities (Hamblet, 2009; Kennedy Krieger Institute, 2011). A college that operates under the assumption that a student with a physical limitation is incapable of the level of independence required for academic success mistakenly promotes an elitist sense of entitlement for the academic rigor associated with higher education that fails to take into consideration the exceptionality of individual students, who are intellectually as qualified as their able-bodied peers.

## **Education and Leadership**

The intent of higher education is to foster student development through intellectual stimulation designed to enhance the capacity of individuals to meaningfully contribute to society (Baum, Ma, & Payea, 2010). Universities endorse the educational benefits of diversity, citing "how diversity promotes innovation, problem-solving, and new ways of thinking" (Tienda, 2015, pp. 467-468), yet very few university leaders and faculty understand how to integrate and cultivate diversity from a pedagogical perspective (Thoma, Pannozzo, Fritton, & Bartholomew, 2008). Higher education needs to keep pace with society as the concept of diversity continues to evolve well beyond race, ethnicity, gender, and religion.

University administrators and faculty are in a unique position to create systemic changes throughout the academy by shaping the behavior of future leaders, thereby, initiating a revolution for inclusion that defies the boundaries of the university. Administrators and faculty, who model inclusion of students with physical disabilities, are setting an indispensable precedent that has been disregarded for far too long. Upholding university sanctions for diversity requires campus leaders to develop and enforce more inclusive policies and practice techniques. Such policies and practices must reflect a commitment to nurture a sense of belonging and develop respect for individuals with physical disabilities.

#### **Social Work**

Advocacy for vulnerable populations, such as college students with physical disabilities, should be a concern among social work faculty, given their influence on future generations of social workers. Social workers make a commitment to advocate for individuals who are oppressed and marginalized, two unfortunate themes that consume many individuals with physical disabilities (Barnar-Brak, Lechtenberg, & Lan, 2010). In addition to advocating for social justice, the social work code of ethics outlines the importance of contributing to research in order to enhance

public knowledge and awareness of the plight of those who are vulnerable and oppressed (NASW, 2008). As such, social workers should be actively involved in the development of policies and practices within higher education and beyond to improve the academic success of college students with physical disabilities.

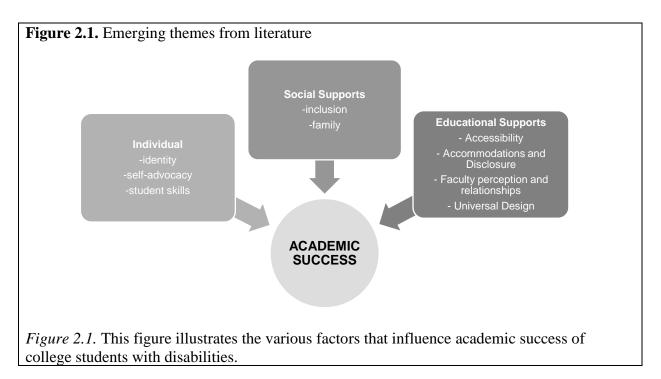
## **Summary**

This qualitative research study of college students with physical disabilities through the method of Photovoice provided a unique opportunity to not only expose the strengths and challenges of participants in higher education, but an opportunity to empower vulnerable individuals to fight for social justice, the foundation of social work practice. Although it is the visibility of a physical disability that results in discrimination and oppression, it is the visibility of the photographs from this study that send a powerful message along with counter-narratives which can counteract the stigma and stereotypes. The findings of this study have the potential to not only shape current practices and policies within social work and higher education, but additional considerations for research among college students with physical disabilities.

## **Chapter 2: Literature Review**

## **Current themes in literature**

The success of any college student is typically measured by academic achievement, specifically, graduation. Understanding, however, that students with physical disabilities have unique needs that must be taken into consideration, it is imperative to develop a deeper appreciation for the factors that contribute to academic success. Current disability literature in higher education, although not necessarily specific to physical disabilities, reveals themes such as: identity; self-advocacy; student skills; inclusion; family support; accessibility; accommodations; and faculty perception and relationships as paramount to academic success. In addition to recognizing the significance of each of the individual factors that contribute to academic success, it is also essential to explore the interconnectedness of such influences in order to expand opportunities for students with physical disabilities in higher education. Figure 2.1, below, illustrates the various factors that influence the academic success of students with disabilities in higher education.



## **Individual Predictors of Student Success**

From an individual level, most studies focus on traits, behaviors, and attitudes of students with physical disability in relation to their success in higher education. Themes that emerged from the literature included: identity; self-advocacy; and student skills (study habits, time management, and communication skills).

**Identity.** Individuals with physical disabilities are faced with stigma and stereotypes related to their limitations, resulting in a profound impact on a person's self-esteem, a major influence of identity development. A person's identity is defined not only by personal attributes, but through group membership, which contributes to shared similar experiences and offers a protective factor to potentially combat stigma (Nario-Redmond, Noel, & Fern, 2013). Students with physical disabilities must understand and accept their disability as part of their identity in order to self-disclose and self-advocate, two important elements of success at the university level (Adams & Proctor, 2010; Rothman et al, 2008). However, many students avoid seeking accommodations for their disability at the college level because it reduces their sense of independence, a major influence in identity development during young adulthood (Wang & Dovidio, 2011).

Betz and Hackett (2006) describe how self-efficacy can explain math anxiety and the society's influence on the underrepresentation of women in science, technology, engineering, and math (STEM) careers. Women have historically been told they were incapable of performing at the same levels as men in such careers, and as a result, women believed that they were inferior. Low expectations lead to negative self-fulfilling prophecies which perpetuated the anxiety women experienced related to math and science (Betz & Hackett, 2006). The same concept can be applied to individuals with disabilities in terms of self-efficacy.

**Self-advocacy.** A review of literature related to post-secondary education and students with disabilities consistently points to self-advocacy as one of the most important skills necessary for success (Ankeny & Lehmann, 2010). Self-advocacy includes the ability to understand one's disability and disability laws, as well as articulating one's strengths and needs in order to advocate for oneself (Rothman et al, 2008). Self-disclosure of one's disability can be obstructed by the stigma that persists within society and may leave one feeling fearful of prejudice from peers, faculty, and greater society (Barnard-Brak, Davis, Tate, & Sulak, 2009). Historically, individuals with disabilities have experienced rejection, neglect, and persecution and as a result, many individuals with disabilities remain vigilant in their attempts to prevent similar atrocities by avoiding disclosure (Ferguson & Nusbaum, 2012). Students with disabilities may be concerned that: 1. registering with the office of students with disabilities may limit their academic choices in college; 2. accommodations may be time-consuming or require additional technology that makes a student with a disability stand out amongst peers; or, 3. disclosure will negatively impact their social status (Marshak et al, 2010).

The concept of self-determination, a key element of social work practice which promotes the appreciation that it is the client, and not the social worker, whose choice will prevail. In order to develop self-determination and self-advocacy skills, fundamental aspects to the transition to higher education, college students with physical disabilities must understand and accept their disability as part of their identity in order to effectively advocate for themselves (Adams & Proctor, 2010). Wang and Dovidio (2011) revealed that using person-first language not only impacts an individual's sense of identity, but also influences "how people with disabilities think and act" (p. 126). When college students with disabilities were primed with their identity as a

student, autonomy increased, in comparison to college students with disabilities who were primed with their identity of having a disability, autonomy decreased (Wang and Dovidio, 2011).

Many students choose not to disclose their disability in college because they are either fearful of the label or worried that they may not be seen viewed as having equivalent educational aptitudes as their non-disabled peers (Hong, Haefner, & Slekar, 2011). Self-determination has been noted as one of the most important skills necessary for academic success among students with disabilities (Barnard-Brak et al, 2009). The concept of autonomy is an inherent element and a personal quality necessary to demonstrate self-determination, begging the questions of whether or not this needs to be demonstrated prior to attending college or whether it can be ascertained as part of the process of being a college student (Doren, Gau, & Lindstrom, 2012).

Developing a sense of belonging for college students with physical disabilities can be especially challenging due to the "spread effect", a term conceptualized by Beatrice Wright, which explains how overgeneralization impacts the interpretation of a person's cumulative abilities due to a disability (Miller, Chen, Glover-Graf, & Kranz, 2009). Societal attitudes toward individuals with disabilities extend far beyond the individual. In fact, studies have demonstrated that society will even stigmatize those individuals without disabilities who engage with individuals with disabilities (Pryor, Reeder, & Monroe, 2011). The concept of stigma by association reinforces negative stereotypes and results in further marginalization and oppression of an already vulnerable population.

**Student skills.** In addition to self-advocacy, research has demonstrated that study skills, organizational skills, and communication skills are fundamental elements of academic success among students with disabilities (Hedrick et al, 2010). Doren et al (2012) established a positive correlation between autonomy and study skills with the completion of post-secondary school

among students with disabilities. Furthermore, time management and organizational skills have been identified as necessary skills that contribute to the success of college students with disabilities due to the fact that some physical limitations require increased investment in time to complete homework and other class assignments (Hedrick, Dizen, Collins, Evans, & Grayson, 2010). Unfortunately, the literature does not delineate between types of disabilities and does not take into account the challenges related to study skills, organizational skills, and communication skills experienced by students with physical disabilities. For example, a student with ADHD may need to have strong organizational skills in order to succeed academically, but those organizational skills will look much different compared to the organizational skills of a student with cerebral palsy who has limited hand and arm movement. As a result of a physical disability, it is often necessary for students with physical disabilities to seek the support of other individuals to assist them with such skills.

#### **Social Supports**

In addition to the individual factors of students, it is imperative to define aspects of social supports that influence the success of college students with physical disabilities. Social supports refer to the relationships with individuals and groups, both formal and informal, that enhance one's overall well-being and opportunities for achievement. Current literature reveals themes of a sense of inclusion on campus and strong family support as indicative of significant accomplishments in higher education among students with physical disabilities.

Inclusion and sense of belonging. Students with physical disabilities, who feel a sense of belonging to their campus community, demonstrate: enhanced self-advocacy skills; greater levels of self-efficacy; and, meaningful relationships with peers (Vaccaro & Daly-Cano, 2015). Literature reveals that developing a sense of belonging within one's university is the "key to academic success and persistence" (Vaccaro & Daly-Cano, 2015) amongst individuals with

disabilities. Cognitive, social, and psychological development transcends the classroom in higher education, with a strong emphasis on the social aspects of higher education and the development of one's identity and sense of purpose in young adulthood (Sachs & Schreuer, 2011; Trainor, 2008). Social inclusion among college students has been positively correlated with grade point averages, as it has been well documented that students who are involved in campus life earn better grades compared to students who feel isolated (Hadley, 2011).

For students with physical disabilities, accessibility and safety are among of the most important considerations with respect to developing a sense of belonging within the university community (Vaccaro & Daly-Cano, 2015). Whether or not one can safely navigate the campus landscape is of major concern to a student with a physical disability, however, accessibility extends far beyond the basic requirements of ADA building codes (ramps, elevators, automatic doors, and the wider width of doors) (Hedrick et al, 2012). Social acceptance and academic acknowledgment are two significant factors in the development of one's identity as a student and a member of the campus community (Sachs & Schreuer, 2011).

Paul (2000) found that almost 50% of college students with disabilities sought psychological counseling to deal with adjustment issues that arise during the transition to college. From a psychological standpoint, acceptance and support from peers and faculty are important factors in the development of a sense of belonging in higher education, negating a sense of isolation from the perspective of a student with a physical disability (Adams & Hayes, 2011). Not only is it important for students with disabilities to be accepted socially by their peers and included in social and recreational activities on campus, but students must also feel a sense of belonging within the classroom in terms of academic integration. Students with physical

disabilities cite the significance of being viewed "as a legitimate student" (Vaccaro & Daly-Cano, 2015) by peers and faculty as integral to their sense of identity and belonging on campus.

**Family support.** High levels of family support prior to post-secondary education are positively correlated with higher levels of self-advocacy and self-determination (Lombardi et al, 2011). Along with peers, family support is viewed as a protective factor for college students with disabilities and academic achievement (Murray, Lombardi, Bender, & Gerdes, 2013). Specifically, parent expectations have a significant impact on the post-secondary outcomes of students with disabilities and are associated with: higher student grade point averages; test scores equivalent to those of non-disabled peers; and, evidence of social adjustment in post-secondary school (Doren, Gau, & Lindstrom, 2012).

## **Educational Supports**

Important educational supports to consider with respect to the success of students with physical disabilities in higher education include: accessibility; accommodations and disclosure; and, faculty perception and relationships. Literature highlights the significance of policies, practices, and programs within the institutions of higher education as substantial influences on the success of students with physical disabilities.

Accessibility. Access to higher education is an element of academic success that cannot be overlooked. It is imperative to note that college students who identify as members of groups who experience oppression and marginalization are more likely to experience drop-out within the first year of post-secondary education (Sachs & Schreuer, 2011). Accessibility for college students with disabilities extends beyond the physical implications of the ADA requirements and must also include the academic and attitudinal barriers (focusing on the person's disability, rather than abilities) that prevent full inclusion on college campuses (Gelbar, Madaus, Lombardi, Faggella-Luby, & Dukes, 2015). The outcomes of such academic and attitudinal barriers,

although less obvious, have devastating and debilitating consequences such as isolation and bullying, which can lead to the development of serious mental health issues and ultimately dropout.

Accommodations and disclosure. Increased expectations for independence of students in higher education adds additional pressure to students with physical disabilities (Gelbar et al, 2015), as universities are not required to provide accommodations that "fundamentally alter" (Americans with Disabilities Act, 2008) their programs. The most common accommodations for students with disabilities in higher education include: extended exam time; notetakers or permission to record lectures; and, the provision of textbooks and readings in alternate formats (Orr & Hammig, 2009). This can be a significant adjustment for students who were previously afforded accommodations such as: alternate exam forms; one-on-one classroom aides; extended time for assignments; and study guides (Hamblet, 2009).

As students transition to college, the burden of disclosing a disability and requesting accommodations falls on the student (Hamblet, 2009). Despite the availability of accommodations to assist college students with disabilities, many eligible students do not take advantage of the existing resources and services. Marshak et al (2010) found that only 40% of college students who received special education in high school identify as a student with a disability in college. In fact, a National Longitudinal Transition Study found that 53% of students who received special education services in high school believed they no longer had a disability in college (Wagner et al, 2005). Among those who identify as having a disability, only 88% seek services and accommodations through the university (Marshak et al, 2010). The most notable reasons for avoiding disclosure of one's disability, denying the existence of one's disability, or not taking advantage of disability services on campus is: stigma (Marshak et al, 2010).

Stigma is often cited as being more detrimental than the limitations of one's disability, and the label associated with having a disability is one that many college students seek to avoid as they try to find their sense of purpose and develop their identity (Barnard-Brak et al, 2009). Student attitudes toward accommodations are vital factors of academic achievement and signify the need to reduce the stigma associated with disabilities in order to promote the success of individuals with disabilities in higher education (Trammell & Hathaway, 2007). According to Barnard-Brak & Lan (2010), four factors are essential to the student's disclosure of a disability and include:

their relationship with able-bodied others; the relevance or 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 (pp. 413-414).

It is imperative, therefore, to consider how institutions of higher education promote or inhibit interactions and relationships among students with physical disabilities and their non-disabled peers, as well as non-disabled faculty and staff. Additionally, it may be necessary for institutions to consider the implications of providing mentors to students with physical disabilities, who can attest to the experience of being a college student and assist students in the process of navigating higher education and beyond.

**Faculty-perception and relationships.** College faculty play an important role in the academic success of students with physical disabilities, and have the potential to profoundly influence the success of their students through their: 1) attitude toward diverse learners (e.g., ignoring diverse learners; making assumptions about their abilities); 2) understanding of disability laws (e.g., ADA and Section 504 protect students from discrimination in higher

education); 3) teaching strategies (e.g., utilizing visual, verbal, and kinesthetic learning to engage students; providing access to lecture notes or Power Point presentations before class); and, 4) utilization of appropriate disability terminology (e.g., utilizing person first language, as in "Chris, who has Cerebral Palsy") (Cook, Rumrill, & Tankersley, 2009; Gerdes & Murray, 2011; Sachs & Schreuer, 2011).

Cook et al (2009) describe the "type and quality of interactions" (p. 84) between students and faculty, in and out of the classroom, as imminent to student success. In comparison to students without disabilities, students with disabilities cite interaction beyond the classroom environment as more important to their academic success, which can be as simple as "prompt feedback" (Hedrick et al, 2010, p. 132). Although the burden of disclosing one's disability and seeking accommodations falls on the student, faculty need to be adequately prepared to understand and feel comfortable having such important discussions with students (Hadley, 2011).

**Universal design.** The term Universal Design (UD) was first conceptualized in the field of architecture over three decades ago by Ronald Mace, an architect and wheel chair user, who suggested that architects should consider their proposals with the needs of diverse individuals in mind in order to make buildings accessible to more individuals (Lombardi, Murray, & Gerdes, 2011). Universal design is a term used to describe a multitude of items and spaces that can be used by a diverse range of individuals with the least amount of adaptations necessary (Lombardi et al, 2011). UD is a proactive approach that intentionally contradicts the perception of functional disability as an anomaly (McGuire, Scott, & Shaw, 2006).

In education, UD has been utilized as a paradigm to create facilities, technology, and instruction that meets the needs of diverse learners (Kimball, Vaccaro, & Vargas, 2016).

Evidence of the acceptance of UD in primary and secondary education throughout the United States can be demonstrated by policies that promote the key principles of universal design in technology, assessments, and training mandates, UD has resulted in more inclusive teaching practices, known as mainstreaming, ultimately providing access to more diverse learners in postsecondary education (McGuire et al, 2006). Given that educational policies do pertain to postsecondary settings, individual institutions of higher education are able to utilize their own discretion for the implementation and enforcement of policies of Universally Design Instruction (UDI) (Hamblet, 2009). Although post-secondary education has been inundated with information and strategies to improve the implementation of UDI over the past decades, few faculty engage in such practices (Lombardi et al, 2011). In higher education, faculty are experts in content, not pedagogy, therefore, suggestions to redesign pedagogical strategies are often disregarded (McGuire & Scott, 2006).

Despite the lack of political mandates for UDI in post-secondary education, the social value of UDI demonstrates ample evidence for consideration in higher education (McGuire et al, 2006). UDI in higher education allows for optimal learning by promoting the inclusion of diverse learners through principles designed to support post-secondary faculty in the areas of: course planning; instructional delivery; and evaluation (Cook et al, 2009; McGuire & Scott, 2006). The foundational principle of Universally Designed Instruction is identical to the Universal Design of architectural blueprints: to extend accessibility to the greatest number of individuals (McGuire et al, 2006). Contrary to the opinion of those in opposition to UDI, UDI does not suggest that individual needs will not be considered or that individualized requests for accommodations will be denied (McGuire et al, 2006). The principles of UDI offer strategies to provide a more inclusive environment for learning so that fewer learners need to make requests for

accommodations. At the heart of the concept of Universal Design and Universally Designed Instruction is the "acknowledgement of human diversity as the norm" (McGuire et al, 2006, p. 168), a statement that closely resembles the fundamental tenet of the social work profession.

The success of UDI that is enforced in public primary and secondary schools through education laws has increased the inclusion of students with disabilities in regular education classes by placing students in the least restrictive environment (Jimenez, Graf, & Rose, 2007). Prior to UDI, special education students spent the majority of their school day excluded from the mainstream student population, however, UDI has provided teachers with options to make the general education classrooms more inclusive (Jimenez, Graf, & Rose, 2007). Four out of five students with disabilities in secondary school now indicate interest in attending post-secondary education, a goal that was thought to be out of reach twenty years ago (Park, Roberts, & Strodden, 2012).

UDI is not enforced in higher education, as colleges and universities are only required to – to anti-discrimination laws, not education laws (Black, Weinberg, & Brodwin, 2014). Smaller, qualitative studies have been conducted in higher education to determine the effectiveness of UDI, demonstrating that faculty attitudes and willingness to accommodate are directly related to "training and degree of contact with students with disabilities (Black, Weinberg, & Brodwin, 2014, p. 50). Park, Roberts, and Strodden (2012) found that after a three-day professional development training for university faculty on students with disabilities, faculty reported enhanced willingness to engage in UDI as well as stronger advocacy skills for students with disabilities on campus. Black, Weinberg, Brodwin (2014) report that outcomes of UDI, from both the student and faculty perspectives, in higher education consistently demonstrate enhanced effectiveness of student learning and the development of more appropriate assessments that

accurately reflect student knowledge. While none of the above studies focused specifically on college students with physical disabilities, the overall premise of UDI appears to be promising.

# **Critique of Existing Literature**

Knowledge of various disabilities has evolved along with a greater number of students with disabilities attending college, however, advances in higher education for students with physical disabilities have remained stagnant (Roessler et al, 2007). The "scarcity of literature on academically successful students with physical disabilities" (Tevis & Griffen, 2014, p. 240) is a concern that cannot be ignored. Several gaps and shortcomings have been identified. First, and foremost, although research on college students with disabilities has increased over the past decade, it can be challenging to separate the specific needs of students with visible disabilities from the students with invisible disabilities. Second, most studies of college students with physical disabilities are qualitative and small in scale, therefore, generalization becomes problematic. Third, the current attention of disability literature, as it relates to higher education appears to be focused on invisible disabilities, such as: learning disabilities; mental health issues; and, medical diagnosis (epilepsy, Chron's Disease, autoimmune disorders, etc.) (Sachs & Schreuer, 2011). While this research has undoubtedly promoted opportunities for students with disabilities in higher education, it does not account for the unique lived experiences of students with physical disabilities often encompass more than one single focus (e.g., individual supports, social supports, or educational supports), exemplifying the complexity of the problem (Gelbar et al, 2015; Sachs & Schreuer, 2011).

## Potential Implications for Evidenced-based Social Work Practice

The micro level of practice refers to social work practice with individuals. From an individual perspective, social workers must consider the strengths and needs of college students with physical disabilities, individually, as each person's academic, social, and overall world

experience is unique. Micro level of social work practice considers the presenting problems of individuals in relation to their environment and seeks to help the individual remedy their situation through counseling, psychoeducation, and advocacy (Rogers, 2013). The macro level of social work practice refers to engagement with larger groups and communities by influencing policies and engaging in research, in order for change efforts to positively impact the greatest number of individuals (Miller, Tice, & Hall, 2008). In the case of college students with physical disabilities, both the micro and macro levels of social work practice are essential in creating parity within higher education.

### **Micro level practice**

The topic of the academic success of college students with physical disabilities is especially relevant to social justice, the field of social work, and higher education. At the micro level, defining factors that promote the academic success of individuals with physical disabilities can be helpful to social workers, counselors, therapists, and secondary educators as they prepare students for the transition to college. By focusing on strengths and improving factors that lead to academic success from an empowerment perspective, these professionals can maximize the potential of individuals with physical disabilities in college, in their careers, and, in life in general. Educational attainment is an important facet of one's identity development, as it creates opportunities to promote status and power, an aspect of intersectionality that has the potential to combat the negative stereotypes associated with one's identity (Tevis & Griffen, 2014).

### Macro level social work practice

Macro social work practice seeks to change conditions that negatively impact vulnerable groups, by challenging the structural and political systems that oppress and marginalize groups (Miller, Tice, & Hall, 2008). College students with disabilities perceive effective implementation of universal design by faculty as paramount to their success in the classroom

(Lombardi, Gerdes et al, 2011), demonstrating that training university faculty "may positively affect faculty attitudes toward disability and inclusive instruction" (Murray, Lombardi, Wren, & Keys, 2009). Developing and implementing evidence-based training for faculty on universally designed pedagogy acknowledges that university administrators and faculty understand the inherent privilege associated with their own education as well as the significance of their position as a role models for students. Albert Bandura's Social Learning Theory demonstrates how students will: 1. observe the faculty modeling the inclusivity of UD; 2. associate positive meaning with faculty, UD, and diverse individuals; and, 3. engage in similar behaviors of acceptance and openness to diversity through imitation (Rogers, 2013).

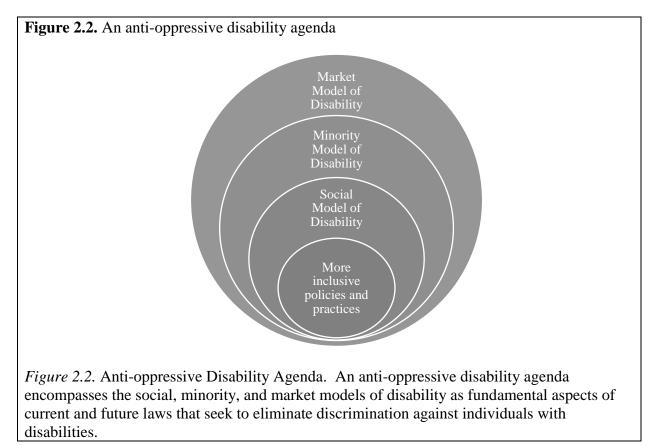
Despite the literatures suggestions for the adoption and implementation of UD in higher education, current research needs to focus on expanding the understanding of the issue of academic success among college students with physical disabilities. Before taking on the responsibility and accountability of UD, it is crucial for researchers to understand the true nature and extent of the challenges experienced by college student with physical disabilities, in more depth, before a solution can be proposed and pursued. Although literature suggest that UD is a part of the solution, further exploration is needed before determining a holistic strategy to adequately resolve the issue of the underrepresentation, as well as the success, of college students with physical disabilities.

#### **Contributions for Further Research**

A review of current literature emphasizes that students with physical disabilities are underrepresented in higher education, especially in four-year colleges and universities (U.S. Department of Education, 2014). Factors that influence the academic success of students with physical disabilities include: identity; self-advocacy; student skills; inclusion; family support;

accessibility; accommodations; and, faculty perception and relationships (Adams & Proctor, 2010; Barnard-Brak et al, 2009; Hadley, 2011; Hamblet, 2009; Rothman et al, 2008; Vaccaro & Daly-Cano, 2015). A social work perspective provides a holistic approach to understanding social problems and assisting clients in the formulation of solutions (Rogers, 2013). This holistic approach mirrors the complexity of human beings in relation to the complexity of the multidimensional aspects of one's surrounding environment.

A current literature review lends itself to an anti-oppressive disability agenda (see Figure 2.2, below), an ideal framework to not only explicate, but also justify the significance of a social work perspective on the eradication of discrimination against college students with physical disabilities through formulation of proposals that focus on enhancing the success of such students.



By incorporating the social model of disability, which focuses on the responsibility of all members of society, along with the minority model of disability, which recognizes the power differential that exits between individuals with disabilities and individuals who are able-bodied, all citizens can be part of the solution to creating more inclusive policies, practices, and opportunities for inclusion. The market model of disability, acknowledges that most members of society have some type of relationship with a person with a disability, and as a result, everyone in society can benefit on some level from the creation of new laws that advance the well-being of persons with disabilities.

# **Chapter 3: Theoretical Frameworks**

## **Prominent Theoretical Frameworks**

Although many theories of disabilities exist and provide frameworks to conceptualize problems experienced by individuals with disabilities, the most influential theories that align with social work practice are those that support social justice and self-determination. Three prominent theories, as shown below in Figure 1, emerged from the literature that reflect these values, highlighting society's accountability for the civil rights of those who are oppressed and marginalized: Critical Race Theory; Intersectionality; and Self-Efficacy Theory.

| Critical Race Theory   | Intersectionality  | Self-Efficacy Theory   |
|--|--|--|
| <ul> <li>Shifts the personal<br/>and group deficit<br/>perspective to<br/>institutional levels<br/>(Abrams &amp; Moio,<br/>2009)</li> <li>Ignorance of privilege<br/>= perpetuation of<br/>inconsiderate policies<br/>and practices</li> </ul> | <ul> <li>Intersection forms<br/>either "privilege or<br/>oppression" (Tevis &amp;<br/>Griffen, 2014, p. 241)</li> <li>Can be utilized to<br/>elicit strengths that<br/>reduce stigma<br/>(Campbell, 2008)</li> </ul> | <ul> <li>Belief in one's ability<br/>to successfully<br/>complete a task<br/>(Chang, Wang, &amp; Lee,<br/>2016)</li> <li>Cognitive appraisal,<br/>NOT personality trait<br/>(Betz &amp; Hacket, 2006)</li> </ul> |

disabilities.

Each theory, individually, offers insight into the explanatory construction of the strengths and challenges experienced by students with physical disabilities in relation to their identity and overall experience in higher education. Collectively, these three theories have the potential to present a unique orienting framework to identify ways in which identity and experiences in college impact students with disabilities, in order to assist with the construction of more inclusive policies and practices in higher education. Examination of each theory through the intended, traditional framework will be followed by further explication of each theory in relation to college students with physical disabilities.

# **Critical Race Theory**

Critical Race Theory (CRT) provides a theoretical foundation for cultural competence in social work education and practice, as it aligns with both the minority model and social model of disabilities. CRT promotes cultural sensitivity through an "anti-oppressive approach" (Abram & Moio, 2009, p. 247), which seamlessly aligns with several of the core values of social work: social justice; dignity and worth of the person; and, the importance of human relationships (NASW, 2008). Critical Race Theory emphasizes the inequalities between those in the majority and those with minority group status. The unearned power that results from one's majority group status, known as privilege, is a challenging, yet necessary concept for those in the majority to accept (Nishida & Fine, 2014). According to CRT, ignorance of the existence of privilege by those in the majority will only "normalize and perpetuate" (Abrams & Moio, 2009, p 250) the inconsiderate policies and inaccessible environments for individuals with physical disabilities.

# **History of Critical Race Theory**

Critical race theory undoubtedly began in the 1970's, on the heels of the civil rights and feminist movement, as a blend of both critical law theory and radical feminism (Delgado & Stefancic, 2017). Critical law theory challenges the status quo of the existing laws by exposing how individuals with power in society are able to maintain control over minorities, directly and indirectly through laws and policies (Delgado & Stefancic, 2017). Radical feminism is a feminist

perspective that seeks to eliminate patriarchy, the root cause of the oppression of women, by opposing social norms and political structures that are inherently rooted in male dominance (Delgado & Stefancic, 2017). Derrick Bell, the founding father of CRT, along with Alan Freeman, Richard Delgado, and Kimberle Crenshaw, among many others were instrumental in the theory's design and movement, just as CRT seeks to eliminate whiteness (Delgado & Stefancic, 2017). Similar to other critical theories, CRT is not only focused on exposing injustices embedded within society, but providing opportunities for the transformation of society (Ladson-Billings, 2013).

## **Basic Tenets of CRT**

Critical race theory seeks to expose and transform the concepts of "race, racism, and power" (Delgado & Stefancic, 2017) that have led to the unequal treatment of minorities in society. CRT is underscored by five basic tenets, which provide a holistic examination of the factors that contribute to racism and discrimination (Delgado & Stefancic, 2017). These five tenets include: racism as an ordinary occurrence; interest convergence; the social construction of race; intersectionality; and, narration (Delgado & Stefancic, 2017; Ladson-Billings, 2013).

**Racism as ordinary.** Racism is the belief that one race is superior to another, and in the United States, those who are white race hold power, authority, and privilege over all other minority groups without white skin (Ladson-Billings, 2013). Racism is not experienced by a small group of individuals, nor is it restricted to a small area of the country. Racism is pervasive and deeply embedded in the social and political structures of society that truly abolishing it is considered an incredible task (Delgado & Stefancic, 2017). Racism exists, and must be acknowledged in order combat practices and policies that perpetuate it. While superficially, the concept of "colorblindness" can be viewed as commendable, critical analysis exposes the

negativity of feigning such an equality that simply has not transpired (Deglado & Stefancic, 2017). Rather than ignorance or silence, minorities deserve respect and compassion for their history, their culture, and their experiences.

Interest convergence. The second tenet of CRT posits that white supremacy "serves important purposes, both psychic and material" (Delgado & Stefancic, 2006, p. 3). The idea of convergence suggests that the dominant group, in this case, whites, gain both tangible and intangible benefits through the very social and political structures that enforce racism (Ladson-Billings, 2013). Critical race theorists affirm that whites are only interested in supporting laws and policies that promote blacks and other minorities if, and only if, there is a benefit for them as well (Ladson-Billings, 2013). The majority of those in law making capacities are white, therefore, critical race theorists suggest that one must consider the true motivation behind the creation of laws that combat racial injustices, which would ultimately decrease the authority of whites (Delgado & Stefancic, 2017). While it is admirable to believe altruism will prevail, history does not paint a likely picture. For example, affirmative action, which serves to improve occupational opportunities for minorities has caused tension among whites who fear decreased employment opportunities for themselves.

**Social construction of race.** The third tenet of CRT is based on the scientific knowledge that there is no biological proof of race, proving that the concept of race is socially constructed (Deglado & Stefancic, 2017). Race is a concept that has been constructed by mankind as a way to categorize groups of individuals who share similar skin color, hair texture, and facial features, and body structure are considered to be of a certain race (American Indian, black, Asian, etc.) in order to create a hierarchy of power in society (Ladson-Billings, 2013). Race has a powerful hold

on the most vulnerable populations in society, creating a colossal barrier that few minorities can seem to overcome.

Intersectionality. Delgado and Stefancic (2017) affirm that "no person has a single, easily stated, unitary identity" (p. 10). Intersectionality refers to the overlapping aspects of identity that co-exist among individuals who identify as members of two or more minority groups (Ladson-Billings, 2013). The concept of minority status, however, extends far beyond race, and includes: gender; sexual orientation; ethnicity; religious affiliation; ability; socioeconomic class; and, much more (Delgado & Stefancic, 2017). It is important to recognize that dual and even multiple minority membership is not as elusive as one may think. Consider for example: a white woman who is Jewish; a gay, single father; an African American man who is Muslim; a woman with Cerebral Palsy; or, an elderly Syrian refugee. Each of these individuals has at least two facets of their identity that places them in the status of a minority. While some individuals may experience access to privileges when aspects of their identity align with the majority (e.g. white, male, cisgender, able-bodied, etc.), others are dealing with multiple minority statuses (e.g. African American, Hispanic, female, homosexual, disabled, etc.) and experience oppression that compounds with each intersecting element (Ladson-Billings, 2013).

**Narration.** Providing a narrative account of an experience from a minority group's perspective is a is significant element of CRT (Delgado & Stefancic, 2017). Without the perspective of a minority group member, the majority's narrative transcends, and this account is often saturated with biased information and a skewed agenda (Ladson-Billings, 2013). Narration provides an opportunity to challenge the status quo by revealing the perception of minority group members' experiences, and transforming society's capacity for compassion, support, and ultimately, acceptance. In fact, many minorities agree that historical accounts of events told by

white men are simply "ridiculous, self-serving, or cruel but not perceived to be so at the time" (Delgado & Stefancic, 2017, p. 50). It is imperative, therefore, moving forward that counternarratives are included to demonstrate a fair representation that will lead to more just practices and policies.

## **Application of CRT to College Students with Physical Disabilities**

The "deficit oriented view of individuals and communities of color" (Abram & Moio, 2009, p. 246) that infiltrates society is also experienced by individuals with disabilities. CRT seeks to shift the personal and group deficit perspectives to the institutional levels of oppression and discrimination that, from a social work perspective, unquestionably impact individuals with disabilities (Campbell, 2008). Critical Disability Studies materialized from the Deinstitutionalization Movement of the 1960's when individuals with disabilities were moved out of institutions and into community programs, to develop awareness as the visibility of individuals with disabilities increased (Meekosha & Shuttleworth, 2009). Critical Disability Theory is an emerging theory that, similar to CRT, is grounded in Critical Legal Theory and Feminist Theory (Hosking, 2008). Critical Disability Theory seeks to expose discrimination against individuals with disabilities and change the structural and political systems in society that reinforce inequality and intolerance (Hosking, 2008).

The five tenets of CRT can be applied to foster an increased level of awareness of the underrepresentation of college students with physical disabilities. Examination of each factor individually can improve the recognition of the plight of college students with physical disabilities and contribute to innovative practices and policies designed to increase parity. Furthermore, post-secondary education has the capacity to provide countless opportunities for

student with physical disabilities to create necessary counter-narratives to actively engage in the process of re-defining the social and political meaning of being able-bodied.

Ableism as ordinary. Although racism refers to the institutional discrimination against minority groups based on race, CRT can be applied more broadly and is applicable for other minority groups, such as individuals with disabilities. Ableism is the term used to describe the institutional discrimination against individuals with disabilities that occurs as able-bodied individuals are viewed as superior (Rogers, 2013). Ableism, just as racism, is commonplace is society. Many individuals are diagnosed with a range of disabilities with varying degrees of impairment, which can be viewed on a continuum. Hosking (2008) suggests that when considering disabilities over the life span, most anyone can be viewed as "disabled" at one point or another. College students, given their age and life stage are expected to be autonomous, therefore, students with physical disabilities are subject to discrimination and exclusion from and within higher education because of the high value associated with this purported social norm (Liasidou, 2014).

**Interest convergence.** The second tenet, interest convergence, demonstrates that those who are able-bodied create agendas, policies, and laws that promote their status and well-being, without considering the implications for those who are disabled. Those with majority status can demonstrate independence, a strong value in American society, and as a result, laws and policies are created to promote and maintain those who can live and interact with the world around them without any assistance or specialized technology (Meekosha & Shuttleworth, 2009). Liasidou (2014) affirms that most research conducted with college students with disabilities focuses on their academic success, rather than the overall college experience, which undoubtedly includes social inclusion. One must consider the interest of those in the majority (i.e. those who are able-

bodied) and the implications of considering a broader experience of college students with physical disabilities in higher education in the areas of research, practice, and policy.

**Social construction of ability.** Just as race is a concept that is socially constructed, so too is disability. An impairment refers to one's functional limitations, whereas the term "disability" subjectively provides social meaning based on a binary category of identity (Meekosha & Shuttleworth, 2009). Higher education has affirmed the status of social categories related to disability by historically rejecting students with physical impairments, deeming them inadequate to compete with the productivity and demands of college in comparison to their ablebodied peers (Liasidou, 2014). Universally Designed Instruction provides an unbiased framework for educating diverse individuals and learners, through teaching methods and strategies that are more inclusive and would serve to benefit many college students, not only those with disabilities (Liasidou, 2014).

**Intersectionality.** The fourth element, intersectionality, is important as one considers individual intersections of identity. The intersection of disability and gender, class, race, or sexuality to name a few provides a distinct position with respect to identity that is certainly worthy of attention. For individuals with disabilities, the most influential intersections are: race, gender, and class (Meekosha & Shuttleworth, 2009). The intersection of identity markers among individuals with physical disabilities plays a vital role in the opportunity to attend and subsequently succeed in higher education. The impact of "multiple sources of social disadvantages on the lives and educational trajectories" (Liasidou, 2014, p. 124) among individuals with disabilities must also be considered, as having a physical impairment limits one's access to an array of privileges well before one is of age to attend college.

**Narration.** The concept of a counter-narrative, from a person who is physically disabled and attending college, provides a missing perspective of the college experience that is likely much different from a person who is abled-bodied (Meekosha & Shuttleworth, 2009). A counternarrative provides an opportunity for a person who is physically disabled to voice their perspective so that the majority's is not automatically accepted as the one and only truth (Delgado & Stefancic, 2017). College students with physical disabilities need an opportunity to share their experiences in higher education to challenge the stigma and stereotypes that lead to exclusion in higher education.

## **Intersectional Theory**

Intersectional Theory, often referred to as Intersectionality, developed from Black Feminist Theory and provides a construct to explain how various elements of one's identity (race, ethnicity, culture, gender, class, sex, sexual identity, religious affiliation, ability) intersect to form one's overall identity, resulting in either "privilege or oppression" (Tevis & Griffen, 2014, p. 241). Although Intersectionality is a tenet of CRT, Intersectionality as a stand-alone theoretical framework offers greater depth and consideration for the multiple interacting aspects of identity. It is the overlapping intersection of identity, referred to as one's *social location* (in the field of public policy), that influence: how one perceives oneself; which group(s) one is considered a member; and, how one is viewed by society (Collins & Bilge, 2016; Manuel, 2006). Society interprets a person's worth based on binary categories of group membership (e.g. male/female; white/non-white; heterosexual/homosexual; able-bodied/disabled, etc.) (Erevelles & Minear, 2010). While identity is a central component of intersectionality, the theory also emphasizes the transformative nature of group identity and the inherent power that can be elicited to alter the social structures that create and maintain oppression (Collins & Bilge, 2016).

Intersectionality aligns with the social work perspective as it illuminates the structural issues of oppression and emphasizes the need for collaborative efforts to change the existing beliefs, policies, laws, and overall culture (Collins & Bilge, 2016).

# **History of Intersectionality**

Although Kimberle Crenshaw has been given credit for coining the term "Intersectionality" in the late 1980's, the theory and movement actually began about twenty years earlier (Collins & Bilge, 2016). Intersectionality came to the forefront of society, with a focus on the intersection of race and gender, as minority women fought for equal rights in employment (Walby, Armstrong, & Strid, 2012) In the 1960's and 1970's, black women found themselves at the margins of the civil rights movement due to their gender, and again at the outskirts of the feminist movement due to their race. Unlike black men, and unlike white women, the intersecting aspects of black women's unique identity made their experience of oppression more complex, thus requiring a distinct framework and model to meet their needs (Collins & Bilge, 2016).

# **Main Tenets of Intersectionality**

A person's identity is multifaceted, making it impossible to narrow down into one a single category. Intersectionality provides a framework for analyzing the overlapping aspects of one's identity, with a focus on: inequality, power differential, and social justice (Collins & Bilge, 2016). Examination of each of these domains fosters greater insight into the application of intersectionality with respect race, gender, class, ethnicity, sexuality, ability, and much more.

**Inequality.** Intersectionality seeks to expose the social, economic, and political disparities that marginalize and oppress individuals as a result of their identity (Collins & Bilge, 2016). Socially constructed categories of identity, for what can be described as first-class

citizenship, include being a white, U.S. born, Christian, heterosexual, able-bodied, male (Walby, Armstrong, & Strid, 2012). These facets of identity provide individuals with access to privileges and opportunities for success in U.S. society (Erevelles & Minear, 2010). Without these identity markers, individuals are assigned minority status, and, as a result experience unequal treatment (Walby, Armstrong & Strid, 2012). Inequality may exist in the form of individual (e.g., person calling another racist name, individuals subscribing to stereotypes) or institutional discrimination (e.g., educational achievement gaps of minorities, overrepresentation of minorities in foster care, overrepresentation of minorities in prison).

**Power differential.** Intersectionality can also be utilized as tool to analyze the various power differentials that create and maintain oppression in society. Collins and Bilge (2016) describe power relations as distinguishing "who is advantaged and disadvantaged in social interactions" (p. 7). Interpersonal, disciplinary, cultural, and structural domains of power contribute to the complexity of power relations in society (Collins & Bilge, 2016). On an interpersonal level, each person's experience and perception of the world is unique. This leads to additional hierarchies within minority groups, based on intersections of other aspects of identity (Erevelles & Minear, 2010). From a disciplinary standpoint, rules and laws are enforced or applied to varying degrees depending upon the aspects and intersections of one's identity (Collins & Bilge, 2016).

The cultural dimension of power differentials demonstrates that as society, which celebrates winning through competitions, sporting events, contests, and politics, the notion that someone must lose in order for someone to win becomes an everyday, acceptable norm (Collins & Bilge, 2016). As a result, the outcomes of those on the losing end of the battle for social equality hardly register on the radar of accountability and consciousness among those who win in

a landslide victory, with little to no effort. Structurally, power differentials are revealed through policies and laws that continue to promote the dominant agenda, while maintaining the inferiority of those regarded as undeserving (Collins & Bilge, 2016).

**Social justice.** Intersectionality extends beyond the analysis of identity, as it is intended to be more than a conversation on inequality (Walby, Armstrong, & Strid, 2012). It is an action-oriented framework that seeks to create equal protection for individuals who experience discrimination, oppression, and marginalization (Collins & Bilge, 2016). Intersectionality provides the underpinnings necessary to not only expose and challenge the institutions and social structures that engage in discriminatory practices, but also engage in social and structural change that reflects the dignity and worth of diverse individuals. Essentially, the 'one size fits all' position of laws and policies, designed by dominant members of society, require more flexible interpretations in order to safe-guard the needs of individuals of the most vulnerable in society, those with dual and multiple minority status.

# Application of Intersectional Theory to College Students with Physical Disabilities

Recognizing the multidimensional aspects of a person's identity provides a comprehensive perspective for understanding how a physical disability impacts the one's identity, as having a disability is only one facet of a college student's identity. Additionally, one should consider how being a college student and, further, becoming a college graduate impacts one's identity. Utilizing Intersectionality as a framework for analysis provides insight into the intersecting aspects of the identity of college student with physical disabilities, among other intersections of one's identity. Employing the framework of Intersectionality allows for the exploration of inequality, power differentials, and social justice, as experienced by college

students with physical disabilities, as well as an action-oriented framework to address the structural and political dimensions of discrimination (Collins & Bilge, 2016).

Inequality. Understanding the inequality experienced by individuals with physical disabilities is vital in the application of Intersectionality among college students with physical disabilities. In order to understand the inequality that persists among college students of minority status, one must first acknowledge the identity of the most dominant group students, which, in U.S., would include the following markers of identity: white; male; Christian; U.S. born citizen; Christian; heterosexual; able-bodied; of at least middle-class status; and, born to parents with college degrees. In comparison, a white, U.S. born, Christian, heterosexual, male, college student with a physical disability is not regarded as equal to the able-bodied male with whom he shares every other aspect of his identity. A white, U.S. born, Christian, heterosexual, female, firstgeneration college student with a physical disability is at an even greater disadvantage, given that she has three markers (gender, ability, and first-generation college student) that classify her as a minority. A first-generation college student with a physical disability, who is Hispanic, female, and of lower-class may certainly share some of the same identity markers of both the white woman and white man who have physical disabilities, however, the oppression she experiences is most likely exacerbated by the complexity of the intersecting dimensions of her identity (gender, race, ability, class, and first-generation college student). Such inequalities can be observed in the social exclusion of students with physical disabilities in campus clubs and activities, in faculty and staff's ignorance of disability awareness and terminology, and, in campus members' lack of acceptance of the individual as a rightful and capable college student.

**Power differential.** The term disability, itself, represents the innate power differential that exists between those who are able-bodied and those who are not (Hutcheon & Wolbring,

2012). The underrepresentation of college students with physical disabilities is further compounded by additional minority markers of identity that create student's unique social location and exacerbate such power differentials (Erevelles & Minear, 2010). Those with the privilege of being able-bodied are deemed to be more capable of successfully completing college (Liasidou, 2014). A college degree affords one with more employment options, financial security, and social networking skills that should augment one's identity with a source of privilege, and yet this intersection is neither well-understood nor appreciated (Terzi, 2007).

Among those students with physical disabilities who attend college, support services designed to be assistive may further stigmatize the students by singling them out (bringing adaptive technology to class; taking exams in the Office for Students with Disabilities due to need for extended time, etc.) (Liasidou, 2014). As Manuel (2006) explains, the analysis of the behavior of minorities in relation to public policies must take into account the social location and the subsequent experiences of exclusion that result. Students with physical disabilities may not be afforded the same level of choices as their able-bodied peers (Hutcheon & Wolbring, 2012). If students are in need of personal care aides, these services may be relegated to specific dormitories, limiting students' choices of where to reside. Students with physical disabilities may not have the same luxury as their able-bodied peers of scheduling classes in the most efficient manner, as they may need more time in between classes for personal hygiene or traveling between buildings.

**Social justice.** While the ADA of 1990 protects individuals with disabilities from discrimination, the underrepresentation of college students with physical disabilities is an indicator that additional awareness and safeguards may be necessary to improve access and enhance success within colleges and universities. Manuel (2006) addresses the concern of a

"double-edged sword" (p. 193) for minorities who combat injustices, to gain access to privileges, and feel obliged to actively engage in combatting social injustices to help others, like them, achieve similar results. From a social justice perspective, improving access to college for students with physical disabilities should be a shared concern of all members of society, not the burden of those with physical disabilities who are successful in their higher education endeavors.

### Self-efficacy theory

Self-efficacy theory is grounded in the work of Albert Bandura and posits that learning is an active cognitive process which occurs in the context of an environment (Rogers, 2013). Bandura's concept of self-efficacy, a person's belief in their ability to successfully complete a task, is essential to consider when analyzing the learning experiences and outcomes of individuals regardless of their abilities (Chang, Wang, & Lee, 2016). When individuals successfully accomplish a task, self-efficacy improves and serves as reinforcement to seek out new experiences (Lee, Arthur, & Avis, 2007). High levels of self-efficacy are positively correlated with performance in school, work, and other areas of one's life (Duffy & Dik, 2009; Gore, 2006). The concept of self-efficacy aligns with social work as it is grounded in the belief that individuals can change and also because it promotes empowerment, a key concept in social work practice.

## Main Tenets of Self-Efficacy Theory

An individual's "persistence and effort" (Lee, Arthur, & Avis, 2007) toward a given task or goal is the result of one's self-efficacy. Self-efficacy theory posits that greater levels of selfefficacy, the belief that one has the skills and knowledge necessary to complete a task, enhances initiation and persistence of a task or goal (Hsieh, Sullivan, & Guerra, 2007). In contrast, low levels of self-efficacy result in fewer initiation attempts and abandonment of attempted tasks

(Lee, Arthur, & Avis, 2007). Self-efficacy theory consists of four main tenets: performance accomplishments; vicarious learning; verbal encouragement; and, physiological and affective states. Examination of each tenet can be useful when considering effective practices and policies in higher education that encourage positive self-efficacy.

**Performance accomplishments.** An individual's history of positive experiences contributes to increased levels of initiation and determination in the completion of a task or engagement in a new behavior (Hsieh, Sullivan, & Guerra, 2007). Among the four components of self-efficacy theory, positive past accomplishments are the most influential factor in determining likelihood of initiation and commitment, as one's personal experience has more meaning (Lee, Arthur, & Avis, 2007) thereby enhancing motivation. Confidence can be improved by breaking large goals into smaller, more manageable tasks in order to develop positive experiences that contribute to self-efficacy (Lee, Arthur, & Avis, 2007).

**Vicarious learning.** Learning a new behavior can occur through direct or indirect observation of others engaging in the same or a similar behavior (Hsieh, Sullivan, & Guerra, 2007). With respect to self-efficacy, it is important that those modeling the desired behavior share comparable characteristics and lifestyle factors (age, gender, race, socioeconomic status, ability, etc.) of the individual observing in order to enhance the individual's belief in oneself (Lee, Arthur, & Avis, 2007). Vicarious learning is especially significant when an individual experiences doubt in one's ability to perform a task or complete a goal (Lee, Arthur, & Avis, 2007).

**Verbal encouragement.** Support from others in the form of verbal encouragement has a profound impact on one's ability initiate a task if one feel's intimidated (Hseih, Sullivan, & Guerra, 2007). Positive feedback can be valuable with respect to an individual's perseverance, if

challenges or setbacks arise, particularly when that encouragement comes from significant others or professionals (Lee, Arthur, & Avis, 2007). It is important to note that feedback must be realistic in order to improve the individual's confidence (Lee, Arthur, & Avis, 2007).

**Physiological and affective states.** Positive experiences generate positive feelings, such as pleasure, excitement, and happiness; while, negative outcomes produce negative feelings, such as sadness, frustration, and fearfulness (Beck, 2011). The connections between thoughts, feelings, and behavior is extremely compelling, as a mere memory of a personal experience is enough to invoke similar feelings of arousal (Beck, 2011). Positive memories can be harnessed to provide the confidence necessary to succeed again, whereas negative memories can be self-destructive and can render one helpless.

### Application of Self-Efficacy Theory to College Students with Physical Disabilities

Betz and Hacket (2006) call attention to self-efficacy as a "cognitive appraisal or judgment of future performance or capabilities" (p. 6), rather than a personality trait, validating that self-efficacy can be learned. The notion that self-efficacy can be acquired holds significant value for academic success in higher education as faculty, staff, and administrators can focus on encouraging opportunities to promote self-efficacy among vulnerable populations, such as students with physical disabilities. Critical analysis of the four elements of self-efficacy theory can assist in the creation of programs and services that prepare students with physical disabilities for college by enhancing self-efficacy, and also increase necessary supports within colleges to help students persevere.

**Performance accomplishments.** Colleges seek to admit well-rounded students who have demonstrated academic success in high school, are active in their school clubs and sports, and contribute to their community. These expectations do not take into consideration students with

physical disabilities whose functional limitations may prevent them from participating in or to the same degree as their able-bodied peers, thus, on paper, the student with a disability may appear to be less desirable to the college admissions office. It is often a result of one's identity of being physically disabled, that prevents students from gaining access to experiences and opportunities in high school that will better prepare them for higher education (Adams & Proctor, 2010). Primary and secondary schools are more likely to associate failure of a given academic task to overall cognitive deficits if the student has a disability or is a minority, making it more likely that minority students with physical disabilities are placed in special education classes, which are not focused on college preparation (Syed, Azmitia, & Cooper, 2011).

As a vulnerable population, students with physical disabilities need to have opportunities to succeed well before high school graduation. When students with physical disabilities are given the chance to succeed academically and socially in primary and secondary school, they, just like all students, build confidence in their ability to continue to succeed in other areas, such as higher education. Beyond academics, providing support services to help students engage in social and recreational activities in primary and secondary school are advantageous in one's transition to college, as past social experiences can increase confidence in the facilitation and success of new social interactions. Furthermore, gaining experience and confidence in one's ability to self-advocate is a necessary component of anyone's transition to college, but is especially important given the vulnerability of students with physical disabilities (Liasidou, 2014). Students who have experience advocating for themselves are better prepared to engage in self-advocacy in college, an extremely important component of student success for individuals with disabilities as the onus for support shifts from school-driven in primary and secondary school, to student-driven in higher education (Rothman et al, 2008).

**Vicarious learning.** Students with physical disabilities often receive messages, both implicit and explicit, that they are incapable of competing with their able-bodied peers in higher education (Hutcheon & Wolbring, 2012). If students are provided with the opportunities to observe other college students with physical disabilities succeed, they are more likely to believe that they too are capable of such an accomplishment. Increasing the visibility of students with physical disabilities in media, social media, and college recruitment marketing may help to create a renewed sense of conviction in the diversification of college students.

**Verbal encouragement.** Verbal encouragement serves as a form of positive reinforcement that helps an individual initiate a new behavior or task when experiencing self-doubt, and can also encourage motivation to persevere through challenging and stressful situations (Lee, Adler, & Avis, 2007). The transition to college can be particularly stressful as students are placed into a new environment, away from home, and without their familiar support network (Wintre & Bowers, 2007). Establishing strong support networks that can provide positive reinforcement and verbal encouragement for vulnerable students, such as those with physical disabilities, may be useful in garnering a positive self-concept, which contributes to self-efficacy leading to higher levels of success academically and socially (Hseih, Sullivan, & Guerra, 2007).

**Physiological and affective states.** The transition to college can be a stressful event for any student, as it "requires student initiation, independence, and self-monitoring" (Hsieh, Sullivan, & Guerra, 2007, p. 468). The stress experienced by a student with physical disabilities may be much greater, depending upon intersections of the student's identity, as well as the student's functional limitations that colleges are not prepared for on a regular basis (Liasidou, 2014). A student's perception of stressful and challenging situations plays a key role in their

overall self-efficacy, highlighting the need for additional support services and policies that are both preventative and reactive (Ferla, Valcke, & Cai, 2009).

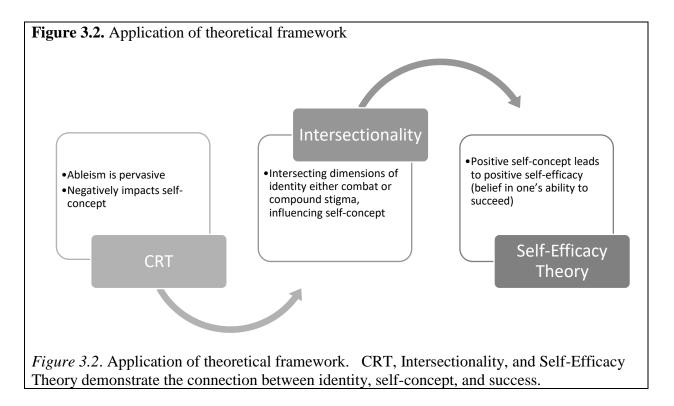
#### Conclusion

Each of the three theories (CRT, Intersectionality, and Self-efficacy theory) are pertinent in the analysis of the influence of identity on the college experience of students with physical disabilities, yet collectively these three theories provide a solid framework to examine the impact of having a disability on one's identity as a college student. Both CRT and Intersectionality provide strong theoretical foundations for the examination of one's identity and the impact of structural and political systems that either limit or empower college students with physical disabilities. Additionally, CRT and Intersectionality provide insight into the impact of one's identity on a student's self-concept. It is one's self-concept that contributes to one's self-efficacy, the belief in one's ability to succeed, which is highly correlated with academic success in higher education (Torres, Jones, & Renn, 2009). By incorporating CRT, Intersectionality, and Self-Efficacy Theory, it may be possible to gain more insight into the influence of one's identity as an individual with a physical disability and a college student, on success in higher education (including both academic and social success).

## Link between CRT, Intersectionality, and Self-Efficacy Theory

Campbell (2008) suggests that Intersectional Theory should not only be utilized to examine categories of identity that evoke negativity, as it was originally intended, but as a framework to identify strengths associated with identity that reduce stigma. Tevis & Griffen's (2014) examination of the intersectionality among college students with physical disabilities revealed that advocacy and independence were important predictors of academic success, and perhaps most notably, that students with physical disabilities "perceive themselves at an

advantage well before attending college" (p. 251). It is important, therefore, to determine the experiences and opportunities of students that lead to positive self-concepts prior to college. Figure 2, below, demonstrates the interconnections among CRT, Intersectionality, and Self-Efficacy Theory, and also provides a framework for qualitative research to develop further insight into the impact of disability identity on the self-efficacy of college students.



Among students with physical disabilities, identity and self-concept are influenced by ableism (CRT) in combination with other facets of their identity (Intersectionality). One's self-concept also develops from, and is a reflection of past experiences (Hseih, Sullivan, & Guerra, 2007). The deficit-oriented perspective of disability that dominates the structural and political systems in society, often lead to negative self-concepts among individuals with disabilities (Smit, 2012). One must then consider, the impact of Intersectionality, as additional identity markers either combat or compound the negative self-concepts of individuals with physical disabilities.

Positive self-concept leads to positive self-efficacy, which is correlated with academic achievement in higher education (Torres, Jones, & Renn, 2009). Given the gap in literature with respect to college students with physical disabilities, this qualitative research study seeks to explore the role of identity in the overall experiences of students with physical disabilities in higher education.

### **Chapter 4: Methodology**

# Introduction

A review of current literature emphasizes that students with physical disabilities are underrepresented, and their strengths and challenges not well-understood in higher education (U.S. Department of Education, 2014). Qualitative research is most appropriate for this study given the scarcity of literature and deficiency of knowledge with respect to the identity of college students with physical disabilities and their experiences within higher education (Creswell, 2013). The purpose of this transcendental phenomenological study is to explore and understand the identity and experiences of college students with physical disabilities at a public university in the northeastern United States, through the implementation of Photovoice. Photovoice, a specific qualitative research technique, has been selected for this study given its value as a method to enhance knowledge and awareness of college students with physical disabilities so that appropriate advocacy efforts can commence in order to increase parity within higher education. The overall aim of the study is to explore what it means to be a college student with a physical disability through images and in-depth interviews. This knowledge has the potential to shape practices and policies to promote and improve inclusion among individuals with physical disabilities in higher education.

This chapter will explore the philosophical assumptions, interpretative frameworks, and reflexivity necessary to provide a solid foundation for this qualitative research study. An examination of photovoice as a phenomenological approach to qualitative research, characteristics of qualitative research, a description of the sample and setting, and ethical considerations specific to this study are analyzed to determine specific factors that must be considered throughout the research process. Finally, the history of Photovoice, the theoretical

framework of Photovoice, and the process of Photovoice are explored to illuminate the rationale for the research design.

## **Philosophical Assumptions and Interpretive Frameworks**

Researchers must understand and convey their philosophical assumptions and biases when engaging in qualitative research, as these beliefs play a vital role throughout the research process (Creswell, 2013). For the qualitative researcher, awareness of one's own assumptions of ontology and epistemology are essential in order to demonstrate transparency and reflexivity throughout the process (Creswell, 2013). Ontology refers to beliefs about the nature of reality, a topic of debate across disciplines of research (Tai & Ajjawi, 2016). Epistemology explains how knowledge becomes known, and must consider the relationship between the researcher and the data, including the researcher's level of objectivity (Carter & Little, 2007; Creswell, 2013). Ontology provides the framework for the epistemological and the methodological approach.

The social model of disability, CRT, Intersectionality, Self-Efficacy Theory, and the inherent nature of qualitative research inform the ontological perspective of this study through what is known as relativism (Andrews, 2012). Relativism is the belief that: knowledge is contextual; multiple realities exist; and, despite conflicting truths, no truth is right or wrong (Andrews, 2012). Reality among individuals with disabilities is based upon power differentials that exist as a result of socially constructed categories of identity. A phenomenological qualitative research study, implemented through Photovoice, allowed this researcher to embrace the notion of multiple realities by engaging several students with physical disabilities in the study through a focus group interview (Creswell, 2013; Padgett, 2008). Photographs provided participants with the framework to define their experiences or stories, reiterating the conviction that reality is contextual, and that each person's reality represents truth.

Qualitative research involves the study of data that is represented in "words,

observations, and descriptions" (Faulkner & Faulkner, 2014, p. 5), particularly when information about the subject or phenomenon is not well understood, such as college students with physical disabilities. With regard to epistemology in this qualitative research study, knowledge transpired "through the subjective experiences of people" (Creswell, 2013, p. 20), through photographs, and descriptive inquiry (Faulkner & Faulkner, 2014). Through Photovoice, college students with physical disabilities had the opportunity to share their experiences with others through their photography, as well as through their shared narratives and the dialogue that emerged through a focus group interview.

**Statement of reflexivity.** Axiological assumptions refer to the beliefs and values brought to the study by the researcher (Creswell, 2013). Axiological assumptions are made known to participants at the beginning of the study to increase transparency (Creswell, 2013). In this study, it was extremely important for this researcher to emphasize: the belief that disability is a socially constructed concept that categorizes individuals as having less power and control over their lives; the value of diversity; the capacity of a community; confidence in research and advocacy efforts to create change; and, the value of higher education as a means toward upward mobility for all individuals (Duffy & Dik, 2009; Tevis & Griffen, 2014).

This researcher provided a statement of reflexivity during the orientation training so that participants are provided with knowledge related to this researcher's values, work history, and current agenda with the proposed research study. This information was conveyed to participants again during the focus group interview, as it was essential for this researcher to acknowledge her position as an outsider, a person without a physical disability. The qualitative researcher must be acutely aware of the dynamic of one's self-awareness throughout a study in order to demonstrate

ethical responsibility to the participants and commitment to the process of qualitative research (Padgett, 2008). A researcher's bias can come across at any time, from method development to the coding process, and reflexivity provides the researcher with an opportunity for self-reflection so that positionality is a constant consideration (Creswell, 2013; Padgett, 2008). Awareness of one's position, as the researcher, with respect to the subject, participants, and process is necessary to ensure that all voices of the study are taken into consideration (Bourke, 2014). CRT focuses on the power differentials that further marginalize oppressed communities; therefore, it is essential for qualitative researchers studying vulnerable populations, such as individuals with disabilities, to be upfront about concerns and to actively engage in efforts to decrease such issues (Padgett, 2008).

This researcher explored her statement of positionality to the participants, which included the following information: This researcher has chosen to engage in this study as a requirement for the completion of a Doctor of Social Work dissertation. This researcher chose the subject of college students with physical disabilities for several reasons: 1. this researcher has a history of working with individuals with disabilities; 2. this researcher has access to a public university known for their exemplary services provided to college students with physical disabilities; and, 3. this research seeks to better understand college students with physical disabilities to improve inclusion of diverse learners in the classroom and to enhance advocacy students with physical disabilities in their internships. This research study does not have any sponsors, nor is it subsidized.

For this researcher, it was also important to acknowledge identification as a social worker and a mandated reporter. As a social worker, this researcher believes in the core values of the social work profession: service; social justice; dignity and worth of the person; importance of

human relationships; integrity; and, competence (NASW, 2008). As an individual, this researcher believes in the value of diversity, the importance of education, and the significance of community. It is this researcher's conviction that all individuals in society, not only those who are labeled as disabled, are responsible for engaging in advocacy efforts to improve inclusion in society (Liasidou, 2014). As an ally, this researcher, seeks to utilize able-bodied privilege and networking skills to engage in advocacy efforts, along with individuals with physical disabilities, to shape current policies and practices to improve parity in higher education.

Objectivity, the notion that results of data collection are void of any bias or researcher influence, is often the feature that creates doubt in qualitative research as a scientific method (Thyer, 2010). It is essential, therefore, to address strategies that will enhance objectivity throughout a qualitative research study. Qualitative researchers using interviews, whether individually or through focus groups, are tasked with taking the subjective experiences of individuals and interpreting these experiences without influencing such data (Creswell, 2013; Padgett, 2008). Objectivity within qualitative research can be enhanced through trustworthiness, which can be assessed through credibility, transferability, auditability, and confirmability (Padgett, 2008).

With a phenomenological study, acknowledging subjectivity of this researcher through reflexivity and the use of a reflexive journal throughout the research process was helpful to enhance self-awareness of biases, preconceived ideas, accumulated knowledge, and hypothesis that may have otherwise influenced the study (Watt, 2007). Photovoice, as a specific qualitative research design, naturally lends itself to both transferability and auditability, given the transparency of the progressive manner of the procedures, which allow others to duplicate the process (Padgett, 2008). The researcher, in a qualitative study, is the instrument; therefore, to

remain objective, this researcher: tasked participants with taking photographs of their lives to show their perspective; asked the same open-ended questions of each participant in the focus group; and, requested assistance from participants to identify themes that emerged during the focus group (Pezalla, Pettigrew, & Miller-Day, 2012).

The utilization of uniform interview protocols for each participant during the focus group interview as well as the use of an audio recorder which was transcribed verbatim, enhanced the reliability of data collection methods (Creswell, 2013; Padgett, 20008). Toward the end of the focus group interview, participants were encouraged to develop and discuss themes in order to enhance the objectivity of the study, rather than solely relying on the thematic interpretation of the researcher, which could have been subject to bias (Goodhart, Hsu, Baek, Coleman, Maresca, & Miller, 2006). Debriefing with peers, as well as respondent validation through post focus group check-ins, increased the accuracy of the researcher's interpretation of themes developed from transcriptions (Tai & Ajjawi, 2016).

#### **Research Design**

Qualitative research is characterized by inductive reasoning, which requires the researcher to be flexible and holistic in their approach, given that hypotheses evolve throughout the research process (Creswell, 2013; Padgett, 2008). Qualitative research naturally promotes descriptive inquiry, which allows one to explore a phenomenon through observation, documents, interviews, and focus groups in order to develop a more thorough understanding of a topic or event (Faulkner & Faulkner, 2014). A phenomenological approach to qualitative research is grounded in philosophy, and provides the researcher with an opportunity to explore the experiences of a group with a shared commonality in order to more fully understand the phenomena (Padgett, 2008). The purpose of phenomenological research is to explore the lived

experiences of individuals and determine a collective "essence" (Creswell, 2013, p. 76) of the identified phenomenon. In this study, the phenomenon was: being a college student with a physical disability.

# **Phenomenological Approach**

A transcendental phenomenological approach was implemented, emphasizing the descriptions of the participants, by employing photovoice as a methodology which included a focus group interview as well as documentation review (of photographs submitted by participants) (Creswell, 2013). Photovoice is a form of Community-based Participatory Action Research (CBPAR) designed to provide a voice to vulnerable, marginalized, and oppressed groups (Hergenrather, Rhodes, Cowan, Bardoshki, & Pula, 2009). Photographs, taken by participants, offer visual images that transcend language barriers, producing a powerful form of communication that can empower individuals and communities (Holtby et al, 2015). As Wang and Burris (1997) identified, Photovoice has

"three main goals: 1. to enable people to reflect and record their community's strengths and concerns; 2. to promote critical dialogue and knowledge about important issues through large and small group discussion of photographs, and 3. to reach policy makers" (p. 369).

Participants are asked to take photographs of images that reflect their story, lives, and the particular phenomenon being explored (Holtby, Klein, Cook, & Travers, 2015; Wang & Burris, 1997). In Community-based Participatory Action Research (CBPAR), participants are viewed as the true experts and are engaged throughout the process as, co-researchers (Brake, Schein, Miller, & Walton, 2012; Hannes & Parylo, 2009; Wang & Burris, 1997). Through a focus group interview, participants then share their photographs and engage in a discussion with other

participants (Wang & Burris, 1997). Photovoice can be utilized with diverse groups and communities, and provide a venue for individuals and communities to share their stories; enhance community cohesion; and, facilitate advocacy efforts to shape public policies that increase parity (Agarwal, Moya, Yasui & Seymour, 2015; Sethi, 2016; Teti, Rolbiecki, Zhang, Hampton, & Binson, 2016; Wang & Burris, 1997).

# Introducing and Focusing the Study

# **Research Questions**

Qualitative research requires the development of open-ended, general, and flexible questions to explore and develop a more thorough understanding of a particular phenomenon (Creswell, 2013). Critical Race Theory (CRT) and Intersectionality serve as interpretive theoretical frameworks in the development of this qualitative study. CRT and Intersectionality provide the framework for questions related to the identity of college students with physical disabilities, while Self-Efficacy Theory offers the underpinnings of questions related to the belief in students' ability to succeed in college experiences. This researcher will ask participants to explore the following, overarching research question through the use of photography over the course of two weeks.

Overarching question: What does it mean to be a college student with a physical disability?

Sub-questions:

1. How do you describe your identity as a college student?

2. How has your physical disability influenced your experiences (academic and social) in college?

## Sample

Purposive and criterion sampling, both forms of non-probability sampling, were utilized in this research study, as specific characteristics of individuals were required in order to participate (Faulkner & Faulkner, 2014). Participants were all registered undergraduate students of the identified public university in northeastern U.S., at least 18 years of age, and selfidentified as having a physical disability. Additionally, participants needed to have access to a digital camera or smartphone camera. Although non-probability sampling is not a true representation of the general population; it is important to recognize that students with physical disabilities are not well represented in higher education (Newman et al, 2009; Thyer, 2010). It was essential for this researcher to be purposeful in the selection of participants in order to gain accurate information and insight into the identities and experiences of college students with physical disabilities (Creswell, 2013).

This study originally intended to recruit 7-10 participants via flyers posted throughout campus, email solicitation, as well as through informational meetings conducted by this researcher in two residence halls that provide services for students with physical disabilities. Seventy-three students were registered with the university's Office of Student's with Disabilities (OSD) with a physical disability as their primary disability during the 2014-2015 academic year (Office of Students with Disabilities, 2014-2015 Fact Sheet, 2014). Students with physical disabilities as a primary disability represent 15% of students who are registered with OSD on this campus, and approximately 1.6% of the total student population (Fact Sheet, 2017). This study was approved by Kutztown University of Pennsylvania's Institutional Review Board as well as the gatekeeper, the public university described in the setting. The application and accompanying documents have been attached to this paper.

## Setting

A public university in the northeastern part of the United States was utilized as the setting for this study. The orientation and ethics training, focus group, and all follow-up meetings with participants were conducted on the university's campus, in a room that is easily accessible to participants. The forums to showcase participants' photographs and engage in advocacy efforts with decision-makers was determined by the participants, as co-researchers in the process (Agarwal, Moya, Yasui, & Seymour, 2015). This university was designated as a "wheelchair campus" in 1974 as a result of their commitment to the Architectural Barriers Act of 1968 and Section 504 of the Rehabilitation Act of 1973 (Event to mark 40<sup>th</sup> anniversary of Edinboro's commitment to serve students with disabilities, 2014). The Architectural Barriers Act of 1968 required institutions in receipt of federal funding to rent, purchase, or renovate buildings to provide physical access to individuals with disabilities; while Section 504 of the Rehabilitation Act made it unlawful for federal agencies, public agencies, and public universities in receipt of federal funding to discriminate against individuals with disabilities (Pingry O'Neill, Markward, & French, 2012; Severance & Starr, 2011).

Over forty years later, the university remains a pacesetter, as it is nationally recognized as one of only three universities in the United States for exceeding the standards of accessibility for individuals with physical disabilities and providing a twenty-four-hour attendant care program (Kennedy Krieger Institute, 2011). For students with significant physical disabilities, the high level of support services, specifically the 24-hour attendant care program, is a determining factor in their choice and ability to attend higher education (Student Resources, 2017). In spite of the university's recognition as "disability-friendly", participants explained that they continue to face barriers that prevent full access and inclusion.

## **Ethical Considerations**

With respect to research studies of human subjects, protecting participants is a primary consideration throughout the process (Padgett, 2008). Protection of research participants minimally requires: an overview and explanation of the study; expectations of the participant; disclosure of the researcher and any funders, including contact information; an explanation that participation is voluntary, and that the participant has the right to withdraw at any time; confidentiality; and, risks and benefits to the participant (Padgett, 2008). Informed consent for participants should be explained verbally and documentation of participant agreement with the signature of both the participant and researcher must be secured in writing (Creswell, 2013). Padgett (2008), suggests that given the iterative nature of qualitative research, informed consent should be revisited throughout the process with participants. Specific to photovoice, the consent needs to include how photographs will be utilized (e.g. focus group, publication, conferences, training, public forum, etc.) and a reminder that participants, as owners of the photographs, can decide at any point to retract their photographs, with the exception of photographs that have already gone into publication (Agarwal et al, 2015; Hannes & Parylo, 2014). Additional ethical considerations related to Photovoice will be explored in the following section.

## **Research Methodology: Photovoice**

Photo-elicitation has been used since the 1950's to add depth to qualitative research interviews; however, photovoice, a form of community-based participatory action research did not emerge until the 1990's (Bugos, Frasso, Fitzgerald, True, Adachi-Mejia, & Cannuscio, 2014). Dr. Caroline Wang coined the term 'photovoice' in 1997 through her research to help Chinese women expose issues related to their reproductive health (Wang & Burris, 1997). Photovoice provides marginalized community members with an opportunity to: document their experiences through photography; engage in an active conversation with others who share

similar experiences; and, subsequently convey their experiences through images and dialogue with community leaders, who ultimately hold the power to change the policies and practices that cause disparity (Castleden, Garvin, & Huu-ay-aht First Nation, 2008).

# **Theoretical Framework of Photovoice**

As a form of participant-employed photography (PEP), photovoice seeks to transform communities by raising awareness of oppression, and initiating political and systemic change to improve the lives of those who are vulnerable, oppressed and marginalized (Castleden et al, p. 1395). Photovoice is grounded in three theories: documentary photography; Freire's theory of consciousness; and, Feminist Theory (Wang & Burris, 1997). All three theories support the notion of exposing inequalities between oppressed and dominant groups in society, and actively engaging social justice efforts to improve the lives of those who experience discrimination, oppression, and marginalization.

**Documentary photography.** Documentary photography refers to the visual representation of historical events and other everyday experiences through photographs (Finnegan, 2015). Photographs capture images and create a human connection in a manner that words cannot necessarily convey. Photographs have been used since the 1850's to provide documentation to expose tragedies of the Civil War; deplorable working conditions; the Great Depression; immigration, and countless other events over the course of history since the invention of the camera (Finnegan, 2015). Photographs have also been useful to gain attention in social movements such as women's suffrage, the civil rights movement, and, the disability rights movement, to name a few (Mattoni & Teune, 2014). Photographs are an influential form of communication, as the objective nature of a camera lens has the ability to capture a moment in

time, and not only expose discrimination and violation of human rights, but also inspire audiences to engage in social action to remedy such atrocities (Mattoni & Teune, 2014).

Theory of consciousness. Photovoice is grounded in the work of Paulo Freire, a Brazilian educator and community activist. Freire recognized visual imagery as an empowering and inclusive communication tool, which can be used to enhance one's ability to engage in critical thinking and dialogue about one's community (Goodman & West-Olatunji, 2009).Freire's work with illiterate adults in Brazil led him to develop the theory of critical consciousness, which considers social problems to be the result of social and political structures, rather than personal flaws or limitations (Watts, Diemer, & Voight, 2011). Action and reflection, according to Freire, are interconnected concepts necessary to understand and transform one's social reality (Rugut & Osman, 2013). Learning requires action, followed by reflection, which invokes further action (Rugut & Osman, 2013). Freire's methodology provides a solid foundation for educators and researchers engaged with oppressed groups to raise what Freire termed 'critical consciousness' about the power dynamics and structures that maintain and enforce inequality (Goodman & West-Olatunji, 2009).

**Feminist theory.** Feminist theory seeks to obtain equality between men and women, by eradicating sexism (Rogers, 2013). Male dominance in society, known as patriarchy, describes the power and privilege associated with the male gender, which is enforced through the political and social structures of society that maintain the inferiority of women (Delgado & Stefancic, 2017). The basic premises of feminism include: an active engagement in the creation of policies to create gender equality; expanding opportunities for choice among both men and women, even when choices do not align with socially constructed ideas of gender; opposing policies that limit upward mobility for women; increasing women's control of their sexuality and reproductive

rights; and, focusing on the expansion of rights and opportunities for women through social and political justice (Collins & Bilge, 2016; Delgado & Stefancic, 2017; Wang and Burris, 1997). Photovoice seeks to combat social injustices by exposing inequalities that limit the choice and power of oppressed and marginalized groups (Wang & Burris, 1997).

# **The Process of Photovoice**

The process of photovoice begins as it does with all other forms of research, procuring IRB approval and subsequently obtaining informed consent from participants (Creswell, 2013; Padgett, 2008). There are six phases to the photovoice process, which include: an orientation and training; a period of time for participants to take photographs; a focus group interview; data analysis; respondent validation; and, a presentation of the photographs. Participants were recruited via flyers around campus as well as by posting the flyers through the university email (See Appendix F). The researcher first conducts an orientation to photovoice for participants, which includes: an overview of photovoice; ethics and safety training; and, basic photography training (Wang & Burris, 1997). At the conclusion of the orientation, participants are provided with research questions to explore through photography (Wang & Burris, 1997). The participants meet again with the researcher for a focus group interview, where photographs and stories are shared (Wang & Burris, 1997). Themes are developed within the focus group in cooperation with the participants and further analyzed through transcripts of the focus group by the researcher (Agarwal et al, 2015). Finally, photographs are showcased in a presentation to gain attention from community members with decision-making power to create positive social change (Tijm, Cornielje, and Edusei, 2011).

**Phase 1: Orientation and training.** After participants were recruited and informed consent was obtained from participants, this researcher conducted an orientation and ethics

training to photovoice introduce the concept of photovoice to participants on a day and time that was convenient for all participants (Hannes & Parylo, 2014). Seven students were originally recruited to participate in the study; however, only five students attended the orientation and ethics training. A second orientation and training was held after additional participants were recruited, in an effort to achieve saturation. Five participants attended the second orientation and training session.

The orientation and ethics training (see Appendix C) covered an overview and purpose of photovoice; the purpose of the study; and the researcher's use of photographs and interview data. The ethics and safety portion of the training included: informed consent to participate in the study as participants (See Appendix B); information related to obtaining consent from individuals who can be identified in photographs taken by the participant; and, basic safety information such as taking photographs in familiar places.

The basic photography training provided tips to participants for photography using a digital camera or smart phone camera, and provided participants with an opportunity to practice taking photographs. In some studies, participants have been given disposable or digital cameras, whereas other studies asked participants to use their own digital camera or the camera on their smart phone (Agarwal et al, 2015; Goodhart et al, 2006; Hannes & Parylo, 2014; Tijm et al, 2011). At the conclusion of the orientation and ethics training, participants completed a Photography Ethics Agreement form to ensure understanding of ethics in relation to Photovoice (See Appendix D). In this study, all participants utilized their smart phone cameras to take photographs. Participants were provided with \$25 Amazon gift cards for completing the Photovoice Orientation and Ethics training and for submitting photographs. Additionally, each participant received another \$25 Amazon gift card as an incentive to participate in the focus

group interview. The money for the gift cards was provided from a graduate student research grant from Kutztown University of Pennsylvania (See Appendix H).

**Phase 2: Data collection: Photography.** At the conclusion of the photovoice orientation, the researcher invites participants to capture photographs that reveal their experience or the phenomenon in question (Goodhart et al, 2006). The photography phase allows participants "to reflect and record their community's strengths and concerns" (Wang & Buris, 1997, p. 369), the first identified goal of Photovoice. Holtby et al (2015) suggest that researchers ask broad, openended, non-leading questions so that participants can utilize their own creativity to showcase their experiences. Participants are given a set amount of time to capture these images (e.g. a day, a week, a month, etc.) and are asked to submit an established maximum number of photographs to the researcher (Wilson, Dasho, Martin, Wallerstein, Wang, & Minkler, 2007).

In this study, participants were given two weeks to submit up to ten photographs for each of the two identified research questions. The overarching question: 'What does it mean to be a college student with a physical disability?' was posed to participants and the following subquestions were asked:

- 1. How do you describe your identity as a college student?
- 2. How has your physical disability influenced your experiences (academic and social) in college?

Participants were provided with this researcher's email address and cell phone number, both of which can only be accessed by this researcher through a passcode, to submit their photographs. Only one student utilized this researcher's email to send photographs, while all others utilized text messaging. Some participants chose to send photographs with captions as the images were captured throughout the two-week period, while other participants sent all

photographs at the conclusion of the photography time period. Photographs were saved to a file, without any identifying information of the participants, through a Microsoft OneDrive Account of this researcher, which requires a password known only to this researcher. Photographs for each focus group were printed and did not contain any identifying information of the participants.

Phase 3: Data collection: Focus group. After the established time-frame for taking photographs, the researcher conducts a semi-structured, open-ended focus group with participants (Creswell, 2013; Sethi, 2016) (See Appendix G). This focus group supports the second goal of Photovoice, according to Wang and Burris (1997), which is "to promote critical dialogue and knowledge about important issues through large and small group discussion of photographs" (p. 369). Participants are provided with copies of their photographs and asked to select the pictures that they feel best capture their experience or essence of the phenomenon (Burgos et al, 2014). Burgos et al (2014) suggest having participants narrow the photographs down to ten favorites, and then placing them three piles such as: positive, negative, and neutral; while other studies propose that participants choose two or three photographs for the focus group (Goodhart et al, 2006). The researcher, as the focus group leader, must be aware of the time allotted for the focus group so that each participant has enough time to share their chosen photographs (Then, Rankin, & Ali, 2014).

There are two main methods of eliciting information from participants during the focus group: SHOWED; and, PHOTO. The SHOWED technique is an acronym that stands for:

"S: What do you see?

H: What happened or is happening in the picture?

O: How does this relate to our lives?

W: Why does this happen?

E: How could this image educate others?

D: What can we do about it?" (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009,

p. 687).

The PHOTO technique is an acronym, which stands for:

"P: Describe your picture?

H: What is <u>happening</u> in your picture?

O: Why did you take a picture of this?

T: What does this picture <u>t</u>ell us about your life?

O: How can this picture provide <u>opportunities</u> of us to improve life?" (Graziano, 2011, p. 5).

Both methods provide a consistent technique for data collection among participants to increase reliability of the data collection process, as well as the credibility of data (Faulkner & Faulkner, 2014).

With Photovoice, focus groups provide the context to elicit dialogues which "draw on the synergy" (Padgett, 2008, p. 100) of participants to create a sense of cohesion to challenge the status quo. Among individuals who have experienced oppression, focus group enhance empowerment as participants validate one another's experiences and provide support and mutual aid by discussing possible solutions (Onwuegbuzie, Dickinson, Leech, & Zoran, 2009). From a logistical standpoint, focus groups promote efficiency of data collection and are more cost-efficient than individual interviews (Creswell, 2013; Onweugbuzie et al, 2009; Padgett, 2008). Limitations to consider with focus groups include: issues related to confidentiality among

participants; lack of depth of interviewing among each participant; and, general issues relate to group dynamics (Padgett, 2008).

During the orientation and ethics training, this researcher was able to establish a time and location to hold the focus group that was convenient for all participants. Collaboratively, it was determined that two hours would be necessary to provide each participant with an opportunity to engage. At the first focus group interview, only three of the five participants submitted photographs and attended the focus group. It is suggested that phenomenological studies engage at least 5 participants in order to reach saturation (Creswell, 2013); therefore, at the conclusion of the first focus group, this researcher wrote an addendum to the original IRB (See Appendix A) to include social work students in this study. The original IRB had excluded social work students from participants, of which only one participant was a social work student.

At the focus group, this researcher provided participants with copies of their submitted photographs and asked each of them to narrow their collection down to one photograph for each of the research questions that they feel best captures their response. The SHOWED method of photovoice data analysis was utilized as an interview guide. Participants took turns sharing each of the two photographs using the researcher's prompts from the SHOWED method. Saturation was achieved after the second focus group interview as a result of the uniformity of the interview protocol, as well as the homogeneity of the sample, given that all participants are current undergraduate students enrolled in the same university and self-identified as having a physical disability.

In addition to audio-recording the focus group interview, this researcher took some notes using an interview protocol during the focus group interview. The interview protocol provided: a

general outline for the focus group; a face sheet, and interview questions. The general outline was distributed to the participants of the focus group and included: an introduction; distribution of photos to participants; photograph selection by participants; sharing of photographs using the SHOWED method; discussion of observed themes; obtaining group's preference for respondent validation (email communication versus additional focus group); considerations for photography presentation; and, debriefing prompts to address any emotional issues that may arise (See Appendix E).

A face sheet identifying participants by a number, rather than name, along with an interview protocol was developed for each participant so that the researcher can take notes during the focus group (Padgett, 2008). Observational notes were particularly beneficial as this information was not captured through the audio file. The transcription of the focus group interview, the face sheets, and the interview protocols were stored on a computer file which requires a passcode known only to this researcher.

**Phase 4: Data analysis.** This researcher planned to set aside time at the end of the focus group to engage participants in a discussion about their perspective of themes that emerged through the group (Agarwal et al, 2015). Time did not permit for a discussion of themes in depth at the conclusion of the first focus group, therefore, this researcher sent an email to all three participants asking them to identify themes that transpired during the focus group. During the second group, time permitted a few minutes to discuss themes with participants to the extent that all five participants agreed that the list of themes was an accurate reflection of the focus group.

This researcher relied heavily on the audio recording and transcription of the audio file from focus group, as each focus group was listened to three separate times in their entirety in addition to being revisited for clarity. For each focus group, this researcher listened to the focus

group recording in its entirety; listened a second time and took notes; listened a third time while engaging in horizonalization from the transcription. Significant statements were highlighted, and subsequently copy and pasted into a four-column word document. Listening to the audio recording three times prior to reading the transcription allowed this researcher to become intimately familiar with the descriptive data that emerged from the focus group, while the transcription itself provided a visual reference for the development of codes and themes. This researcher utilized a transcription program, Trint, to transcribe the audio file and was then able to go back through and make corrections as necessary. A word document was utilized for coding and thematic development.

*Coding and thematic development.* Researchers need to recognize the dynamic process of qualitative research, and demonstrate flexibility and an open-mind with respect to the themes that naturally transpire through the process (Creswell, 2013; Padgett, 2008). A traditional phenomenological approach to analyzing the transcripts was implemented using a three-step process after engaging in horizonalization, the division of the written transcript into individual statements (Creswell, 2013). Significant statements that demonstrate the essence of participant's experience as college student with physical disabilities were highlighted from the horizonalization process (Creswell, 2013). These significant statements included sentences or quotes, and were taken from the original transcription, using the cut-and-paste function, and placed into a Microsoft Word documents. The document contained four-columns, with the first column titled, "significant statements", followed by a second column titled "textural or structural meaning", a third column titled "meaning units", and a final column titled "themes" (Creswell, 2013; Padgett, 2008). Sections of the document were separated by the participant and photograph shared during the focus groups.

The first step of data analysis required the researcher to identify whether or not each significant statement or quote was textural or structural in nature. A textural description provides a description of participants' perspective on each of the research questions (Creswell, 2013; Padgett, 2008). In contrasts, a structural description, provides information related to the context and setting of the experience (Creswell, 2013; Padgett, 2008). The textural description emphasizes the participant's perspective of the experience, while the structural description focuses on the meaning of the participants experience in relation to the phenomenon.

This researcher utilized the "meaning units" column to identity concepts or ideas that emerged from the list of themes identified by participants, known as codes (Creswell, 2013; Padgett, 2008). Codes were subsequently reviewed, and either combined or eliminated in order to narrow the focus and develop themes, which became the third and final phase of the data analysis (Padgett, 2008). The identified themes provided the foundation for the summary for the third, and final phase, of the data analysis. In this final phase of data analysis, this researcher reviewed the themes and corresponding statements to create a summary of the major themes which resulted in a composite description of the participants' responses to each of the research questions (Creswell, 2013; Padgett, 2008).

*Validation strategies.* Prolonged engagement, triangulation, peer review and debriefing, clarifying researcher bias, member-checking, as well as obtaining rich and thick description enhanced the validity of this study. The design of this Photovoice study naturally lent itself to prolonged engagement between the researcher and the participants. As such, developing rapport with participants was important for this researcher in order to learn about the culture of disability from the perspective of college students, and inquire about stigma and stereotypes that influence their experiences (Creswell, 2013). Triangulation, the use of multiple methods to demonstrate

common themes, was employed through the photographs with textual descriptions submitted by participants as well as the focus group interview. Through peer review and debriefing, this researcher was able to review the findings with colleagues, who then inquired about the methods and findings of the study, providing this researcher with an outsider's perspective that assisted in the validation of the results of the study (Creswell, 2013).

In addition to thematic development from participants, this researcher engaged in secondary analysis of the transcription of all photographs and captions submitted by participants. The transcription analysis allowed this researcher to find quotes and descriptions from participants' captions of photographs that matched the themes developed from the focus group (Creswell, 2013; Padgett, 2008). Quotes from photograph captions were added to the "significant statements and quotes" column of the word document, and were highlighted in yellow to indicate that they were obtained from captions, rather than the focus group. Review of the photographs and captions of the photographs provided an opportunity for this researcher to either glean additional themes from the focus group interview that did not emerge as part of the discussion of themes among participants or demonstrate further support of the identified themes (Creswell, 2013). Secondary analysis also included a separate examination of all photographs submitted by participants to determine additional evidence of themes (Newman, 2010; Overby, Eggert, Dinkel, Huberty, Stluka, Meendering, 2015). Photographs were numbered by hand and coded using the original list of themes developed by participants. This process required not only crossreferencing with the transcription of the focus group interview, but member-checking with participants through email communication to ensure credibility.

It is also suggested that researchers 'bracket' or sideline prior knowledge to cultivate the inductive process of qualitative research (Creswell, 2013; Padgett, 2008; Tufford & Newman,

2010). Bracketing can occur through the use of a reflexive journal, and can be effective in identifying biases and other concerns that may otherwise undermine and invalidate a research study (Creswell, 2013; Padgett, 2008; Tufford & Newman, 2010). Given this researcher's knowledge of CRT, Intersectionality, and the current literature, it was imperative to bracket this information to maintain the credibility of the study. Through the process of member-checking, this researcher reviewed independently developed themes and interpretations to determine reliability with participants' experiences and perspectives. Inter-rater reliability, a process whereby researchers compare the development of codes and themes with one another for cross-validation, can be employed through the member-checking, as participants in Photovoice studies are viewed as co-researchers.

Furthermore, this researcher provide "rich, thick description" (Creswell, 2013, p. 252) in the analysis and write-up of the stud. Detailed description of participants' responses to the research questions were provided in addition to the photographs shared by participants (rich) which is evident through the details captured through a counter-narrative of each participant in relation to both research questions (thick). This comprehensive approach using textural and structural analysis supports readers' ability to determine whether or not the results can be transferred to other contexts (Creswell, 2013).

**Phase 5: Respondent validation.** Although it was essential for the researcher to audiorecord and transcribe the focus group interview, it was vital for the researcher to glean themes from the perspectives of participants, given their role as co-researchers. Teti et al (2016) recommend the use of "participant check-ins" (p. 53) to ensure themes developed by the researcher through the coding process are truly representative of participants' experiences. This researcher inquired about the best way to contact participants for member-checking at the

conclusion of each of the focus groups, and also scheduled a follow-up meeting for each of the focus groups at the start of the Spring semester in February 2018. This researcher has engaged in member-checking through email to ensure the accuracy of the findings as written in this study. The follow-up meetings will be advantageous not only to ensure that interpretation of codes and themes accurately reflect the voices of the participants, but to focus on social change efforts in the community as identified by each of the focus groups (Hergenrather et al, 2009).

**Phase 6: Presentation of photographs.** The final phase, and the third goal of Photovoice, is to create an opportunity for participants to present their photographs and share their experience with the masses, including community stakeholders who hold the power to shape policies (Brake et al, 2012; Wang & Burris, 1997). The presentation may simply be an informational packet with the pictures and captions from the participants, or it may be an interactive event where participants have an opportunity to engage with those who attend (Brake et al, 2012; Bugos, et al, 2014; Goodhart et al, 2006; Tjim et al, 2011). With respect to research, Tijm et al (2011) notes that this last step of participants focusing on data analysis and writing the results of the study. Creating a platform for participants to showcase their project, as coresearchers, can be empowering and provides participants with the confidence and skills necessary to continue to advocate for themselves, as well as others who are oppressed and marginalized (Hergenrather et al, 2009).

Allowing participants, as co-researchers, to determine how to utilize the photographs to engage in advocacy efforts is fundamental in building empowerment and engaging in efforts that can be sustained within the community. Providing participants with an opportunity to engage in

advocacy towards social change will hopefully enhance self-efficacy, leading to increased levels of self-advocacy and advocacy for others who experience oppression and discrimination.

The first focus group, which consisted of three participants were interested in creating a training program for faculty of the university in order to increase awareness and knowledge of disabilities, disability laws and accommodations in relation to higher education. The second focus group, which consisted of five participants was interested in educating children in the community about physical disabilities and also starting a support group for student with physical disabilities. This researcher, as an ally, utilized networking skills within the university to assist participants in this process. As a result, participants from this study will be starting a student organization on campus which can address all of their ideas for social change.

## **Limitations of Proposed Study**

Despite the many advantages of photovoice, this method does have its limitations. Participants may feel that the process is too time-consuming between participating in a photovoice orientation, taking photographs, participating in focus groups, and engaging in a forum to promote public policy (Brake et al, 2012; Goodhart et al, 2006). Researchers may also have concerns about the amount of time necessary to engage in qualitative research methods, such as photovoice, as they have less control over aspects of the study such as scheduling in comparison to quantitative research (Holosko, 2010). Challenges may include access to cameras, phenomena that are simply too traumatizing for the participant, or, participants who feel threatened by challenging the status quo or leadership in their community (Burgos et al, 2014; Holtby et al, 2015; Sethi, 2016; Tijm et al, 2011). The ethics training, although a necessary component of the photovoice orientation, may also leave the participant feeling limited in their ability to feel authentic with their photographs (Hannes & Parylo, 2014). Furthermore,

photovoice as a qualitative method is generally conducted with smaller samples, therefore, the results of the study lack generalizability of quantitative research (Hergenrather et al, 2009).

*Ethical and safety considerations specific to photovoice.* All research studies must consider ethical issues related to human subjects and this is addressed with photovoice participants through IRB approval and initial consent. Ethical considerations are further explored through: confidentiality statements, changing names to pseudonyms in transcripts and publications, and the additional removal of identifying information within transcripts to promote confidentiality and anonymity, all of which were employed in this study (Creswell, 2013; Padgett, 2008). Using photovoice as a qualitative research technique requires additional ethical considerations, as participants are acting as co-researchers and need to understand and protect human subjects captured in images. Implementing ethical training for photovoice participants becomes a necessity in order to increase participants' awareness of ethical issues related to privacy and confidentiality in order to determine when consent is needed from others whom the participant would like to capture in photographs (Bugos et al, 2014). In this study, participants chose not to include faces of people in their photographs in order to help maintain their own anonymity.

Although ethics training is mandatory, such training may cause participants to feel restricted with respect to their ability to tell their story, causing participants to avoid taking pictures that may be a true representation of their perspective and lose their sense of commitment to the project and the cause (Haynes & Parylo, 2014). One example cited by Haynes and Parylo (2014) was the participants' tendency to avoid taking photographs of strangers because they felt uncomfortable explaining the purpose of the study and asking for the person's consent. Providing participants with an opportunity to engage in role-playing during orientation may help to

alleviate this concern. Although participants of this study did not engage in role playing, participants did share ideas about possible photographs to be captured at the conclusion of the orientation and ethics training.

While photovoice provides opportunities to empower marginalized individuals and groups, this opportunity must be balanced with ethical issues related to "visibility and representation in their daily lives" (Holtby et al, 2015, p. 317). Participants may struggle with the pressure to accurately represent a larger community of marginalized individuals without reinforcing stereotypes (Holtby et al, 2015). Among invisible populations, such as LGBT, photography has the potentially to cause repercussions for individuals who may be captured in images, even with informed consent (Holtby et al, 2016). This researcher made every attempt to alleviate any concerns about the pressure to represent one's community during the orientation by emphasizing the opportunity for participants to document their own individual reality, which aligns with the overall ontological assumptions of the study.

As important as it is to address issues of invisibility, it was necessary for this researcher to acknowledge physical limitations that may restrict participants' ability to engage in aspects of the research process. Certain physical disabilities may limit participant's ability to take photographs or to engage in a focus group. Each potential participant participated in a screening interview to determine whether or not they are appropriate for the study. As part of the screening process, this researcher inquired about the need for any modifications or assistance that may be required for full participation and make every attempt possible to accommodate requests. None of the participants required any accommodations to engage in the photography portion of the study, although several participants stated that their photographs may be "crooked" or "blurry".

Researchers give up a sense of control in the process of photovoice, as participants engage as co-researchers through the process of taking photographs (Brake et al, 2012). In the quest to decrease the risk to participants, researchers should include safety precautions as part of the photovoice orientation process. Safety measures may include: partnering with other photovoice participants; taking photographs in familiar places; and avoiding anything or anyone that could "indict, stigmatize, embarrass, or shame individuals or groups" (Burgos et al, 2014, p. 2). Providing examples of scenarios and allowing participants to ask questions during the training will be beneficial in reducing safety concerns. The researcher emphasized the importance of safety when taking photographs during the orientation and ethics training, and this was information was subsequently reviewed by each participant when completing the Ethics Agreement Form.

#### Summary

The ontology, epistemology, and interpretative theoretical frameworks outlined in this chapter demonstrate a compelling rationale for a transcendental phenomenological qualitative research study aimed at improving the understanding of college students with physical disabilities, and the influence of their disability on their identity and experiences of in higher education. The implementation of Photovoice further embraces the identified ontology, epistemology, methodology, and interpretive theoretical frameworks which is reflected in the research questions, the sample and setting of the study, the reflexivity and objectivity of the researcher, the purpose and process of photovoice, and the photography presentation designed to initiate social change.

# **Chapter 5: Findings**

The purpose of this qualitative study was to ascertain what it means to be a college student with a physical disability, particularly with respect to the student's identity and their experiences, both academic and social, in higher education. Photovoice provided an opportunity for each participant in the study to tell their unique story about their identity and experiences as a college student with a physical disability. Although each participant's story was certainly unique, it was evident that each participant's experience resonated with the other participants. Participants would jump in and share "something similar happened to me too" or "Yes. I feel the same way." The depth of the discussions that transpired during the focus group developed a deep sense of cohesion among participants. The photographs were particularly powerful for the researcher, as an able-bodied person. The visual images allowed this researcher to truly take on the participants' perspectives.

This findings chapter will include: a description of participants; a narrative account of each participant's response to each of the research questions; a discussion of participantdeveloped themes that emerged; and, a summary of the themes in relation to each research question. Participants selected one photograph to answer the first research question, "How do you describe your identity as a college student?". Each participant's photograph is shown below and followed by a summary, which was developed from participants' responses to the SHOWED prompt. The descriptive results from the semi-structured focus group interviews have been documented in a narrative format to provide an account of both the textural and structural reactions (textural refers to the description of the participants' experiences while structural provides the context behind the experience) of each participant. The same format was utilized to explicate the results of the second research question, "How does your physical disability

influence your experiences in college (academic and social)?" Finally, common themes are explored, as identified by participants at the end of the focus groups. The same themes were then used to examine additional photographs and captions submitted by participants. By utilizing the themes identified by participants, this researcher was able to continue to bracket previous knowledge and pre-conceptions, maintaining the authenticity of the participatory action research of this study. The following chapter, the Discussion Chapter, will provide a more in-depth analysis of the emerging themes in relation to the literature review and the theoretical framework previously identified in Chapters 2 and 3.

# **Participants**

Eight undergraduate students, who self-identified as having a physical disability participated in this qualitative research study. Six of the participants identified as female and two participants identified as male. All eight participants have a mobility impairment that impacts their ability to walk. Participants chose their own pseudonym to utilize in this study in order to remain authentic to the participatory action research. Lillian, Claudia, Emily, Lynn, and Daniella utilize power wheelchairs, Rupert utilizes a manual wheelchair, Clover uses a walker for assistance, and Brandon is able to walk independently with a prosthetic leg. Participants represented eight different majors within the university. Clover was a freshman and Brandon transferred to this university, but is still considered a freshman. Daniella was a sophomore, and Brandon was a transfer sophomore. Claudia, Emily, and Lynn were juniors, and Lillian was a senior. Rupert was the only non-traditional student, given his age of 28. The other participants ranged in age from 18 through 23.

# **Responses to Research Questions**

The SHOWED interview prompts of Photovoice, utilized to guide the focus group interview, elicited information from participants which naturally imparted both textural and structural descriptions, maintaining the transcendental phenomenological approach of this research study. The textural descriptions, provided a first-hand perspective of each participant's experience and originated from the first two questions of the SHOWED technique: "What do you see, and, What happened or is happening in the picture?" (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009, p. 687). The structural descriptions, which provide the context for the participant's experience, developed from the last two questions of the SHOWED technique: "How could this image educate others, and, What can we do about it?" (2009, p. 687). It is interesting to note that the questions, "How does this relate to our lives, and, Why does this happen?" resulted in varying responses from participants with respect to textural and structural descriptions. Some participants provided objective responses to these questions, while others engaged in more subjective reactions. The first research question focused on the participant's identity as a college student, while the second research question concentrated on the academic and social experiences of participant's in college.

# **Description of Identity as a College Student**

The first research question: "How do you describe your identity as a college student?" was asked to participants. Each participant selected a photograph, which they felt best represented their response to the research question. The SHOWED prompt of Photovoice assisted in extrapolating more details about both the textural and structural description of the photograph. The photograph selected by each participant to answer the research question about their identity is shown below, followed by a textural and structural description of the participant's responses to the SHOWED prompts.

**Rupert.** Rupert is a non-traditional student, who identifies as a person with a spinal cord injury, "a disabled-athlete", a person who utilizes a manual wheelchair, and young man on probation hoping to change his path in life with a college degree and his dream to become a professional athlete. Rupert is originally from a large city in the northeastern United States. He describes people at home as not nearly as "compassionate" as they are on campus and in the small town where the university is located. Rupert was able-bodied until eight years ago, when he sustained a spinal cord injury and became "a paraplegic."



*Figure 5.1.* Rupert's photograph of a welt on his side, chosen to represent his identity as a college student.

*Textural Description.* For the first question about his identity as a college student, Rupert chose the above photograph in Figure 5.1, that showed a bruise on the side of his stomach. To him, this type of injury is a "normal occurrence for someone who plays" adaptive sports. In this particular photograph, Rupert was assessing his "welt" to determine whether or not he needed to go to the emergency room. For someone like him, a person with a physical disability in a manual

wheelchair, a broken finger leaves him unable to push his wheelchair which leaves him incapable of doing just about everything that is a part of his daily routine. Rupert explained that in relation to injury or illness, "it's a whole different ballgame.... It's a big deal...it's much more serious when you have disabilities."

"I hate to say it, but my physical disability dictates my entire life... Everything I do is around my disability." Rupert shared that he is often referred to as a "part-timer" by other students with physical disabilities, meaning that he is "not as disabled as they are", when in fact, Rupert explained that his spinal cord injury is actually more severe. He acknowledged his own feelings of "resentment", at times, toward other individuals with disabilities who experience fewer limitations than him. He also recognizes that a person in a power wheelchair may resent someone like him in a manual wheelchair for the same reasons.

Rupert shared "I think I'm used to my injury, it's getting my injury used to my environment, you know?" To Rupert, independence is a vital facet of his identity and it aggravates him when other students with physical disabilities "manipulate the system here" and utilize services when "they are capable of doing things for themselves." He feels that not only will these individuals not be ready to be "actual adults when they leave", but this type of behavior fosters the stereotype that people with physical disabilities are incapable of taking care of themselves.

In relation to his own identity, Rupert finds himself feeling aggravated when professors claim to be experts in certain subjects without first-hand experience. He also finds it challenging to have friendships with able-bodied men. Prior to his injury, Rupert described himself as "aggressive and competitive" with men and now he feels that he can no longer compete with men on those same levels. "We [men] think we gotta be tough...I have a really hard time getting

along with men now." As a result, Rupert spends either more time by himself or in intimate relationships with women. Rupert explained that being "a disabled athlete is more than a hobby." For Rupert, the photo of the bruise represents the invisible aspects of a person's life that others do not always consider.

*Structural Description.* Rupert spoke of stigma and stereotypes of individuals with disabilities, messages that perpetuate the limitations, and barriers that maintain the status of individuals with disabilities as inferior. Rupert's discussion about being called a "part-timer" by other students with disabilities shed some light on the stereotypes and stigmas that exists within the disability community on campus. He explained that the campus culture with respect to people with disabilities is more positive than other places. "It's a different image too cause where I'm from most people with disabilities are like homeless, like drugs addicts. Everyone here with disabilities is educated, trying to get a degree, and doing different things... The image of people with disabilities is way different from than where I'm from."

Despite the overall positive environment with respect to Rupert explained his concern for the invisible factors and minor incidents that influence students with physical disabilities, but often go unnoticed. As he stated, "what's beneath the surface isn't always visible" and this can impact one's "attitude, performance, and personality" in relation to academic achievement in higher education. With respect to injuries and illness, Rupert spoke about the seriousness of illness and injury to a person with a physical disability. To an able-bodied person, an injury such as "a broken finger might seem minor", as that person can still go about their normal day. For a person with a spinal cord injury, like himself, it is essential that he takes the time to look for injuries on his body, especially because he does not have any feeling from the point of injury on

his spine down through his feet. As Rupert explained, he could have a bruise or a bed sore and not know it, because he does not feel pain as a result of his disability.

In addition, Rupert finds a disconnect between expertise and experience among members of the college community. As Rupert put it, "I could read a hundred books about the Amazon, but I'm still never going to know as much as someone who lives in the Amazon." In relation to his own identity, Rupert shared, "People think they know what it's like to be disabled, but they can't possibly understand unless they are me... or one of us." In his view, expertise should never transcend experience. Rupert talked about professors claiming, for example, to know what it is like for a person to be in jail, and yet, "How could they possibly know what it's like if they have never been in jail themselves?"

In relation to his social experiences, Rupert's disability influences the manner in which he interacts with others. He finds himself less social with able-bodied men, as a result of "the gender roles of society", as well as his lack of confidence as a result of his disability. He described himself as "aggressive" and "competitive" before his injury when he interacted with other able-bodied men prior to his injury. Although he still feels "aggressive" and "competitive", he feels that he is not relatable to able-bodied men due to the limitations of his physical disability. This is the reason why he is so passionate about the adaptive sport he plays. When playing sports with other men in wheelchairs, he is able to be himself. He can compete with other men, who also have physical disabilities, and this allows him to feel as though he has not lost all of his identity as a man.

As a college student, Rupert believes that professors need to develop a better understanding of "what we [student athletes with disabilities] are really doing to make this work." Increasing awareness among "professors is where it really starts because they are going

to continue to deal with students with disabilities, whereas students and students with disabilities are going to graduate and move on to their everyday lives."

**Brandon.** Brandon is an out-of-state transfer sophomore and a traditional college student. He transferred to this university for the opportunity to play an adaptive sport at the collegiate level. He identifies as first and foremost a college student, but also as a "disabled athlete." Brandon sustained an injury five years ago and has a prosthetic leg. As Brandon says, "I'm still getting used to it [disability]." He is able to walk independently with his prosthetic leg and utilizes a wheelchair to play adaptive sports.



*Figure 5.2.* Brandon's photograph of two people in wheelchairs talking to each other to show his identity as a person with a disability.

*Textural Description.* Brandon chose the photograph above, Figure 5.2, of two people in wheelchairs to represent his identity as a college student. Brandon talked about relationships between people and his social experiences as important facets to his identity. Brandon expressed a wish to eliminate the divide that seems to exist between people with disabilities and those without. "Some guys in chairs won't go up to a girl who isn't in a chair…say if he thinks she's

pretty", which he attributes to their lack of confidence as a direct result of their physical disability. For Brandon, his disability initially made him less confident and less social. Being able to play a college sport has increased his self-esteem, especially because he plays his sport without his prosthetic leg. Although his confidence has improved, he still feels that it is easier to talk to people with disabilities because they "understand one another."

On the other hand, he also emphasized, "I don't understand why people feel weird sitting down at a table and eating lunch with someone with a disability." Brandon described the visibility of group membership in places like the cafeteria as, "It's like mixing oil and water." For Brandon, college is "all about meeting new people" and that a student's experience should not be limited to "able-bodied persons if you are able-bodied or a person in a chair if you're in a chair." The students with disabilities sit together and the able-bodied students sit together at another table reinforcing the division among social circles.

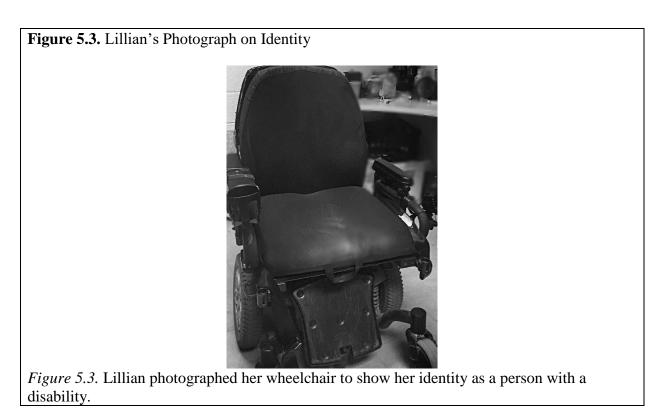
He spoke at length about the strengths of the university setting and described the university and surrounding community as "safe" and the people as "friendly". Brandon stated, "It's different here, you know...I wish it could be like this other places as well." Compared to his experience in his hometown, people at this university and in the surrounding community are "much more relaxed", they are not "always in a hurry." This type of environment makes it easier to be a college student with a physical disability compared to other places, especially big cities. Brandon discussed the need for the university, professors, and other staff to be more intentional with activities that increase opportunities for students with disabilities and students without disabilities to interact with one another and find common ground. He feels that professors within the department of his major are "pretty understanding" because "they have all studied the body and they know what injuries do."

*Structural Description.* Brandon explained that for him, his situation is a little different because there are times when people do not realize that he even has a disability. "More people here know that I have a disability than at home." In Brandon's experience, the segregation that occurs between those with disabilities and those without disabilities is "both their faults." Just as people without disabilities might feel uncomfortable talking to people with disabilities, people with disabilities do not feel that they are able to engage with able-bodied individuals.

As Brandon stated, "we are all people", and as such, all students on campus should be able to interact with everyone. He believes that most able-bodied individuals are afraid to engage with a person with a disability because they might offend them by saying the wrong thing or asking questions related to their disability. Brandon believes that many people who are ablebodied simply "don't know", and often times the challenges and barriers experienced by a person with a disability simply are not things that an able-bodied person has to think about. "They don't know that someone with spina bifida and someone like [Rupert] don't have the same disability just because they are in a wheelchair."

People on campus are accepting of the idea of students on campus with physical disabilities because "it's been this way for a long time here." Despite that, Brandon feels strongly that students need to have a relationship with their professors to feel comfortable talking about how their disability influences them in the classroom. He also shared his concern that some students with disabilities might be more shy and need the professor to initiate those lines of communication. The strengths of the university in relation to the opportunities that are available to college students with physical disabilities can be utilized to create changes in other communities to increase overall inclusion for individuals with physical disabilities. As Brandon stated, "that's something that could change."

Lillian. Lillian is a traditional college student finishing up her final semester of undergraduate school. Lillian is another out-of-state student who chose this university because of the level of services provided to students with physical disabilities, like herself. Lillian was born with a Cerebral Palsy and utilizes a power wheelchair. Lillian was originally an education major, but due to issues related to access and inclusion during her internship, she will be graduating with a generalized liberal arts degree. Lillian was thrilled to share with the focus group that she was just accepted into a graduate program at the university.



*Textural Description.* Lillian used the photograph above, Figure 5.3, of her wheelchair in relation to her identity as a college student. Lillian explained that her wheelchair is part of who she is. "It's my legs." The wheelchair provides her with the independence that she needs to be mobile and be able to do the things that she wants to do. Although the wheelchair is certainly a part of her, there is "so much more" to her than being "just a person in a wheelchair." Lillian

shared, "I might not do it the same way as someone else, but I can do it my way", in reference to breaking down barriers that prevent students with physical disabilities from being included in the same manner as able-bodied students.

Lillian is willing to do things that others may see as "unconventional", such as choosing a major where her career puts her "on the front line." "Despite moments of doubt and anxiety" a college degree represents proof to herself that she can do anything she puts her mind to. When she started college here, she "didn't hang out with anyone in a wheelchair for the first two weeks" because she was not used to associating with friends in wheelchairs. Her freshmen year, she lived in a dorm, "on the other side of campus", where all of the residents had a physical disability. She shared "I hated it." For Lillian, being as independent as possible is vital to her identity. She tries to do as much as she possibly can for herself. Lillian has always known what she wanted to do, and her motivation has helped her get to the point where she is almost ready to graduate from college.

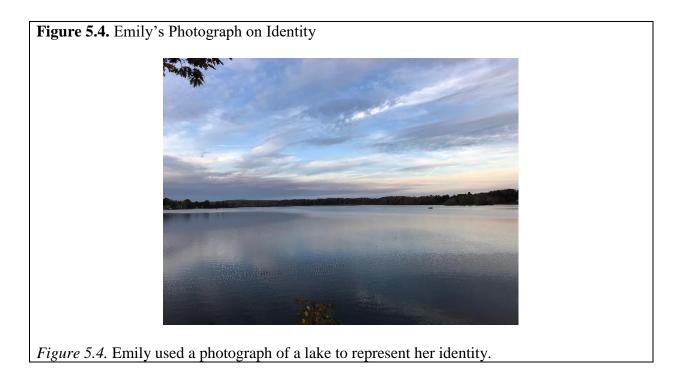
*Structural Description.* Lillian came from a high school where she was the only student in a wheelchair, therefore, all of her friends were able-bodied. Lillian is a very outgoing, as she states, "I'm social and I've always been social. I'll go up to anyone and say anything." In terms of independence, Lillian expressed her view that a person's level of independence depends upon their experiences prior to college, such as how they were treated by their family and as well as their level of motivation to be independent. She credits her attitude to her family, who "never babied" her, raised her with a strong work ethic, and refused to accept less simply because of her disability

She is a determined young woman with strong self-advocacy skills. "If you tell me I can't do something, I'll show you I can." This attitude has helped her combat the stereotype that a

person with a physical disability is not capable of certain tasks, although she noted that this stereotype is not as common within the university community as it has been for her in other environments. Lillian's ability to advocate for herself came from previous experience with her IEP teams in primary and secondary school who prepared her to be a self-advocate.

Lillian believes it would be helpful to educate professors and other students on campus about various disabilities and different types of wheelchairs. If professors understood more about disabilities, they may feel more comfortable having conversations with students about how their disability may or may not influence their experiences in the classroom, in internships, and in their careers. The obstacles that Lillian has had to overcome during her experience in college can be useful in preparing future students with physical disabilities as well. For Lillian, a college degree will have a significant impact on her identity, as it represents "that I can do anything I set my mind to."

**Emily.** Emily is a traditional college student and a science major. She was diagnosed at age 12 with a degenerative muscle disorder. Emily is no longer able to walk, so she utilizes a power wheelchair. Emily was the only in-state student among the participants, although the university is still about five hours from her home. Like all of the other participants, Emily chose this university because of the services provided to students with physical disabilities.

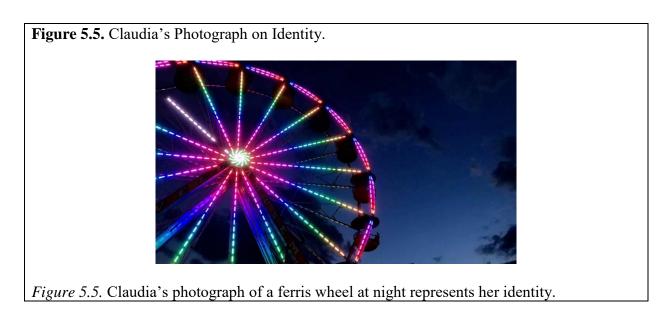


*Textural Description*. To answer the question about identity, Emily, showed a photograph of a lake, shown above in Figure 5.4, and shared, "The lake is calm. This was a day when we went to the lake this summer." As Emily explained, "I stayed up here this past summer because at home I can only lay on the couch all day, every day. So being up here has given me independence and has made me feel so much better about myself." Emily explained that this was a difficult decision for her parents. "I fought with my parents so much about that, but it gave me so much more confidence." Spending the summer on campus, rather than at home, "it helped me to be on my own." For Emily, attending a college with other students with physical disabilities has inspired her with respect to her independence, an important aspect of her identity as a young adult. It's "really nice to know that someone else in a similar situation can be independent and that kinda gives you the encouragement that maybe if I just try, I can do it."

*Structural Description.* As Emily's condition progressed, she lost the ability to walk. Emily feels that parents "don't know" what to expect with physical disabilities as their child

grows up. As she stated, "it's not a generalized category", but something that is individual to each person. "I grew up, pretty much, my parents told me, 'You're gonna live with us forever' or like, 'it's not possible to live on your own'." This is a common stereotype that Emily believes many people with physical disabilities experience. People with physical disabilities "are raised under the idea that you won't be independent and you're always gonna need help." Emily suggests that parents need to "Have faith. Don't just assume", and understand that "we can do things." People with physical disabilities can inspire one another and show people without disabilities "what is possible."

**Claudia.** Claudia is an out-of-state traditional college student with a pre-med major. Claudia was diagnosed with Muscular Dystrophy when she was a toddler, around the time her parents noticed that she wasn't crawling and walking. She has been using a wheelchair since the age of five, and currently uses a power wheelchair. Claudia felt limited with her school choices within higher education and noted that this university is one of three that she could choose to attend in order to obtain the services she needed due her disability. This university is the closest of the three schools and is a 13-hour drive from her home.



*Textural Description.* Claudia chose to show the photograph above in Figure 5.5, of a ferris wheel lit up at night, to show her identity. "I was actually at a fair this summer with two friends. And I was like, 'You know, guys, we should really go to the fair, but I only want to go if you guys are gonna ride the rides." On the day this photograph was taken, Claudia shared,

We watched demolition derby. It's not like they went off and did their own thing and I went off and sat by myself. I went with them and I was taking pictures. You know, I ended up seeing a lot of other people there I knew so it gave me time to catch up with them while they were on a ride, you know?

Claudia enjoys being active within the university, especially with her sorority. Social activities are important to her sense of identity as both a young woman and a college student. It's important for Claudia's friends to understand that she can still be a part of activities even if she can't participate in the exact same way as an able-bodied person. She was not afraid to tell them,

I want you to ride the rides so I can laugh my head off at you making a fool out of yourself. I'm having a good time by watching you guys have a good time. It's still fun. I'm living vicariously through you while you're riding the rides.

As she shared her photo she stated, "This picture, it's not just a ferris wheel to me", it represents "friendship" as well as the fact that "this was the first summer I lived on my own." Living on her own, with a friend, who provided care for her, meant to Claudia that independence is possible.

*Structural Description.* As Claudia described, "my disease is progressive, so I've gotten weaker over the years...I've not been able to do as many things as I used to." This is challenging for Claudia and others who experience continued loss with respect to functional limitations

because "people assume you have been this way your whole life." She is learning more about her strengths and challenges as she goes.

Claudia grew up with younger siblings who played sports, "things I couldn't do, but I'm proud" of them, and she always enjoyed watching her siblings play sports. "My friends and I used to go out roller skating all the time. I can't roller skate, but I can go on the rink and drag them behind me and we can laugh our heads off the whole time." Some peers are unsure how to include a person with a physical disability. As Claudia says, "Friends don't want you to feel left out." "That's the big thing, just being social", she explained. "It's fun to create those memories. Even though I'm not necessarily participating, I'm still getting to soak it all in."

Lynn. Lynn is another out-of-state, traditional college student and a social work major. Lynn was diagnosed with Cerebral Palsy at a very young age and uses a power wheelchair. Lynn chose to attend this university because of the services offered to students with physical disabilities, as it is only one of three colleges in the United States that provides the personal care services she needs. She met a man with a physical disability who went to college in California and he inspired her to get a college education. This university is a 10-hour drive from Lynn's hometown, but the closest school available to meet her needs. The distance makes it nearly impossible to go home for small breaks with her family or to receive essential therapy services.

Figure 5.6. Lynn's Photograph on Identity.



Figure 5.6. Lynn's photograph of a soda bottle represents her identity as a college student.

*Textural Description.* For the photograph that represents her identity as a college student, Lynn chose a picture of a soda bottle sitting on the tray of her wheelchair, as seen above in Figure 5.6. "I can't open it without using my teeth" Lynn shared, but this soda bottle shows how "I always have a bottle of something with caffeine" to keep her awake for classes during the day. This photo has several meanings to Lynn. On one hand, it represents the impact of her disability on her sleep which influences her academic performance. Although she can utilize services at night to call someone to assist her in being repositioned "if I'm uncomfortable", it does not always help, and she often has to wait quite some time for someone to answer her call. Lynn feels it is important for others to know about her sleep related issues, so they can better understand why she experiences exhaustion during the day. On the other hand, this photograph also demonstrates some of the challenges and limitations of being an out-of-state student as Lynn is unable to fill her prescription for medical marijuana that assists her with sleep regulation. *Structural Description.* Because of her disability of Cerebral Palsy, Lynn explained that she has a difficult time getting comfortable at night and therefore, she "can't sleep." As an out-of-state student, Lynn is unable to utilize her medical marijuana card, because "it's not legal here." In addition to occupational and physical therapy that Lynn receives at home, she has been prescribed medical marijuana to help her sleep, as it eases her muscle tension and spasms that occur as a result of her Cerebral Palsy. Lynn's state health insurance from her home state will not pay for occupational and physical therapies in this state, which would help provide some relief from the significant muscle tension she experiences. The university provided occupational therapy services to students with physical disabilities up until the start of this academic year, as the occupational therapist's position was cut due to budget constraints within the university.

**Clover.** Clover is an out-of-state freshman, majoring in secondary education. Clover was diagnosed with Cerebral Palsy when her parents noticed she wasn't crawling and walking at the same time as her twin sister. Clover utilizes a walker the majority of the time and occasionally uses a wheelchair if she knows the terrain is uneven or might be challenging for her. Although Clover does not need the personal care services offered by the university, she chose this university because it is known for supporting students with disabilities.



*Textural Description.* Clover chose the photograph of a sign on her dorm room door, shown above in Figure 5.7, that reads, 'Shhh... future teacher is studying'. As Clover explained, "I feel like that represents my career choice and I am a secondary social studies major with special ed." Also, "my door is shut and I spend a lot of time studying, maybe a little too much time." To Clover, being a college student and a future teacher represents her hard work and her ability to do anything she sets her mind to. She chose to major in social studies because she has always loved history. Additionally, her ability to relate to students with disabilities

is one of the reasons I want to do special education...I can show someone that even if you have a disability, you can still end up having a future and being independent. Look where I am, you could be in the same place too.

As for the field of education, Clover sees herself as a person that can help diversify the field "because even if you have a disability, you can still have a career and an impact on people."

The message, "I am not defined by my disability. I can reach beyond what is expected", is one that Clover wants to make loud and clear to students and professors on this campus, as well as her future students and colleagues.

Structural Description. Clover's responses about her identity reflected her conviction that "it's the mindset of people that needs to change." She shared the story of being placed in a special education classroom from kindergarten to second grade because the school district assumed that she had an intellectual disability as a result of her Cerebral Palsy. Clover has a twin sister, and in second grade Clover started catching on to what her sister was doing in school and even started doing her sister's homework. Her sister's teacher found out and she was moved out of the special education class, but at that point she had not been part of the "mainstream classroom" for three years, so the school held her back one year. Because her twin was always a grade above her, people just assumed "I wasn't smart", Clover said. Clover tutored students in high school and they would say things like, "Why are you helping me and how do you know what you're doing?" Clover explained that after some time the students she tutored would start understanding the material "and their grades would improve, and they'd be like, 'Oh, I'm sorry I judged you'." The stigma and stereotypes that influence people with physical disabilities can play a strong role in one's emotional development. Clover, however, exudes positive energy and never let this get her down.

**Daniella.** Daniella was diagnosed with Cerebral Palsy and utilizes a power wheelchair. Daniella can stand on her own and walk across the room as long as she has something to hold onto and support herself. Daniella is another out-of-state student who travels through six states to get to this university, which again is the closest university to her home that provides services to students with physical disabilities. Daniella is getting a degree in Communications.

 Figure 5.8. Daniella's Photograph on Identity.

 Figure 5.8. Daniella photographed her favorite sweatshirt to represent her identity.

*Textural Description.* Daniella chose to show a photo of a hooded sweatshirt with the logo, 'That's how I roll' and a figure of a person in a wheelchair, shown above in Figure 5.8, to represent her identity. The sweatshirt is designed by a company called "3E Love, which stands for Embrace, Empower, Educate." As Daniella shared, "I like what it stands for...This started my collection and now I buy lots of stuff from this company." The message on the sweatshirt is empowering for Daniella. Daniella describes herself as "extremely introverted", but the logo on this apparel is a conversation starter and people will ask her about it, which "gives me something to talk about." She informed the focus group, "I don't necessarily want to have a disability, but I'm not embarrassed by it either."

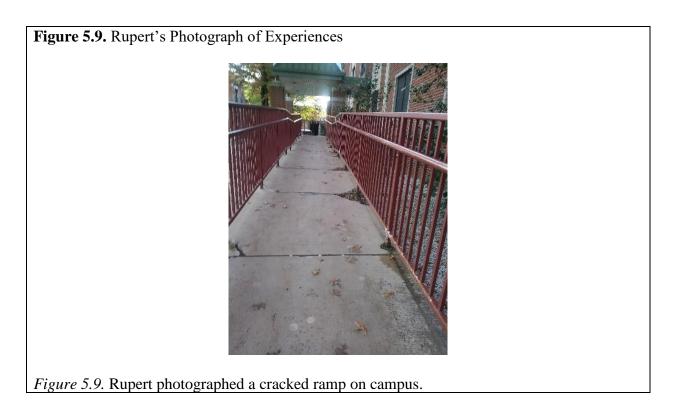
*Structural Description.* The message of the 3E Love Company that Daniella wants to share with those who are able-bodied on campus is that people should be "more open to getting to know others…and not make judgments." The sweatshirt is important to Daniella because she

lives in the south and the weather at this northern college campus is much different than what she is used to. She also likes to keep warm because it helps her muscles to relax. She tends to have more muscle spasms as a result of her Cerebral Palsy when it is cold. Budget cuts at the university resulted in occupational therapy services no longer being provided on campus and as an out-of-state student, Daniella's insurance is not accepted by anyone in the community. As winter approaches, Daniella is concerned that she will likely have to go back on medication to address her muscle spasms, something she did not need to take when she was getting regular occupational therapy services.

# **Description of Academic and Social Experiences in College**

The second research question: "How does your physical disability influence your experiences in college (academic and social)?" was asked to participants. Each participant again selected a photograph, which they felt best represented their response to the research question. The same SHOWED prompts were utilized to examine the details of the photograph as well as participants' responses to establish textural and structural descriptions of their experiences. Each participant's photograph, selected to represent their response to the second research question is shown below, followed by a textural and structural description of the participant's responses to the SHOWED prompts.

**Rupert.** In relation to his academic experience, there are times when Rupert's disability interferes with his bathroom routine prior to class. He indicated that he is hesitant to leave the classroom to use the restroom during class because professors think that he is "just trying to get out of something." To Rupert, this speaks to the professor's lack of understanding of individuals with disabilities and the stereotypes subscribed to by individuals within the campus community of students with physical disabilities.



*Textural Description.* In relation to how his physical disability influences his experiences as a college student, Rupert showed the photograph above, Figure 5.9, of a cracked ramp. As he stated, "I see a ramp, but I also see, I see a hill." To Rupert, the ramp represents access and inclusion into the physical buildings of university that allow him to be part of the campus community. In stark contrast, the ramp also reminds him of stairs and "not being able to go upstairs limits what you can do and who you can hang out with in college." On one hand, Rupert acknowledges his gratitude for the ramp itself, "You appreciate the ramp…what if there wasn't a ramp? Then you'd really be out of luck." The cracks on the ramp demonstrate the need for the university to fix the ramps throughout campus from a safety standpoint, so that cracks are not preventing students from getting in and out of buildings.

With respect to the influence of Rupert's disability on his academic experiences; Rupert focused on the barriers that he experiences within college. Rupert says that he has made attempts

to talk to his professors about his disability; however, "here they are desensitized" because they have "dealt with so many other students with disabilities who have tried to get one over on them." Rupert identified ways in which his physical disability has influenced his social experience in college. Students with physical disabilities are segregated in dorms and this restricts "the people you're getting to know" to mostly other students with physical disabilities. Rupert acknowledged the connection between one's identity as a person with a disability and one's confidence in social relationships. "I don't have half as much confidence as I used to have."

*Structural Description.* Rupert was asked to expand on what he meant by the word "hill" when he stated, "I see a ramp, but... I also see a hill.." Rupert responded by saying, "College, for me, has been an upward battle", which he acknowledged as representative of both his academic and social experiences in college. Rupert defined the hill as symbolic of the constant battle with gravity that he feels in order to balance being a college athlete and a student. In the photograph, the ramp has cracks, to which Rupert stated, "It's already hard to push up a hill, never mind like when you put cracks and stuff in it. There's just more beneath the surface than I think what people realize." Rupert explained that he believes a lot of students with physical disabilities "have a hard time keeping their grades up when they have physical limitations." The unpredictability that accompanies his disability results in anxiety, which makes it challenging for him "to be present in the classroom..., to not be angry all the time..., to keep a smile on my face."

Rupert sustained his injury as a young adult, therefore, he had no prior experience of with education laws or engaging in a transition program that assisted him in self-advocacy after secondary school. Rupert shared that he is learning about how his disability impacts him

academically as he goes. He was under the impression that all of the information he provided to OSD about his disability and accommodations would be shared with professors prior to the start of classes. He was not prepared to have to approach each professor on his own and finds this challenging at times.

With respect to socializing with others in college, Rupert feels he is at a disadvantage for several reasons. Rupert, who is in his late 20's, experienced most of his life as an able-bodied person, and received his GED rather than graduating from high school. He believes the lack of social inclusion of students with physical disabilities is a direct result of where students reside on campus, as students with physical disabilities who utilize Personal Care Assistants often reside in one dormitory or two dormitories, on the opposite side of campus where other students reside.

Again, Rupert expressed concern about the need for professors to understand the many factors that influence students with physical disabilities. The cracks of the ramp signify the gaps of knowledge among professors with respect the to the barriers that prevent students with disabilities from being successful in college.

**Brandon.** Because Brandon utilizes a prosthetic leg and walks independently, his disability is not always obvious to others. As he shared in relation to his identity, most people do not initially know that he has a disability until they realize that he plays an adaptive sport. Sports are not only an important part of who Brandon is as an individual, but he also enjoys watching sports and feels that this is an important aspect of his social experience in college. Social activities have the potential to bring able-bodied people and people with disabilities together, but only if the physical setting promotes such inclusion.

Figure 5.10. Brandon's Photograph on Experiences.



*Figure 5.10.* Brandon showed a photograph of a football to describe his experiences as a college student.

*Textural Description.* The second photograph Brandon chose was a football, shown above in Figure 5.10. As a person who loves sports, Brandon talked about the need for enhanced inclusion of people with disabilities at campus events. He was surprised to learn once he became a student that the university does not take into account the amount of space necessary for students who utilize wheelchairs. This limits the students' ability to watch the game or participate in the event, which takes away from the students' "overall college experience" which "everyone deserves." Watching a football game through "wires" of a gated fence, as he described the experience of many students who utilize wheelchairs during the homecoming football game this year, does not offer the same experience as students who can see the entire field from up in the stands.

Brandon mentioned that making physical spaces on campus designed for social interaction on campus more accessible and more inclusive would more accurately align with "the university's identity." "Maybe a person in a wheelchair wants to sit with his friends who are able

bodied. There aren't any seats for the able-bodied person to sit next to the person in the wheelchair." Although Brandon's photograph focused on sporting events, he recognized the need for a multifaceted approach to social inclusion across campus that would represent diverse interests of students with physical disabilities.

While he does not think that interactions between students with disabilities and students who are able-bodied should be "forced", he does believe that the university should be more intentional with activities that promote such interactions. For example, students who utilize personal care aides should not be segregated to only one or two dorms. "Sometimes people make it harder than it has to be", Brandon stated in reference to able-bodied individuals creating policies or making decisions about architectural designs that impact individuals with disabilities. By including individuals with disabilities in the decision-making process, this would likely eliminate some of the segregation that occurs.

*Structural Description.* Although there are a considerable of number of students who utilize wheelchairs at this university, there is limited space designated for people who use wheelchairs within the current architectural designs of stadiums, gymnasiums, and venues for events on campus. Through this dialogue, Brandon was able to convey the difference between access and inclusion for college students with physical disabilities. Access focuses on meeting the minimum ADA requirements, for example, assuring that students in wheelchairs can get into the football stadium and the basketball gymnasium when there are sporting events. Inclusion, however, as Brandon described is the centered on the quality of experience in relation to a person who is able-bodied. Inclusion, as Brandon describes requires one to think outside of the box, as people with disabilities lack opportunities compared to others because able-bodied people do not consider other ways to include people with disabilities. For example, a person who utilizes a

wheelchair may not be able to play football, but "might be a great coach or a photographer" for the game and can be included in that way.

**Lillian.** Lillian's disability influences her ability to independently care for her personal needs. She pays for and utilizes personal care aides provided by the university to meet her needs so that she can participate in the academic and social experiences of college to the greatest extent possible. Lillian wants others, especially professors to understand that she does the best she can to organize her schedule; however, there are many times when she has no control over when help is available to assist her, despite her best efforts to plan ahead.



*Figure 5.11*. Lillian photographed an empty room where she often finds herself waiting for assistance.

*Textural Description.* The second photograph Lillian chose was of an empty room, shown in Figure 5.11, above. The room is where students are supposed to go when they need a Personal Care Aide; however, there are often times when no one is in the room. Lillian finds herself waiting for someone or searching for someone to help her with tasks so that she can

engage in activities that she is able to do independently. Students pay for personal care services, and Lillian often finds herself frustrated because the aides are not available when she needs them. Staff cut-backs have left Lillian at times, waiting for hours to get the assistance she needs to go to bed, which can then throw off the entire next day because she is tired. She appreciates the help and acknowledges that the personal care aides are understaffed and significantly underpaid for the work they do. Lillian is paying friends to complete tasks for her, such as laundry.

*Structural Description.* To Lillian, this photograph of an empty room represents her lack of power and control over certain aspects of her life. The empty room is a reminder of a barrier to independence that she feels on a regular basis. Given the lack of reliability of personal care aides as well as the excessive costs of services, Lillian feels her money is not being well spent. She tries to plan ahead as much as possible by following protocol and going to the Personal Care Attendant room for assistance when needed, however, there are times when aspects of her schedule are out of her control. Depending upon other people for personal care is a part of her daily routine and Lillian feels that it's important to appreciate what one can do independently, as she stated, "I know I appreciate what my abilities are."

**Emily.** Emily spoke at length about how access influences her experiences as a college student. This university provides access to students with physical disabilities, yet in some ways, just like the second floor of her home, the university is not fully accessible. As Emily shared, "what takes a person two seconds to go down a flight of stairs might take me five minutes." She wants other able-bodied students and professors on campus to be more understanding of what a person with a physical disability goes through on a daily basis.



*Textural Description.* Emily showed a photograph of her stair chair at home, shown above in Figure 5.12. In the picture, Emily shared, "I'm at the top of the stairs looking down at the rail of the stair chair and my wheelchair at the bottom." The photograph of the stair chair "represents a lot about my disability...It represents access...It shows the difficulties stairs pose", but mostly it "shows kinda how limited we are." To Emily, it would be helpful if "they [ablebodied individuals] could be a little more understanding of that and not necessarily take advantage" of the abilities and privileges they have. With respect to limitations of individuals with physical disabilities, providing physical access as a college student is vital to their success. "It's the things people do on a daily basis and they don't think about what that might be like if you're in a wheelchair and you can't bend over." When able-bodied individuals become more aware of the needs of those with physical limitations, "it puts things in perspective." For example, going to Walmart just to go shopping, "I'm the only one of my friends who can bend over and reach up high." Emily wishes other people understood, "to do our normal daily lives, we have to go through so much more."

*Structural Description.* Emily is diagnosed with a progressive muscle disease, but she "wasn't diagnosed until I was 12." At that age, she began "tripping and falling." She also sustained a knee injury from sports and began having a lot of difficulty going up and down the stairs in her home. "I walked normally until about age 15 when I started with a walker." As a result of not being diagnosed with a physical disability at birth, she explained, "my bedroom was upstairs." "We got a stair chair because I had more trouble going up and down stairs." As Emily stated, "half of my house, I'm not really able to go into…I can't leave my couch all day cause I'm home alone and no where's accessible." Learning to cope with her disability is still a process for Emily, especially because she lived most of her life being able-bodied.

**Claudia.** Claudia focused on judgments other people, mostly able-bodied individuals make when they see a person with a physical disability. The negative assumptions that a person with a physical disability is less capable in the classroom or somehow less social than an ablebodied person are both stereotypes that Claudia has experienced in college. Claudia is a confident and determined young woman with tremendous self-advocacy skills. She refuses to allow her physical disability to limit her academic and social experiences in college.

 Figure 5.13. Claudia's Photograph on Experiences

 Figure 5.13. Claudia took a photograph of her back x-rays.

*Textural Description.* Claudia showed the photograph above, Figure 5.13, of an x-ray of her spine from the back, as well as a side view, because she feels that it represents her disability and explains how her disability influences her academic and social experiences as a college student. The meaning behind the photograph was what prompted Claudia to share, "It's not always what you see on the outside." People see her wheelchair and make assumptions, like her professors who have thought "she's not the smartest because she's in a wheelchair."

Some people might get offended, but I really like to teach people about what my life has been about and make them understand that just because you see the wheelchair on the outside doesn't make me any different than you.

Claudia shared, "I like when people ask questions, so I can educate them." As a pre-med student, Claudia knows a lot about the human body and she enjoys teaching other people.

Claudia is breaking down barriers to social inclusion as a college student with a physical disability.

I'm in a sorority and we have mixers where we hang out with other sororities and fraternities, and like I can't really participate because I can't get into the houses... So last year, my sorority sisters and a couple of my friends threw me a surprise birthday party and there were like so many people there. It was just, it was like 'there are people who care.

This year, the girl who threw Claudia the birthday party "was like, 'I'm getting you into the house.'." Claudia shared that as a result,

I brought my portable ramp this year. It's a three-step process...so she moves the ramp like a hundred times and she's like, 'I don't care if I have to move it 3,000 times, I'm getting ya in the house.

This year, Claudia has made plans to go on Spring Break with her friend, who she had to ask to help take care of her while on vacation. Her friend responded by saying, "We are going to have fun. If I have to get you out of bed in the morning, so be it."

Because Claudia is involved with her sorority, she has met a lot of other students on campus. In classes, students will ask her to take quizzes with them, do homework together, or study for tests. She believes that "not everyone is naïve to our situations" and that for the most part, students on campus are generally accepting of her. In fact, Claudia shared with the other members of the focus group, "I think sometimes we pay too much attention to the people who are inconsiderate when there are a lot of people who are just fine with it [our disability]."

*Structural Description.* "I had bad scoliosis as a kid due to Muscular Dystrophy. Surgery straightened my back, prevented my lung from being crushed, and ultimately saved my life." As Claudia further clarified, "scoliosis is common... as a result of muscle deteriorating disease." As

a result, Claudia has utilized a wheelchair for most of her life. The stereotype of a person in a wheelchair as being less capable than an able-bodied person "influences everything. It influences having a boyfriend, having professors understand you..." As Claudia explained, "the initial judgment, 'I'm not going to try to associate with her because she's different'" continues to create barriers for individuals with physical disabilities. People can easily see her wheelchair, "but other things" aren't as obvious, such as understanding how "I had to go through other things....I have gone through major surgery because of my disability. There are other things underneath that you don't see that represent my disability." From a social perspective, Claudia believes that this photograph in Figure 5.13 represents the need for more "understanding."

Lynn. Lynn has Cerebral Palsy and developed scoliosis as a result of her disability. Despite Lynn's "spunky" attitude, her physical disability has dictated both her academic and her social experiences in college. Lynn was forced to leave college on two separate occasions due to issues related to her disability that required surgery. Not only was she unable to complete her academic work, but she was forced to leave her close friends that she had made at the university. As a result, Lynn is now a year behind where she expected to be with graduation.

Figure 5.14. Lynn's Photograph on Experiences.



*Figure 5.14.* Lynn had someone photograph her back to show her experiences in college.

*Textural Description.* Lynn showed a photograph, seen above in Figure 5.14, of someone lifting her shirt to take a picture of her back after her spinal surgery. The photograph shows "the scar down my back and my two tattoos", but for Lynn, it represents much more than what is on the surface. This photograph represents what she went through with her surgery and how far she has come from a physical and mental perspective. It demonstrates her strength, her determination, her appreciation, and also her loyalty. Lynn's tattoos are replicas of her grandparents' tattoos. When asked how this photograph depicts how her disability influences her academic and social experiences as a college student, Lynn explained, "I was in the middle of college." This meant leaving in the middle of the semester, putting her academics on hold, and leaving her friends behind. Recovery from this major surgery was lengthy, and impacted her on more than just a physical level. "Because of the surgery, I developed severe depression. It took a toll on my body. I was addicted to pain killers for months."

The surgery, and the scar it left behind, represents something new for Lynn. As she said, "it's changed my whole life." She is no longer in constant pain; however, as she explained "I used to be able to bend over, but now I can't because my spine is so rigid." She went further in to detail explaining that "there are things I could do as a kid that I can't do as an adult. There are things that get worse over time as you get older", which leaves her feeling frustrated. "I've had to leave school (college) twice now. I'm one year behind where I should be." Now that she is back in school, she finds "when I get home from classes, I'm tired and I nap for like four hours at a time before I can get back up and be social or do homework...I just don't have the energy anymore." During classes, muscle spasms can impact her level of pain, but "there are days when

I will be that weirdo... I'll just put my seat back and put my feet up because I don't care. I'm in pain, but I need to be here, so I have to deal with it."

*Structural Description.* Lynn uses a wheelchair, so the scar and the tattoos on her back are generally not visible. To Lynn, this photograph represents the aspects of a person which are not always visible that should be considered when interacting with a person with a physical disability. Lynn's parents were "young and not ready to take care of a child...They [grandparents] stepped up and changed their whole lives to accommodate me." Lynn described feeling lucky that her professors in her major "get it", and she doesn't feel that she needs to explain why she is adjusting her wheelchair and looks as though she is lying down during class. Lynn is confident in who she is and does not mind doing whatever it takes to be successful in college. Lynn recalled that her grandparents were made to use a wheelchair when she got her first wheelchair to increase their awareness of what it is like to be in a wheelchair. On campus, Lynn feels that a simulation experience similar to the one her grandparents went through would be helpful in showing the perspective of the disability community.

**Clover.** Clover focused on the importance of access and inclusion as influential to her academic experiences. Clover is an independent and determined young woman, who wants to do as much as possible for herself. Clover's disability has influenced her academic experiences in the past, and as a result, she feels as though she needs to constantly prove to others that she is more than capable of completing a college degree. From a social perspective, it was surprising to learn that Clover is just starting to come out of her shell. Clover has a positive energy about her and a smile that can light up a room. Clover disclosed "sometimes I study a little too much" and that she is trying to find a better balance between her academics and her social life.

 Figure 5.15. Clover's Photograph on Experiences.

 Image: Figure 5.15. Clover photographed a push-button on campus that opens doors.

*Textural Description.* Clover showed the photograph above, Figure 5.15, of a pushbutton that opens the doors of building and classrooms on campus. She stated, "Here, I'm about to push the button to go into the building for class." Clover shared that she is one of many students on campus who utilize the push-buttons to open doors. This button "provides me with as much independence as possible." Maximizing her autonomy on campus allows her to feel more "empowered." Clover shared how important it is for her to be as independent as possible. "I don't like it when people automatically assume you need help with everything just because you are different, or like when people talk down to me." Clover explained that "just because someone has a disability, doesn't mean that we need help." To those individuals, including her own caseworker, who doubted her ability to succeed in college, Clover feels confident in her success and wants to convey the message, "I deserve to be here", loud and clear. *Structural Description*. Clover has Cerebral Palsy and uses a walker to walk. To her, the push-button represents her ability to be independent. Without the push-buttons, it would take Clover a long time to open the door, situate her walker to hold the door, and then try to move into the building or the classroom. In relation to being talked down to by others, Clover told a story about going to a fair a few years ago. She used her wheelchair because of the uneven terrain. She placed a bag of canned goods in a donation box as she entered the fair, and a woman behind her yelled "Good girl!" Clover expressed how angry this made her and how it took everything in her not to yell at the woman. She explained that it is times like this when she wants to scream, "I am not a dog. I'm a person." Although she doesn't experience these stereotypes to the same degree on campus, she finds herself frustrated when someone goes to open the door for her because doing things for herself is an important aspect of her identity.

**Daniella.** Daniella, similar to Clover, focused on independence as paramount to her academic and social experiences in college. Independence gives her a sense of power and control over the choices in her life, whether it's within the classroom environment or going out to socialize with friends. Daniella wants to make the most of her college experience and is not afraid to advocate herself when it comes to social opportunities. For example, right after the focus group interview, Daniella was leaving for a weekend bus trip to New York City sponsored by the Student Government Association.



*Textural Description.* Daniella showed a photo of an adaptation to her wheelchair labeled "iLevel", shown above in Figure 5.16. As she explained, "it's a chair elevator" that allows her to raise and lower her wheelchair. Daniella has only had her new wheelchair with the iLevel elevator since the start of this semester. "I can't tell you how much easier my life has been" since getting this. "I'm able to reach things that are higher up, I don't have to ask someone to reach it for me." Even more exciting for her was the fact that she can "help someone else now" by reaching things that some of her other friends who use wheelchairs cannot access. Perhaps most surprising to learn, was the safety that the chair elevator provides for individuals in wheelchairs. Daniella shared,

Even crossing the street, I can raise my chair to see if a car is coming without like having to go all the way out there and be in the middle of the road to see that there's actually a car coming.

The iLevel has allowed Daniella to adjust herself so that she can access tables of different heights around the university, do her laundry independently now that she can reach the buttons on the washing machine, and improve her safety when navigating campus and the local community. Daniella stated that she enjoys talking to other people at eye level now. She stated, "I always tell people, 'I don't like talking to you at crotch level'. I can raise my chair and have a normal face to face conversation."

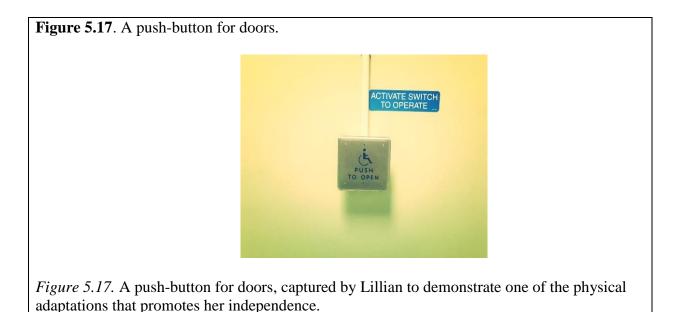
*Structural Description.* Daniella believes that the iLevel or another version of a chair elevator "should be standard on all wheelchairs." It provides a person who utilizes a wheelchair with enhanced safety and increased levels of independence. The issue with the chair elevator is "it's really expensive and most insurance companies won't cover it." In order for insurance companies to cover adaptations, equipment must be "medically necessary and safety and independence is not related to medical necessity in their eyes." Insurance companies will say "you can live without it" and deny coverage for equipment. This is an area of advocacy that Daniella is very passionate about because being more independent allows a college student with a physical disability to be more successful both academically and socially.

## **Emerging Themes**

To maintain authenticity to participatory action research, participants identified themes that transpired within the focus groups. Participants in each focus group identified themes from the focus groups which were then narrowed down to five salient themes: independence, relationships, access/inclusion, visibility/invisibility, and awareness. Interestingly enough each of the five themes were identified in relation to the first research question about identity, as well as the second research question about academic and social experiences in college. Each of the five themes will be explicated below in relation to both research questions.

# Independence

All eight participants discussed the value of independence as intrinsic to their identity. Although participants described independence as being able to do something without the assistance of another person, the focus groups provided insight into additional topics relevant to one's independence, such as: power and control; self-advocacy; and prior experiences. Participants described being grateful for their abilities, yet keenly aware of the lack of insight most able-bodied individuals have with respect to everyday privileges like walking, dressing, and bathing oneself. As Emily shared, her environment influences her independence. "I can't leave my couch all day cause I'm home alone and no where's accessible." Her parents both work, therefore, when she is home from college on breaks and during the summer she finds that she's unable to do anything because she needs help getting in and out of her wheelchair.



**Abilities.** Environmental adaptations and adaptive equipment promote independence among individuals with mobility impairments. Among the eight participants, five students utilize

power wheelchairs, one student utilizes a manual wheelchair, one student uses a walker, and the other student is able to walk independently with a prosthetic. All six students who utilize wheelchairs captured images that either directly or indirectly referenced their wheelchair as integral to their independence. Three participants photographed various push-buttons for doors, like the one above in Figure 5.17 focusing on the necessity the buttons provide for students with physical disabilities to navigate campus independently. Equipment and adaptations such as: wheelchairs; walkers; Hoyer lifts (as shown below in Figure 5.18); shower chairs (seen below in Figure 5.19); and, push-buttons that open doors to building, classrooms, and bathrooms, can make a significant difference related to one's safety and autonomy. As Daniella explained, using the chair elevator for her wheelchair means that she no longer has "to ask someone" to help her reach something. Her smile radiated across the room as she shared her newfound confidence.

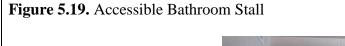
Figure 5.18. Hoyer Lift



Figure 5.18. Claudia's photo of her Hoyer lift which helps someone to get her in and out of bed.

**Power and control.** Beyond functional capabilities, independence relates to the power and control a person has over their own life. Relying on other individuals for help with various aspects to one's daily routines takes away the element of control. As a college student with a

physical disability, one's routine often depends upon another person's schedule, diminishing opportunities for choice in comparison to an able-bodied college student. "To do our normal daily lives, we have to go through so much more", Emily explained about daily routines and relying on others for assistance with certain aspects of her day. Two participants described the degenerative nature of their disability and coping with additional loss of power and control due to factors outside of their control. Other participants shared their struggles with losing functional capacity over the course of their lifetime, despite the fact that their disability is not degenerative in nature. As Rupert shared, "my disability is unpredictable… some days are better than others." Lynn described being "more flexible when I was a kid."





*Figure 5.19.* Rupert's photo of the only accessible bathroom stall on a dorm floor of men who utilize wheelchairs.

Lillian shared a similar photograph to Rupert's above, in Figure 5.19, of the only

accessible bathroom stall on her dormitory floor.

For seven girls in wheelchairs there is only one accessible bathroom stall. Normally there isn't much of an issue unless it's the morning. Everyone's trying to get ready for class and sometimes there's a traffic jam. When this happens, there is a bathroom in the lobby that we go to. It is outside of the security of our (dorm), so if you have to use the bathroom and you're still in your nightgown you just hope that no one else sees you going to the lobby restroom.

# Figure 5.20. Waiting for someone to help after midnight



*Figure 5.20* Lillian took screenshot of the time on her smart phone as she waited for over two hours for someone to help her to bed.

Lillian shared another photograph, Figure 5.20, of a screenshot on her phone, depicting the time, 12:23 am. At this time, she was waiting for personal care aides to assist her to get to bed for the night.

Needing help with daily living tasks means we have to schedule out routines. This included getting up and going to bed. One this night, my go down was scheduled at 10:30 pm. They did not get to me until almost 12:30 am. That's two hours late. Making sure

you get enough sleep is challenging enough but when you depend on others to accomplish this, it is at times frustrating.

**Self-advocacy.** Self-advocacy is yet another element of independence that is necessary for college students with physical disabilities. Several students discussed the importance of learning to advocate for themselves throughout primary and secondary school. Many spoke of the influence of their family of origin on their self-advocacy skills. Other students were not as familiar with disability laws and self-advocacy efforts because their disability was something that was acquired later in life. Clover spoke at length about the importance of advocating for oneself.

I feel totally comfortable with that. It's a way to educate others... I send each of my professor's a nice email detailing my situation, the accommodations I'll be using, asking if it's okay if I use these...and please email me back if you have any questions.

Other participants also acknowledged feeling confident in their self-advocacy skills; however, some participants spoke up and shared that "not everyone feels comfortable". Other participants, such as Rupert shared that he was injured as a young adult, therefore he never experienced the need to advocate for himself in this manner before. As Brandon shared "it's different being in college" compared to high school, relating to the challenges of self-advocacy.

**Prior experiences.** As Brandon explained, "I played football before I got hurt", therefore athletics will always be a part of his identity, whether he is participating in adaptive sports or watching others play sports. In relation to what motivates a person with a physical disability to be an autonomous as possible, Lillian shared with the group, "it goes back to your parents and maybe when you got injured." Many of the participants agreed that at times it requires "tough

love" from caregivers and siblings to learn to be independent. "My brothers used to push me on the floor and kick things out of my reach when we were little", Daniella stated. She feels that these experiences helped her to be resourceful and persistent regarding her independence.

### **Relationships**

Relationships with other people plays a profound role across all stages of human development, yet some aspects of personal relationships are unique to young adults and specifically, the college experience. Important relationships among college students, regardless of ability, include: friends, significant others, caregivers and family support, and professors within the university. Brandon explained that part of the college experience is "meeting new people." College provides students with an opportunity to figure out who they are, without the influence of their caregivers. College should be a place where students feel safe to push themselves out of their comfort zones and change the status quo. For example, Brandon expressed a desire to change the current climate on campus so that students with disabilities are not only sitting with other students with disabilities in the cafeteria, at events on campus, and even within the classroom. Brandon feels that a university, such as the setting of this study, should know how to be more proactive with inclusion because the university is known for providing services to students with physical disabilities even before the American with Disabilities Act of 1990 was passed.

Figure 5.21. Family Support



Figure 5.21. Clover shared, "This is a magnet that my twin sister got me."

Family. Clover showed the photo above, Figure 5.21, and explained, "It's a Gemini for our zodiac sign." As Clover described, "my sister is my other half." She is the person who understands Clover the most and is her "indirect advocate", as Claudia inferred from the focus group. Many participants credited their relationships with their parents as significant to their success in college. Claudia's mother pushed to have her enrolled in a special school before preschool, so she could get the physical and occupational therapy she needed. Brandon shared his family's concern for him now that he is in college in another state. They worry that he is lonely in his apartment and want him to get a dog to keep him company. Emily shared a photograph of flowers she received from her parents one year and noted how much it meant for them to send those to her. Although family support was mentioned by the majority of participants as essential to their success in college, others acknowledged some of the challenges they experienced with caregivers. Emily's parents believed she would always live with them because her disease is degenerative. Emily's relationship with her parents became strained for some time because she wanted to stay on campus over the summer to maintain her independence. As she described in Figure 5.22, below, "This is a picture of flowers that my parents sent me. It

was really important to me at the time because we were going through a lot." Lynn recalled her grandfather crying as he dropped her off at school for her sophomore year. Lynn said to him, "You'll be fine. Just go!"

Figure 5.22. Flowers sent by Emily's parents.



Figure 5.22. Emily showed a photograph of flowers her parents sent her.

**Friends.** All eight participants discussed the importance of friendship as a college student. The physical environment plays a significant role in who one can associate with in college. Although campus buildings are accessible to individuals with physical disabilities to some degree, most off-campus housing is not as accessible, limiting who students can "hang out with", as Rupert shared. Without ramps to get into off-campus housing, students with physical disabilities are unable to participate in off-campus events, which are viewed as important facets of the overall college experience.

**Professors.** Perhaps one of the most overlooked relationships in college is that of the student and the professor. For many students with physical disabilities, this relationship can be tenuous. Despite the strong presence of students with physical disabilities on campus, six of the

eight participants reported at least one experience in which professors treated them as if they were less capable than their able-bodied peers. All participants conveyed the concern that these experiences with professors are a result of "lack of knowledge." As Brandon explained, "students need to feel comfortable with their professors to tell them what's going on." Rupert shared, "there is stuff going on when it comes to a person with a disability that no one wants to share. It's embarrassing." In figure 5.23, below, the photograph demonstrates the private issues that influence a college student with physical disability that may not even occur to an ablebodied professor. Many participants brought up the private challenges related to their physical disability that are challenging to discuss with others, especially professors.

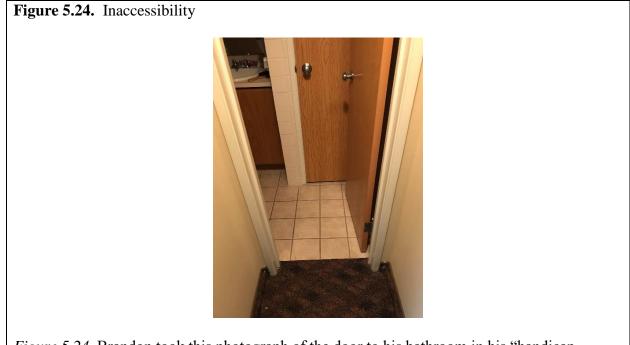


Rupert described several activities of daily living that are much more complicated for an individual with a physical disability. As he described,

There is no bio-waste bin, therefore everyone is required to empty catheter bags before disposing of them. This may not seem like a big deal but when your hands don't work this can become a very difficult task.

# **Access/Inclusion**

Access and inclusion are essential with regard to understanding the trials and tribulations of a college student with a physical disability. As Brandon clarified, access refers to compliance with ADA laws, while inclusion signifies the quality of one's experience. This message was reiterated by all other participants of the research study. Access is a matter of whether or not a person with a physical disability can get into a building or room, and whether or not an institution promotes policies that are aligned with ADA law of 1990 and its subsequent amendments. Inclusion, on the other hand focuses on the conditions that promote the inherent quality of the experience of a person with a physical disability compared to an able-bodied person.

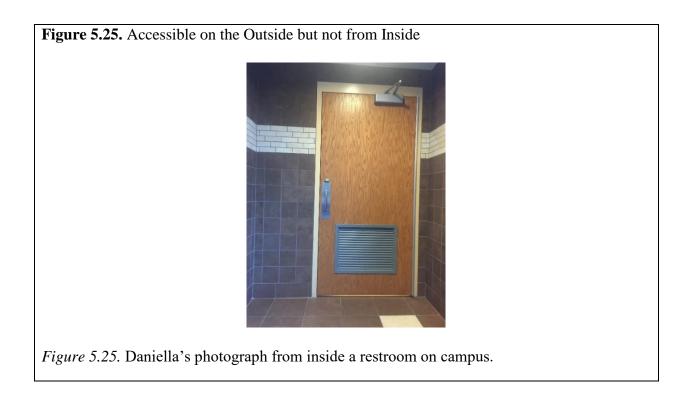


*Figure 5.24.* Brandon took this photograph of the door to his bathroom in his "handicap accessible" apartment.

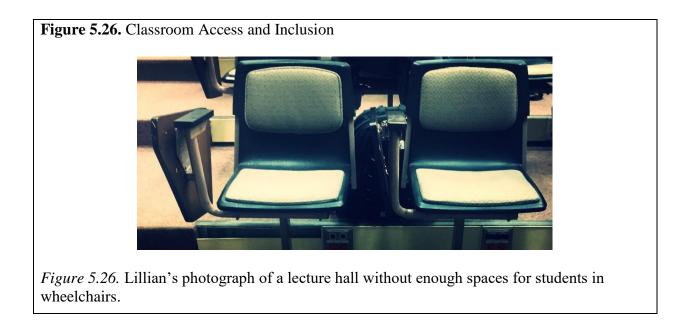
Access. In Figure 5.23 above, Brandon photographed the inside of the apartment he

currently rents an off-campus apartment, which was advertised as "handicap accessible." In

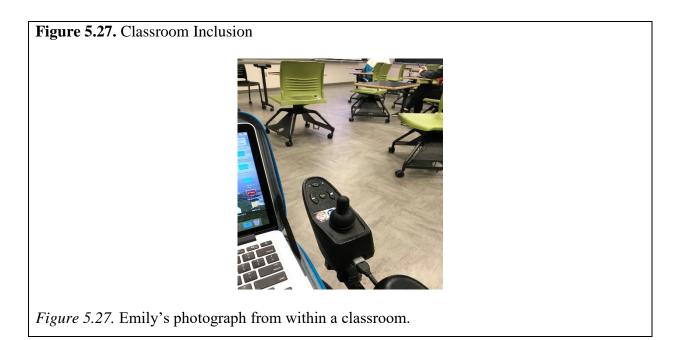
terms of accessibility, the apartment is on the first floor of an apartment building, however, the apartment unit itself is not accessible to a person in a wheelchair given the fact that the bathroom door is not wide enough for a wheelchair to pass through. Brandon expressed concerns about places that claim to be accessible, when in fact they are not.



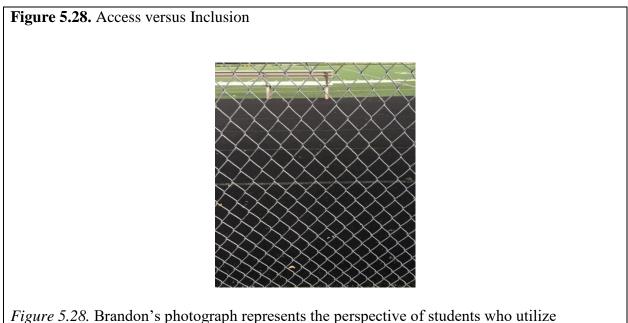
Daniella shared a photograph, shown above in Figure 5.25, from inside a restroom on campus, where she recently found herself stranded. She utilized the push-button in the hallways to open the restroom door; however, there was no push-button on the inside of the restroom and the door was too heavy for her to open. She was able to open the door a crack and wedge her wheelchair in to keep it open a few inches, until a person walked by and she could ask for assistance.



**Inclusion.** Within the classroom environment, several students shared the concern that not all rooms are "disability friendly." For example, some lecture halls do not have specific seating areas for students in wheelchairs. As a result, Lillian explained through her photograph, found above in Figure 5.26, that chairs in some lecture halls are bolted to the ground. In those classrooms, students in wheelchairs have to sit off to the side in the front of the room and it often feels as though they "are on display."

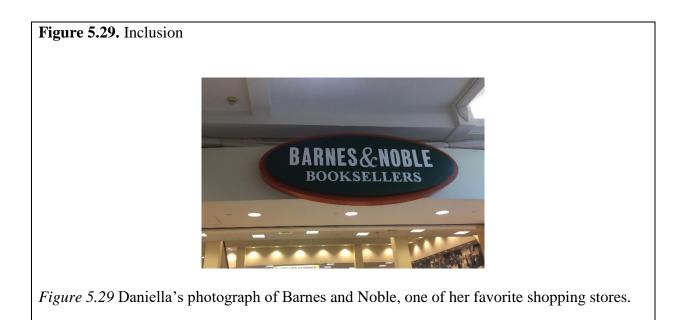


Emily shared a photograph, above in Figure 5.27, of one of her classrooms, in which there is limited space for a student in a wheelchair. "This is a picture from class, where there isn't enough space for my wheelchair, so I'm like ten feet away from everyone else."



wheelchairs at the homecoming football game.

Social inclusion in the university setting is equally important as inclusion within the classroom. "College is about meeting people", Brandon shared. The photograph, above in Figure 5.28, portrays the limited view of the homecoming football game for students who utilize wheelchairs. There is no handicap accessible area, therefore students with wheelchairs had to line up against the fence while their able-bodied peers were up in the stands with an unobstructed view. "They couldn't see the game", Brandon stated, "Who wants to watch a game through wires?" He also explained that the stadium stands provide seating for able-bodied individuals; however, if a person in a wheelchair wants to attend the game with an able-bodied person, there aren't any seating arrangements that accommodate such scenarios.



Several participants shared that the main barrier to social inclusion is fear from the ablebodied person. "They are afraid they'll say the wrong thing or offend us", Rupert explained. "Sometimes people don't know, so they just avoid a person with a disability", Brandon stated. Several other participants voiced concerns that they are not included in social events and

activities with able-bodied peers because those able-bodied individuals are not sure how to include them. Figure 5.29 above, was shown by Daniella. She described how she loves going shopping with her cousin, "just like other people my age." "Social activities are important", Claudia shared. She tells her friends, "My experience might be a little different than yours. It's still fun. I'm living vicariously through you."

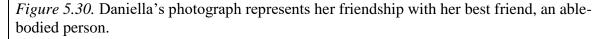
# Visibility/Invisibility

Visibility refers to the aspects of oneself that are apparent to others, while invisibility focuses on the issues that are below the surface and not as obvious to those around us. To a person with a physical disability, it is often the visible aspects of one's impairment or the equipment one utilizes to be independent that draws the attention of others. The invisible aspects of one's disability are often less obvious or only known to those who are close to the person with a physical disability.

**Visibility.** As Lillian shared, "There's a lot more to me than my wheelchair." Some AB's [able-bodied persons] just see a chair and not the person in the chair", she explained. Brandon shared that when he is wearing pants and his prosthetic is not visible, "people don't realize" he has a disability. Clover stated, "I wish people would understand and see there's more on like the inside, rather than just see my disability." Clover went on to say, "It's like they say, 'Don't judge a book by the cover'." Daniella shared, Figure 5.30, below, "I'm really lucky. My best friend doesn't see my disability at all. She's like, 'I know your disabled, but…'."

Figure 5.30. Friendship





People, especially able-bodied people, make assumptions about people with physical disabilities based on what they can see. It is often assumed that a person is in a wheelchair must have been that way their whole life. "They don't understand that someone like [Emily] was perfectly fine for most of her life", as Claudia said. Emily shared that people often question her when they see her move her legs or cross her ankles when she is in her wheelchair in class. They assume she has been in a car accident and ask her questions related to how much longer she will be in a wheelchair, when in fact, Emily's disease is progressive, therefore muscle deterioration will likely continue.

**Invisibility.** Rupert shared in relation to his bruise, "a lot of us are dealing with issues below the surface... When I'm sittin' in class wearing my hoodie and pants, people have no idea what's going on underneath." The invisible factors that influence a person with physical disabilities may be physical, emotional, or both. Claudia explained that it's "not always what you see on the outside... not just the wheelchair, but other things... There are things underneath that you don't see that represent my disability."

*Scars.* While some scars are visible, many of the students discussed the scars from surgery that are not as noticeable. Three of the participants shared that having surgery was influential in their ability to participate in college and to be afforded not only access, but inclusion. Claudia, Lynn, and Daniella reported having back surgery. As Claudia explained, "I have gone through major surgery because of my disability." Lynn has had both back surgery and hand surgery to remedy the impact of Cerebral Palsy and scoliosis. Although the recovery process for these surgeries was excruciatingly painful, all three acknowledged the positive outcome of the surgery on their ability to participate in a meaningful way in their environment, including the college classroom and social activities on campus.

*Emotional pain.* In addition to less discernable physical scars, the invisible emotional challenges related to being treated as "less than or different" has taken its toll on each participant. As a result of surgery, participants experienced depression. The recovery process from surgery prevented them from being able to do things they could previously do on their own. As Lynn shared her story of struggling with depression and addiction to pain medication while healing from back surgery, Claudia interrupted, "her physical issue with her surgery caused mental issues." She further explained how common she has found that among other individuals with physical disabilities. "It gets you in a dark place", she described.

As a young adult in college, students are looking to fit into their new surroundings while also searching for their independence. Using a wheelchair or a walker make it more difficult to "sneak out of class" like an able-bodied person. It certainly is not unusual to have a student get up during a lecture to use the restroom; however, as participants pointed out, this task is nearly impossible when you have a physical disability. Lynn recalled an incident during her freshman

year when she tried to leave the classroom to use the restroom. The instructor stopped Lynn before she could leave the room and said, "What are you doing?" As Lynn explained, "It was so uncomfortable. I had to announce to the entire class that I was going to the restroom."

Figure 5.31. Anxiety



Figure 5.31. Lillian shared a photograph of a salt lamp she has for her dorm room.

Having a physical disability limits one's independence and can create emotional challenges such as: anxiety, anger, and frustration. As Lillian shared in Figure 5.31, above, she has tried just about everything to reduce anxiety. The salt lamp, "They say it's good for anxiety. It's probably just the placebo effect, but hey, whatever!" Rupert described the unpredictable nature of a spinal cord injury making it difficult for him to "fake a smile" and "be present in class." Lynn finds herself experiencing frustration in relation to her hand. In reference to Figure 5.32, below, Lynn shared, "I've had so many issues with this hand", referencing how despite surgery, she has less control over the mobility and dexterity of her hand than she has in the past.

Figure 5.32. Scars



Figure 5.32. Lynn photographed the scar on her hand.

# Awareness

The theme of awareness in relation to college students with physical disabilities encompasses general knowledge of able-bodied individuals, stereotypes and stigma that perpetuate the status of individuals with disabilities, and the need for increased education. Each participant spoke of the need for increased awareness, specifically from able-bodied individuals who are unaware of their privilege. All participants acknowledged that despite the physical accessibility of this campus and the university's identity as being "disability friendly", many of the professors are unaware of the challenges and barriers that prevent inclusion of students with physical disabilities.

**Stereotypes/Stigma.** The visible aspects of one's physical disability or the adaptive equipment that promotes one's mobility are often what provokes initial discrimination toward people with physical disabilities. A stereotype refers to a generalized idea about individuals who share similar characteristics, such as individuals with physical disabilities, whereas stigma refers

to a characteristic which makes the individual less valuable in society (Werner, 2015). While all participants shared experiences with stereotypes and stigma, each participant acknowledged fewer experiences within the campus community.

The negative stereotype that was expressed within both focus groups was the assumption that having a physical disability implies that one must also have a cognitive disability. Clover stated, described a time when a man was yelling and talking slowly when he tried to speak to her. "So, the fact that I use a walker, suddenly I am deaf?" Claudia shared how annoyed she gets at restaurants when a waiter "asks your parents, 'what will she want'... My mom would say, 'Well, she's right here, why don't you ask her?" Lynn shared a similar story where she was at a doctor's appointment and someone handed her grandfather paperwork to fill out on her behalf. Lynn said, "I snatched those papers" and left the room.

Participants shared that despite being on a campus known for providing services for students with physical disabilities, they are not immune to the negative stereotypes that peers, faculty, and staff subscribe to. As Claudia explained, she feels judged by her professors who think "she's not the smartest because she's in a wheelchair." Even when Clover graduated from high school in the top 5% of her class, others questioned whether or not her teachers "just passed her along." College students with a physical disability are supposed to be prepared to advocate for themselves; however, students who sustain an injury that leads to a disability may not have had any opportunities to advocate for themselves in a school setting. Other students with physical disabilities face new challenges related to deterioration as a result of their disease or impairment and may simply be unaware of how these changes will impact their experiences in college.

The negative stereotype that a person with a physical disability cannot live on their own was brought up in both focus groups. Claudia interrupted at one point to "play devil's advocate." She stated, "We do need to realize that we will need help forever. I'll never be able to get out of bed by myself and that's something I've come to terms with, but that doesn't mean that I have to live with my parents for the rest of my life." The message that participants want to send to ablebodied individuals is: "We are people", "We are not sick", "We are not broken.", and "We are capable."

The relationship between stigma and intimate relationships came up in both focus groups as developing intimate relationships is viewed as a natural part of the college experience. "It's really hard... I'm still trying to figure that out", Claudia shared. All participants agreed that developing intimate relationships can be particularly challenging when someone has a physical disability. The stigma that a person with a physical disability is "less desirable" is a barrier that maintains individuals with physical disabilities in their "safe zone", as Claudia described. "It's intimidating", Brandon described. "Being in a relationship with someone else in a wheelchair is difficult as well", Lynn explained. Clover shared that even her close friends "would automatically assume if I ever got into a relationship, it would be with someone with a disability and it's like, 'that's not the only thing I'm limited to. There are people who would understand.'." Claudia responded to Clover,

often times that's out only community, other people in wheelchairs or other people with disabilities. And that's not a bad thing, most of my friends are in wheelchairs, but it's unfortunate that we don't feel comfortable enough to get out of that.

**Knowledge.** The stereotypes and stigma of society that maintain the minority status of individuals with disabilities are often a result of a lack of knowledge or awareness. Although the

college campus exists to promote learning and enrich knowledge, many able-bodied students, faculty, and staff on campus simply do not understand how a physical disability impacts one's life and one's experiences as a college student. Rupert stated, "Professors need to be more understanding of disabilities and each person as an individual... They think all people in wheelchairs are the same." Rupert feels that on this campus, professors question his limitations and challenges because they "think they know about disabilities because they work here." Daniella replied, "some professors have an attitude, like, 'You chose to be here and go to college, so you need to deal with it.'." The majority of participants agreed with Brandon, that "certain departments are better than others" when it comes to professors' knowledge of disabilities. Participants believe some of this knowledge can be attributed to the professor's field of study, such as: nursing, social work, or health and physical education.

All participants agreed that they have experienced some level of resistance or doubt that can be attributed to their physical disability from professors. As Brandon shared in relation to able-bodied individuals who are unaware of their privileges, "People just don't think about." Rupert agreed, "If it doesn't directly impact them, they just don't think about it." Lillian shared that it is important for able-bodied individuals to not only "appreciate" their privileges but become more educated about how their privilege can influence others. Brandon stated that people don't consider their ignorance because "from the able-bodied person's eyes, it looks great."

Claudia explained, "I like when people ask questions so I can educate them." Clover concurred, "I would rather people ask than just assume... kids used to ask me questions when I was little like, 'Did you break your legs?'." Claudia affirmed, "Kids are the best to explain to!... You can teach kids at a young age and they'll be able to teach others." Clover eloquently

concluded, "I wish that those who do understand will go and educate those who don't understand. And hopefully, those who don't understand will learn to understand."

# **Summary of Findings**

The themes of *independence, relationships, access/inclusion, visibility/invisibility, and awareness* emerged from both research questions, demonstrating the strong connection between a college student's identity and their experiences, both academic and social. Although all eight participants spoke of being a member of the disability community, they all acknowledged that the limitations of their disability are not what defines them as a person. Seeing themselves as a person, first and foremost, rather than a person with a disability gave each participant the courage to apply to college. When challenges have surfaced during their college experience, having mentors (other students with physical disabilities), who have successfully navigated similar challenges, serves as a reminder that their identity as a person with a physical disability does not diminish their identity as a person worthy of an education.

# **Themes in Relation to Identity**

For a person with a physical disability, being a college student is an important aspect of their identity. Being a college student means that equal opportunities are possible and that one's limitations do not define their hopes and dreams for the future. For most of the participants, being a college student means being able to be *independent*. The college experience provides students with opportunities to demonstrate that "we do not have to live with our parents for the rest of our life". College has also provided participants with opportunities to engage in *relationships* with diverse individuals, which most participants acknowledged they would not have otherwise met.

This particular university has provided participants with *access* and *inclusion* to higher education, unlike most other colleges and universities in the United States. For the majority of the participants, the specific services available to students with disabilities at this university makes a college education possible. These services support students by enhancing independence, essentially leveling the playing field between college students with physical disabilities and ablebodied college students. As most participants described, being a successful college student and becoming a college graduate is important to promote continued independence after college. Participants often deal with negative stereotypes and stigma that result from the *visible* aspects of their disability, and yet they feel that the *invisible* aspects of their identity often go unnoticed. Both the visible and invisible aspects of one's disability play a significant role in one's identity as well as one's confidence. Several participants noted that being a college student helps to spread *awareness* to others that individuals with disabilities deserve opportunities in higher education just as much as able-bodied individuals.

# Themes in Relation to Experience in College

In relation to the second research question about how one's physical disability influences one's academic and social experiences in college, *independence* and one's functional abilities play a significant role in one's academic and social experiences. One of the most overlooked *relationships* deemed important by participants is that of the student and the professor. Without an established relationship, college students with physical disabilities are often not comfortable sharing the details of their disability and the ways in which their disability influences their academic performance. The *visible* aspects of a student's disability as well as their functional ability can limit their *access* to choice with respect to their major in college. A college student's functional limitations can also restrict one's social experiences, influencing the degree of

*inclusion* among other college students. Rupert's statement, "Not being able to go upstairs limits what you can do and who you can hang out with", describes the social challenges students with mobility impairments experience, especially with respect to off-campus events such as: Greek life events, hanging out with friends in off-campus apartments, or getting in a car to go shopping with friends. The *invisible* influence of one's physical disability, such as physical or emotional pain, makes it challenging to fully participate in both the academic and the social environments of a college campus. With respect to the theme of *awareness*, participants reiterated the importance of the messages, "I am more than my disability" and "I deserve to be here", throughout each focus group. Although the overall climate of the campus was described as "better" than other places, participants concentrated on their need to be better understood by peers, faculty, and staff within the university.

## **Summary**

The results of this research study provided significant insight into the identity and the experiences of college students with physical disabilities. Photovoice provided participants with an empowering opportunity to share their story and their experiences. The focus groups provided a unique experience for participants to share their experiences among others who understood their trials and tribulations. Several participants made it a point to mention how "helpful" the focus group itself was. Although many of the participants knew each other from campus, and some of them were even good friends, they all mentioned that they learned something new about another person that normalized some of the challenges they were experiencing as a college student with a physical disability. All eight participants are interested in using the photographs from this study to increase awareness on campus and in the community. The first focus group consisted of three individuals, who would like to create a training program for faculty on campus

with the hopes that this training can be utilized on other college campuses to increase access to higher education. The second focus group consisted of five individuals, who are interested in increasing awareness of individuals with physical disabilities among youth in the community as a well as creating a support group for new students to assist in the transition to college experience.

# **Chapter 6: Discussion and Implications**

This qualitative study was able to shed light on what it means to be a college student with a physical disability, a population not well-understood. The existing and most current literature on college students with disabilities focuses on invisible disabilities, which provides a strong foundation for consideration among students with physical disabilities. This study, however, suggests that the visible nature of a physical disability is a distinct characteristic that increases the likelihood of discrimination, oppression, and marginalization among college students with mobility impairments. Interestingly enough, it is the visibility of the photographs captured through Photovoice, that provided an opportunity for participants of this study to create a counter-narrative, which can be used to create social change. Through the use of Photovoice and focus groups, the findings of this study corroborate information found in the existing literature on college students with disabilities, yet it also highlighted ten significant additional factors that are more specific to college students with physical disabilities, including: visibility; independence; membership in a university organization; support from the disability community; limited college options; money; health insurance; power and control; mood; and, faculty awareness within a "disability friendly" university.

The findings of this study were narrowed down into five themes, as outlined in the previous chapter, and developed from the perspective of participants in effort to preserve the value of participatory action research. This was especially important, given the researcher's status as an able-bodied person. This chapter, however, will focus on ten of the themes which transpired in this study and can contribute to the existing research on disabilities in higher education. The findings of this study will be analyzed in comparison with the existing literature,

as well as the theoretical framework previously outlined in this study. Limitations and implications of this Photovoice study will also be explored in this chapter.

# **Examination of Findings within Context of Current Literature**

As demonstrated below in Table 6.1, eight of the nine themes from the literature review emerged in this study. These themes, as discussed in the previous chapter, included: identity; self-advocacy; student skills; inclusion with peers; family support; accessibility; accommodations; and, faculty perceptions and relationships. To maintain the authenticity of community based participatory action research, at the end of each focus group, participants provided themes which transpired. Although the terminology identified by participants for themes was not exactly the same as in the reviewed literature, the meaning behind the participants' themes were similar in nature to those from the literature.

# Table 6.1

Comparison of Themes from Literature and Themes from Study

| Themes from literature found in study | Themes from literature not found in study |
|---------------------------------------|---|
| Identity                              | Universal Design                          |
| Self-advocacy                         |   |
| Student skills                        |   |
| Family support                        |   |
| Inclusion with peers                  |   |
| Faculty relationships and perceptions |   |
| Accessibility                         |   |
| Accommodations and disclosure         |   |

Universal Design was the one theme found in the literature review which did not emerge in the study. While the term Universal Design was not used by participants, it was certainly referenced by the majority of participants through themes such as: independence; equipment; accessibility; inclusion; and, awareness. The principles of Universal Design take into consideration the needs of diverse persons so that individual requests for specific accommodations are not necessary, as the original design has already taken into account such needs (Lombardi, Murray, & Gerdes, 2011; McGuire, Scott, & Shaw, 2006). The lack of acknowledgment of Universal Design by participants may demonstrates unfamiliarity of the term within the context of higher education, as exemplified by the literature (2011). Educational laws that protect students with disabilities in primary and secondary school become null and void in post-secondary educational institutions, therefore, Universal Design at their own discretion (Black, Weinberg, & Brodwin, 2014).

Although participants did not use the term Universal Design, the underpinnings of this concept are anything but foreign to them as college students with mobility impairments. Because the university has been known for providing services to students with physical disabilities for over 40 years, all participants agreed that the university community is more accepting of people with disabilities than their home communities and does consider the needs of individuals with physical disabilities more than society, in general. However, all participants concurred that increasing disability awareness among able-bodied individuals on campus would benefit all members of the community. If administrators and faculty were more aware of the challenges students with physical disabilities faced on a daily basis and they were trained on ways to

incorporate Universal Design, they may be more inclined to make changes that will benefit more students (Park et al, 2012).

# New Findings from Study that Can Contribute to Literature

As shown below in Table 6.2, the findings of this Photovoice study demonstrate that there are ten themes, in addition to themes from current literature, that can provide enhanced insight into the identity and experiences of college students with physical disabilities. Four of the themes (visibility, independence, membership in a university organization, and support from the disability community) play a significant role in the identity of a college student with a physical disability. The other six themes (limited college options, money, health insurance, power and control, mood, and faculty awareness in a disability friendly university) offer additional insight into the academic and social experiences of college students with physical disabilities.

# Table 6.2

| <b>T</b> • |        | c    | <b>a</b> . 1 |    |
|------------|--------|------|--------------|----|
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| Themes in relation to identity        | Themes in relation to experiences            |  |
|---------------------------------------|--|--|
| Visibility                            | Limited college options                      |  |
| Independence                          | Money  |  |
| Membership in university organization | Health insurance                             |  |
| Support from disability community     | Power and control                            |  |
|                                       | Mood   |  |
|                                       | Faculty awareness within disability friendly |  |
|                                       | university                                   |  |

**Identity as a college student.** With less than 1% of college students with physical disabilities enrolled in post-secondary education, little information is known about this vulnerable and historically oppressed population within higher education (U.S. Department of Education, 2014). Among those individuals with physical disabilities who do attend college, only one out of three actually graduate from college, causing concern as to the reason why academic

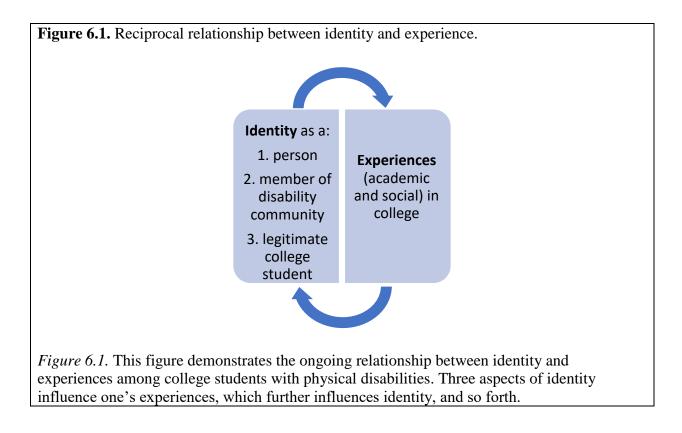
success among students with physical disabilities is so low (Newman, et al, 2009; Wang & Dovidio, 2011). While the theme of identity arose from the literature review of students with disabilities (in general) in higher educations, research about the influence of having a physical disability on the identity of college students is non-existent. A person's sense of identity develops from personal characteristics, group membership, and experiences (Campbell, 2008). While Nario-Redmond and colleagues (2013) point to the influence of stigma and stereotypes as negative factors of the identity of a person with a disability, this study reveals that for a college student with a physical disability, there are several additional components that contribute to one's sense of identity, including: visibility (of one's physical disability, meaning that one's disability is obvious to others); independence (being able to do as much for oneself as possible); membership in a university organization; and, support from the disability community.

The influence of participants' physical disability on their experiences in college. Literature demonstrates that themes of identity; self-advocacy; student skills; family support; inclusion with peers; faculty relationships and perceptions; accessibility; accommodations and disclosure; and, Universal Design all contribute to the academic and social success of college students with disabilities. As mentioned previously, this study uncovered all of these themes, with the exception of Universal Design. Furthermore, this qualitative study revealed six additional themes which considerably impact the academic and social experiences of college students with mobility impairments. These themes include: limited college options; money; health insurance; power and control; mood; and, faculty awareness within a "disability friendly" university.

**Relationship between Identity and Experiences.** The findings of this study underscore important factors that influence the identity of college students with mobility impairments as

well as their academic and social experiences in college. The overall findings of this study suggest that among college students with mobility impairments, a strong sense of identity is essential for positive experiences, both academic and social, that lead to success in higher education.

As participants answered research questions related to their identity as college students and the influence of their physical disability on their college experiences, a common element of confidence and security in one's identity as a person, a member of the disability community, and as a legitimate college student surfaced as the foundation for positive academic and social experiences in college. Furthermore, positive academic and social experiences among college students with physical disabilities contribute to a more sound sense of identity, providing students with a sense of conviction in their identity as college students, and the continued belief necessary to engage and be successful in additional academic and social opportunities. The relationship between one's identity and experiences in college as a student with a physical disability can be seen below, in Figure 6.1, and will be further explicated using the theoretical framework of this study in the following section.

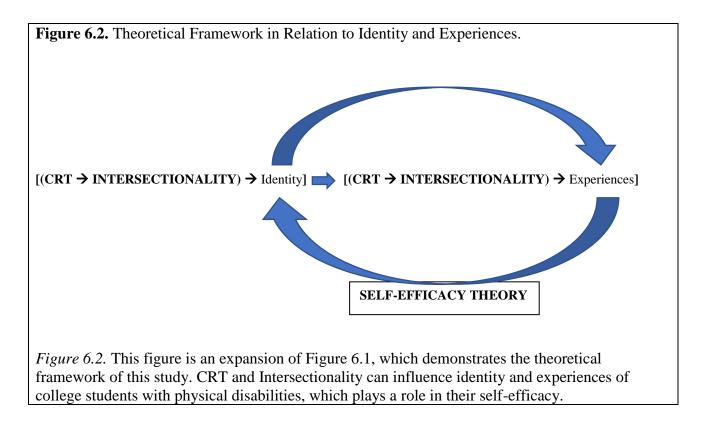


# Analysis within Context of Theoretical Framework

The tenets of Critical Race Theory, Intersectionality, and Self-Efficacy Theory surfaced through photographs, written captions of photographs, as well as through both of the focus group interviews. Critical Race Theory seeks to shift the burden of socially constructed deficits of persons with disabilities to the institutional level (Delgado & Stefancic, 2017). This includes: able-bodied students, faculty, staff, and administrators, as well as policies and programming within the university. Intersectionality focuses on the overlapping identity markers, which yield either privilege or oppression (Collins & Bilge, 2016). Participants unanimously voiced the need to be seen as more than students with mobility impairments. As one participant stated, "We are all people.". As participants shared their trials and tribulations as college students, it was evident that each person's identity (as a person, a member of the disability community, and as a

legitimate college student) plays a compelling role in their academic and social experiences within college.

While the interconnections of CRT, Intersectionality, and Self-Efficacy Theory derived from existing literature, additional themes revealed by this study provide essential knowledge that can further contribute to this theoretical framework to understand the specific needs of college students with physical disabilities. Figure 6.1, above, demonstrates the continuous cyclical relationship of identity and experiences, as it provides a visual representation that provides the groundwork for understanding how CRT and Intersectionality play a role in the identity of a college student with a mobility impairment, as well as their academic and social experiences. Figure 6.2, found below, will be explored in relation to Figure 6.1, above, to demonstrate how the theoretical framework of this study can be used to explicate identity and experiences of college students with mobility impairments to answer the overarching research question: What does it mean to be a college student with a physical disability?



# The influence of Critical Race Theory and Intersectionality on the Identity of a College Student with a Physical Disability. This section will explicate the first part of the equation, found above in Figure 6.2, [(CRT $\rightarrow$ Intersectionality) $\rightarrow$ Identity]. Critical Race Theory (CRT) provides the foundation to understand how individuals with physical disabilities experience minority status in society (Nishida & Fine, 2014). Those who are able-bodied are viewed as superior in society and thus have more power and control over their own lives and the lives of those who are not able-bodied (Ferguson & Nusbaum, 2012). As a result, persons with physical disabilities are placed in an inferior social status, and experience discrimination, oppression, and marginalization, which have a profound impact on their sense of identity within society (Hosking, 2008). Despite claims of college campuses' desires to embrace diversity, university communities are not immune to the stigma and stereotypes that perpetuate the subordinate status of students with physical disabilities (Campbell, 2008). Among college

campuses, just as in other aspects of society, ableism is pervasive (Liasidou, 2014). Intersectionality explains how overlapping aspects of one's identity either promote or combat the negative stereotypes and stigma experienced by individuals with physical disabilities (Erevelles & Minear, 2010). As explicated above in Figure 6.1, membership within the disability community and consideration as a legitimate college student are significant identity markers that contribute to one's success in college.

CRT seeks to shift the deficit perspective of a disability from individuals and groups to the institutional level, thereby making society, and in this case institutions of higher education, accountable for their deficits in policies and practices that make accessibility and inclusion among individuals with varying abilities challenging or impossible (Delgado & Stefancic, 2017). In relation to CRT and identity of college students with mobility impairments, the themes of visibility (others are able to see that a person has a physical disability) and independence (being able to as much physically for oneself as possible) arose as new concepts that can contribute to literature on disabilities in higher education. Participants of this study shared photographs and narratives within the focus groups that pointed to themes of: support from the disability community; and, membership within a university organization, as positive influences on aspects of their identity. These two factors not only provide opportunities to create new intersections of students' identities, but may also counteract some of the negative perceptions that impact influence the overall identity of a college student with a mobility impairment.

*Visibility.* The photographs and focus group interviews of this study suggest that the visibility of a mobility impairment plays a major role in the identity of a college student with a physical disability. The visible nature of a physical disability leaves little room for individuals to pass as members of the majority group, those who are able-bodied. Participants of this study

explained that as a result of their physical disability, they are more likely to experience stigma and stereotypes that negatively influence their sense of identity, and ultimately their experiences within college. The findings of this study suggest that a college campus is simply a microcosm of the larger society, and as such, students with mobility impairments are plagued by the same negative stigma and stereotypes that stem from the social construction of disability that places individuals with disabilities in an inferior social status, although to a lesser degree on campus in comparison to larger society (Meekosha & Shuttleworth, 2009).

*Independence*. A significant aspect of any student's identity as a college student is: independence (Sachs & Schreuer, 2011). Independence is just as important for students with physical disabilities, and a compelling reason why many students with disabilities avoid seeking accommodations in college, as such requests reduce one's sense of independence. Each participant in this study voiced their need to be able to be as independent as possible. For participants in this study, independence was expressed as desire to be able to do as much, physically, for themselves without relying on someone else. For all participants, independence requires adaptive equipment and adaptations to the physical environment. The most common forms of adaptive equipment included: wheelchairs, shower chairs, and Hoyer lifts; whereas the most common environmental adaptations were: ramps; automatic door buttons; bed rails; accessible bathroom stalls; personal care assistants; and, one-on-one assistance for written exams.

*Support from disability community.* Although all of the participants pointed out the need to first and foremost be considered a person, each one also shared how having other students on campus with physical disabilities has had a positive effect on their sense of identity and their experiences in college. For a person with a disability, membership in the disability community is

often a significant facet of their overall well-being (Nario-Redmond, Noel, & Fern, 2013). Among college students with physical disabilities, watching upper classmen with physical disabilities achieve success and push the boundaries of independence gives others the confidence they need to succeed. Because there are so many other students with physical disabilities on the campus where this study was conducted, all participants agreed that the campus community is much more accepting of individuals with physical disabilities than most other communities. Despite this overall acceptance, all participants concurred that there are still many issues that prevent full inclusion on campus.

*Membership in university organization*. Rupert and Brandon, the two men who participated in this study, described themselves as "disabled athletes". For both men, it was the athletic program for individuals with disabilities that brought them to this university. Rupert and Brandon expressed how athletics and competition are important to their identity, and the adaptive college sports team of this university provides them with an ability to not only participate in a sport, but enjoy the camaraderie of their teammates and receive recognition from others for their athletic abilities. The positive acknowledgment Brandon has received for being part of this college sport has increased his confidence, influencing his identity in a positive manner. Similarly, Claudia shared how being a sorority member has increased social opportunities for her and exposed her to meeting other sorority and fraternity members on campus. Claudia feels that her involvement in her sorority has helped to dispel some of the stereotypes and the stigma that affect individuals with physical disabilities.

The influence of Critical Race Theory and Intersectionality on the Experiences of a College Student with a Physical Disability. This section will explicate the second part of the equation, found above in Figure 6.2, [(CRT  $\rightarrow$  Intersectionality)  $\rightarrow$  Experiences]. Stigma and

stereotypes affect what opportunities and experiences are made available to individuals with physical disabilities, as minority group members. It is the pervasive ableism that exists among college campuses which promotes the continuation of discriminatory practices against individuals with physical disabilities, stemming from the erroneous belief that all individuals with physical disabilities are incapable of the skills necessary to obtain a college degree. In the United States, higher education is a viewed as privilege, as it is not something that is afforded to every citizen. Individuals of minority status and those with less resources (whether material or personal) have fewer opportunities to take advantage of a college education in order to enhance their social location.

CRT seeks to shift this deficit perspective to the institutional level, demonstrating that it is the functional limitations of the university as a system, along with the negative perceptions that are deeply engrained in society, and not the individuals with physical disabilities, that prevent accessibility and inclusion (Delgado & Stefancic, 2017). Intersectionality can be incorporated to demonstrate that having a physical disability is only one aspect of a person's disability and should not preclude them from obtaining education beyond secondary school (Liasidou, 2014). Participants of this study revealed that their academic and social experiences in college are influenced by: limited college options, power and control, and, faculty awareness within a "disability friendly" university. Additionally, among participants of this study, themes of money, health insurance, and mood, in relation to their disability, emerged as relevant factors that influence various components of their identity, ultimately influencing their experiences in college.

*Limited college options.* As an individual with a physical disability, a person's identity status as a member of the disability community limits their college experience before it even

begins. Students with physical disability requiring personal care aides have only three college options in the United States (Kennedy Krieger Institute, 2011). Hypothetically, students should be able to attend any university and hire their own personal care aides, covered by medical health insurance or waiver funded programs; however, colleges and universities often view this as a liability and are able to legally deny access for students who require such assistance (Hamblet, 2009). As demonstrated by the findings of this study, the most overlooked aspect of accessibility to able-bodied individuals, is the level of openness of the university, in general, to students with physical disabilities. Given that this university is one of only three universities in the United States that provides 24-hour personal care for students with physical disabilities, the university in and of itself represents accessibility that is not found in most other colleges and universities (2011). All nine participants chose this university because of the accessibility to students with physical disabilities.

*Power and control.* Attending college is a common experience during one's transition to adulthood that provides individuals with opportunities to exert more power and control over their own life. All nine participants in this study acknowledged searching for a greater sense of autonomy. Planning ahead is essential for college students with physical disabilities, especially when one has to rely on assistance from another person for activities of daily living. Many of the participants expressed concerns that professors do not realize that students with physical disabilities may be doing everything in their power to plan ahead, yet despite their best efforts, students may fall behind or fail to complete an assignment on time because of something completely outside of their control. Participants described how even the most well-organized schedule can go awry when the person you are relying on for assistance is late or does not show up as scheduled.

*Faculty awareness within a "disability friendly" university.* One of the most salient themes to emerge from this study was the influence of faculty knowledge and awareness of students with physical disabilities. While the theme of faculty relationships and perceptions transpired from the literature, each participant acknowledged choosing this university because of the university's identity as being "disability friendly", and as such, were under the impression that professors at this university were well-versed in disabilities and disability laws. Most participants, however, brought up challenges related to the negative perceptions of faculty as a result of their physical disability. Participants spoke of the significance of faculty perceptions of physical disabilities as having a profound impact on their academic experiences.

All participants shared how important it is for professors to understand the distinctions among various types of physical disabilities, and recognize individuality among students with physical disabilities. Participants in this study explained how relationships between faculty and students are significant to allow students to feel comfortable sharing the details of how their disability might influence their academic experience. While some students feel secure enough to engage in self-advocacy efforts on their own behalf, others may not feel as confident in their communication skills or may feel embarrassed to share the situation with a person who feels like a complete stranger.

*Money.* As a result of limited options of colleges, the majority of the participants in this study were "out-of state" students, which plays a considerable role in their identity as a college student with respect to the cost of attendance. At the university, where this study was conducted, out-of-state students pay over \$4,000 more each academic year in comparison to in-state-students. Lillian explained that in addition to tuition, room, and board, it costs \$30,000 each academic year for personal care services on campus, and she considers herself to be a more

moderately limited student. Given the cost of personal care services, one would assume that students, like Lillian, would have control over when they can schedule help; however, as Lillian shared, it's not unusual to have to "go on a scavenger hunt" to find someone to help her because the university's current budget constraints. As participants in one of the focus groups shared, having money allows individuals with physical disabilities to buy the best equipment, or as Rupert said, "more money, more assistance... if you have money, you can buy people to help you."

*Health insurance.* Another concern that arose from this study was that out-of-state students may not be able to utilize their health insurance within the state where the university is located, leaving them unable to receive occupational and physical therapy services to address concerns related to their disability. The university previously provided Occupational Therapy (OT) services for students on campus, however, the OT position was recently cut due to budget constraints. As a result of not receiving necessary occupational or physical therapy services, participants described how symptoms of their physical disabilities have increased, such as muscle spasms. Muscle spasms for some participants can become so intense and painful that remaining in class becomes nearly impossible. For one participant, the lack of available occupational therapy services this semester will likely result in the need to take medication, which in the past has caused other unwanted side effects.

Assistive technology has come a long way, and yet, for many individuals with physical disabilities the products and equipment that could provide more independence are not covered by health insurance. As Daniella shared, she had to fight with her health insurance company to get the wheelchair elevator that allows her to raise the height of her wheelchair. She described this piece of equipment as "life-changing." Not only is Daniella able to increase her independence

and improve her safety with this feature, she is now able to assist other people. This one adaptation to her wheelchair has elevated her sense of power and control, ultimately influencing her identity, and her academic and social experiences.

*Mood.* Participants spoke about the unpredictability and the progressive nature of their physical disability as having a significant influence on their mood from day to day. Several participants shared how these issues cause anxiety which impacts their academic and social experiences. Lillian showed a photograph of a salt lamp she keeps in her dorm room. "Salt lamps are supposed to fend off anxiety and generate positive feelings. Yes, it may be a placebo effect but hey, whatever works right?" As an amputee, Brandon shared that at times he just wants to take off his prosthetic leg, but he feels anxious taking his leg off around other people, therefore he ends up isolating himself in his apartment. Rupert explained that the unpredictability of having a spinal cord injury leaves him feeling anxious and angry. As he stated, "It's hard to maintain a smile if you're angry all the time... hard to be present in the classroom and answer questions or be cordial." As a result, Rupert is still questioning whether or not graduating from college is an attainable goal for him. Additionally, while able-bodied individuals often assume that people with disabilities have been dealing with functional limitations their entire life, seven of the nine participants expressed how the progressive nature of their disability has led to regression of functional abilities, and negatively influences their emotional well-being.

**Influence of identity and experiences on self-efficacy.** The continuous relationship between one's identity and experiences, which can both be positively influenced by CRT and Intersectionality, influences the self-efficacy of college students with physical disabilities, as evidenced in the full equation, found above in Figure 6.2. Self-efficacy theory explains how one establishes a belief in one's ability to succeed (Duffy & Dik, 2009). In this study, it was

imperative to understand how being a college student with a physical disability plays a role in both academic and social success. As a result of the research questions posed to participants about their identity as college students and the influence of their physical disability on their experiences in college, a positive identity was reported by participants to have a perceived positive effect on academic and social experiences, which contributed to positive student selfefficacy.

Participants of this study reported that among college students with mobility impairments, a confident sense of identity is correlated with constructive academic and social experiences, which contributes to an optimistic belief in one's ability to succeed in other experiences. Conversely, a negative self-concept and sense of identity is correlated with negative experiences in college, contributing to a negative belief in one's ability to succeed in future experiences. It is not only a person's identity nor simply their experiences that contribute to a college student's belief in their ability to succeed, but a combination of the two. Understanding how CRT and Intersectionality can be incorporated to positively influence the identity and experiences of college students with mobility impairments, which would ultimately influence their belief in their ability to succeed in other experiences is a theoretical framework that can significantly contribute to the literature on students with disabilities in higher education.

#### **Empowerment Outcomes of the Study**

The process of Photovoice allowed participants to not only share their photographs and their experiences during a focus group interview, but also develop a plan to engage in community organization efforts to improve access and inclusion for students with physical disabilities in higher education. The spirit of empowerment which arose from this experience, demonstrates the inherent value and effectiveness of Photovoice as a sound research method,

which upholds the values of the social work profession. By engaging collaboratively with vulnerable and marginalized populations to create social change, the participants from this study gained an increased sense of confidence in their ability to create changes on campus. As a result, participants are in the process of starting an organization on campus for students with physical disabilities. The purpose of the organization will be to increase awareness, inclusion, and equality for current and future students with physical disabilities on campus.

# **Display of Photographs**

The essence of Photovoice is the enhancement of empowerment among participants to encourage ability to empower participants to create changes in their community. The enthusiasm exhibited by participants throughout the process was certainly more invigorating than this researcher anticipated, given the demanding schedule of college students. The first focus expressed an interest in using the photographs to conduct a training for faculty on this campus and other campuses to increase awareness of various physical disabilities, the impact of disability laws, and the day-to-day experiences as a college student with a physical disability. "These photos can help us show them what it's really like", Brandon said. Participants from the second focus group suggested incorporating a simulation into the training. Claudia shared an experience she had when she was in fourth grade. "I was in a rough point during that time…My teacher had me bring in my manual chair and I got to pick a student each day who had to use the wheelchair… Those kids definitely remember it. It makes an impact."

While the participants of the second focus group are interested in assisting with the faculty training, they also expressed an interest in educating younger children in the community about physical disabilities. Another participant shared that the focus group itself "was really helpful", and that perhaps a support group for new students with physical disabilities would be

useful. Having another student with a physical disability as a mentor would help new students navigate their new environment and "the photos could help them see what challenges they might encounter and what really is possible."

As a result of participants' ideas, a meeting was held with the Director of Social Equity to discuss participants' plans to utilize the photographs to create changes on campus and in the community. The director explained that the best plan of action would be to start a student organization on campus for students with disabilities, something that does not currently exist. The director shared that by starting a student organization, students would have access to funding through the Student Government Association, be able to attend conferences, and host events on campus. While there is not a Commission on Individuals with Disabilities on campus, there is a Diversity Commission. The President of the student organization and the faculty advisor can then become members of the Diversity Commission, and start a committee to address further needs of students with physical disabilities. The student organization will allow students to create a faculty training, host events to educate children in the community, and promote opportunities for enhanced visibility of student with disabilities on campus.

Participants are excited about the idea of starting a student group and plan to convene at the start of the spring semester of 2018 to begin the organization start-up process. The process of Photovoice and community-based participatory action has led to an opportunity to begin to put some of findings from this study into action with respect to practice and policies within the university. This new student organization will not only offer individuals with physical disabilities *support within the disability community* and an opportunity to become a *member of university organization*, but a chance to engage in advocacy efforts aimed at shifting the *visibility* of the deficit perspective from individuals to the institutional level, which can further increase

*independence, power and control*, and, *faculty awareness*. Taking the findings of this study and including the themes into practice and policies on campus can help to create a more inclusive environment, so that more individuals with physical disabilities have a positive experience in higher education. Figure 7.3, below, was taking by Clover to demonstrate how she feels about college.



# Limitations

While this qualitative study provides valuable insight into what it means to be a college student with a physical disability, this study also had several limitations including: a small sample size of eight participants; all participants attended the same university; the two male participants were both college athletes; and, the homogeneity of a mobility impairment among participants. The small sample size of eight participants reduces generalizability of the findings. One of the biggest challenges was the recruitment of participants, which most likely reflects the time commitment of the method of Photovoice, a known limitation of this research method.

Within this study, even with an incentive of a \$50.00 Amazon gift card, the challenge of participant recruitment among college students with physical disabilities likely reflects difficulties related to planning and adding something additional to an already full schedule. Participation in this study required a time commitment of almost five hours with this researcher (orientation and ethics training, and focus group) and additional time to take submit photographs. Additional limitations related to Photovoice in this study included the restrictions of photography that developed from the ethics training. As a result of the ethics training and in an effort to protect their own identity, participants did not capture images of the university logo or faces of other individuals.

All participants of this study attended the same university, which again may decrease the degree of generalization to other college campuses. Among the eight participants, two identified as male whereas six identified as female. Additionally, both males are members of the adaptive college athletics program on campus, which they both described as having a significant positive effect on their identity as man with a disability. As a result, the findings that emerged from their photographs and focus group interviews would not be representative of all male college students with physical disabilities. Additionally, while the purpose of the study was to understand college students with physical disabilities, all participants of this study had a disability that stemmed from a mobility impairment which may not be representative of all physical disabilities. Employing Photovoice through future research of college students with physical disabilities at the other two disability-friendly universities in the United States, could promote participation of students with a variety of physical disabilities and yield more generalizable findings.

#### Implications

The findings of this transcendental phenomenological study on the identity and experiences of college students with physical disabilities not only revealed similar themes to the current literature on students with disabilities (in general) in higher education with disabilities, but also highlighted additional information that illuminates the unique experiences of a historically marginalized minority group, individuals with mobility impairments. The emerging themes from this study, which can supplement current research included: visibility of physical disability; independence; membership in a university organization; support from disability community; limited college options; money; health insurance; power and control; mood; and, faculty awareness (even among a disability-friendly university). The implications of this study are relevant to the profession of social work and higher education, providing significant considerations for future research, and policy and practice recommendations aimed at improving access, inclusion, and success in college among students with physical disabilities.

**Social Work.** Themes which emerged from this study can supplement the current literature and have implications at the practice and policy levels within the profession of social work. Increased knowledge of the defining factors that influence the identity and experiences of college students with mobility impairments provides social workers with additional areas to concentrate on for assessment and interventions designed to promote self-determination and optimal success. The theme of visibility as it relates to reducing the stigma and stereotypes of individuals with physical disabilities can have a profound influence on several other themes that emerged from this study, namely: independence; limited college options; money; health insurance; and, mood.

Social workers can engage in community practice and policy efforts, that aim to decrease the stigma and stereotypes of individuals with physical disabilities in order to increase college

options available to students. As a result, students may find it easier to attend a university within their home state, resulting in lower tuition costs and the ability to continue to utilize health insurance for necessary therapies to maximize independence. All of these factors have the potential to enhance students' sense of power and control, as well as, improve mood related issues that impact the identity and experiences of college students with mobility impairments. Social workers can also help to develop assessment tools and intervention strategies designed to meet the specific needs of college students with physical disabilities. Such tools and techniques can be implemented proactively, before students begin college and continue as needed while students are enrolled in college. The emerging themes of this study are necessary considerations for social workers to assist individuals with physical disabilities in achieving post-secondary education and upward mobility by maximizing strengths and minimizing barriers.

**Higher education.** As for higher education, this study provides important information related to recruitment and retention of diverse students, a shared concern among colleges and universities (Hong, Haefner, & Slekar, 2011). All participants of this study stressed the challenges and barriers they have experienced in college as a result of their physical disabilities. Universal Design, was the one theme from the literature that did not surface during the focus groups nor the photographs and captions submitted by participants. The principles of Universal Design in the realm of higher education focus on proactively designing policies and practices and can be utilized to address the themes of: limited college options; faculty awareness (even within a disability friendly university); independence; power and control; membership within a university organization; and, mood, which emerged from this study,

Recommendations for Universal Design within higher education will require both practice and policy considerations. With only three universities in the country known for

providing services to individuals with physical disabilities, the findings of this study can contribute to the knowledge and awareness among other college campuses, which may result in more opportunities for college choices among students with physical disabilities. Additionally, future research using the method of Photovoice at the other two disability-friendly universities would provide significant contributions to literature. If more institutions are prepared with proactive teaching strategies and methods of Universal Design, which takes into consideration the needs of diverse learners, students with physical disabilities will experience enhanced levels of independence as well as more power and control (Black et al, 2014).

The underlying principles of Universal Design that provide accessibility to physical spaces, like ramps, can be utilized within the classroom environment as well. Universal Design can be implemented within the realm of instruction, services, and information technology in higher education to provide a more level playing field for individuals of all abilities (Burgstahler, 2013). As the needs of students in higher education become more diverse, Universal Design within the classroom environment can assist in proactively promoting the success of all students through curriculum development, teaching methods and strategies, as well as assessments (2013). Additionally, principles of Universal Design can be incorporated into student policies and procedures that increase social experiences for students with mobility impairments on and off campus (Cook et al, 2009; McGuire & Scott, 2006). The principles of Universal Design can enhance opportunities for membership within university organizations for students with physical disabilities, an important aspect of social success in higher education.

This study provided findings that indicate specific strengths and barriers that influence success among students with physical disabilities, which can be utilized as part of the training on Universal Design in higher education. As mentioned previously, there are no political mandates

to enforce the concept of Universal Design in post-secondary education; however, college faculty are more likely to engage in Universal Design efforts after receiving training to enhance awareness and provide strategies (Black et al, 2014). By focusing on strengthening practices and policies that maximize each student's academic potential, regardless of abilities, colleges and universities can set a new standard for inclusion. Institutions of higher education, which implement the principles of Universal Design will be able to model inclusive behaviors which can be further replicated by students well beyond graduation from college. In this manner, higher education not only contributes to upward mobility, but may also combat negative stereotypes experienced by individuals with physical disabilities.

#### Conclusion

An anti-oppressive disability agenda, as explored in Chapter Two, provides the underpinnings to merge the above suggested practice and policy efforts within the social work profession and higher education, which developed from the findings of this study. This agenda requires the application of the social model of disability, the minority model of disability, and the market model of disability in order to create social change. The social model of disability explains that it is not simply the responsibility of those individuals with disabilities, but that all members of society are accountable to fight for social justice, regardless of ability (Ferguson & Nusbaum, 2012). The minority model of disability requires the recognition of the socially constructed power differential that exists between those who are able-bodied and those who have a physical disability (Anastasiou, & Kauffman, 2013). Furthermore, the market model of disability promotes the notion that most members of society will likely, at some point in their life, either experience a degree of physical disability themselves or have a relationship with a person with a physical disability (Enwereji, 2016). These three models of disability can reinforce

the perception that is necessary in order to create necessary social change that can shape new policies and practices that enhance the future of individuals with physical disabilities.

The findings of this Photovoice study on college students with physical disabilities demonstrate that there are several factors deserving of further exploration through research, which can maximize opportunities for students with physical disabilities in college. Individuals with physical disabilities have experienced discrimination, oppression, and marginalization for far too long. Despite the Americans with Disabilities Act of 1990 (ADA), which was designed to protect the rights of individuals with disabilities, higher education is riddled with obstacles that prevent both access and inclusion among individuals with physical disabilities (Pingry O'Neill et al, 2012). Breaking down the barriers to higher education for students with physical disabilities can lead to upward mobility and the eradication of stigma and stereotypes that perpetuate the inferior status of individuals with disabilities. In conclusion, institutions of higher education appear to hold a source of power that can lead to a newfound revolution for the inclusion of individuals with physical disabilities. The photographs and textural descriptions of this study help to create a much-needed narrative to better understand what it means to be a college student with a physical disability.

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# Appendix A

Kutztown University Institutional Review Board

# **Application for IRB Initial Review**

## **Date Submitted**:

Title of Study: Understanding College Students with Physical Disabilities

**RESEARCHERS' INFORMATION** – All student applications and applications submitted by non-university personnel must have a Kutztown University advisor or sponsor.

## Principal Investigator

Name of Investigator:

 Please check one:
 \_\_\_\_\_\_Administration/Staff

 \_\_\_\_\_Faculty
 \_\_\_\_\_Administration/Staff

 \_\_\_\_\_Undergraduate student
 \_X\_\_\_Graduate student

 \_X\_\_\_Affiliation other than KU Edinboro University of PA

Department/Program/Affiliation: Doctoral of Social Work Program E-mail: khard972@live.kutztown.edu Phone: 814.873.7030 Fax:NA Mailing Address : 6053 Larch Dr., Fairview, PA 16415

Date of when the IRB training was completed: <u>May 25, 2016</u> Submit a copy of the certificate with this application. Applications will not be reviewed until training is verified.

#### **Co-investigator(s) or Sponsor/Advisor** (if applicable) (copy and paste this section as needed)

1. Name:

Department/Program/Affiliation: Social Work Department, Dr. Juliana Svistova, Dissertation Chair E-mail: svistova@kutztown.edu Phone: 610-683-4330 Mailing Address: Old Main 339, PO Box 730, Kutztown, PA 19530 Date of when the IRB training was completed: 1/22/2017 Submit a copy of the certificate with this application. Applications will not be reviewed until training is verified.

2. Name:

 Please check one:
 \_\_\_\_\_Administration/Staff

 \_\_\_\_\_Faculty
 \_\_\_\_\_Administration/Staff

 \_\_\_\_\_\_Oraduate student
 \_\_\_\_\_Graduate student

 \_\_\_\_\_\_Affiliation other than KU
 \_\_\_\_\_\_\_

Department/Program/Affiliation: E-mail: Phone: Mailing Address

Date of when the IRB training was completed:\_\_\_\_\_\_ Submit a copy of the certificate with this application. Applications will not be reviewed until training is verified.

Will there be Research Assistants (RA) involved in this project who will have direct contactwith participants and/or identifiable data? RA must complete IRB training program.\_\_\_Yes\_\_X\_No

List any other individuals who will assist or view data:

Dr. Sharon Lyter, Dissertation Committee Member, KU Social Work Department Dr. Mary Weller, Dissertation Committee Member, KU Social Work Department

Dr. Molly Wolf, Dissertation Committee Member, Edinboro University of PA Social Work Department

# **PROJECT TYPE AND FUNDING**

# **Type of project:**

\_\_\_\_ Faculty/Staff project to be submitted for external funding

-Funding institution or agency:

-Date of grant submission:

Include copies of grant applications with this application.

\_\_\_\_ Faculty/Staff project NOT to be submitted for external funding

\_\_\_\_ Master's thesis

- Class project (provide course name and number:\_\_\_\_\_)
- \_X\_\_ Other\_\_ DSW Dissertation
- \_\_\_\_\_How will this research be funded?

Non-funded research
 X\_ Internally funded (department, college, university)
 Externally funded (state, federal, private)
 Corporate sponsor
 Other, please describe

This student is applying for research funding through Kutztown University's Graduate Student Grant Application. If approved, this funding will be utilized to purchase Amazon gift cards as incentives for participants, and also to pay for a research assistant to transcribe the audio-recorded focus group.

## **RESEARCH PROJECT DESCRIPTION**

You must give the IRB enough information to enable them to make judgments regarding the status, approval or disapproval of your research. So it is very important that you answer each question and section carefully and completely. If a section or subpart does not apply to your research, please indicate this by putting "N/A" in that space. Use as much space as you need. If the IRB doesn't have enough information to make an adequate judgment, it will table your submission and request additional information. This can cause significant delays in the process.

Please use language and terminology that is understandable by people who are unfamiliar with your area of research.

#### A. Purpose and Significance of the Research Study

1. Clearly explain the goals and/or hypotheses of this study, including their significance.

The purpose of this study is to explore and understand the identity and experiences of college students with physical disabilities at a public university in the northeastern United States, through the implementation of Photovoice. The overall aim of the study is to explore what it means to be a college student with a physical disability. This knowledge has the potential to shape practices and policies to promote and improve inclusion among individuals with disabilities in higher education.

Photovoice is a form of Community-based Participatory Action Research (CBPAR) designed to provide a voice to vulnerable, marginalized, and oppressed groups (Hergenrather, Rhodes, Cowan, Bardoshki, & Pula, 2009). Photographs, taken by participants, offer visual images that transcend language barriers, producing a powerful form of communication that can empower individuals and communities (Holtby et al, 2015). As Wang and Burris (1997) identified, Photovoice has "three main goals: 1. to enable people to reflect and record their community's strengths and concerns; 2. to promote critical dialogue and knowledge about important issues through large and small group discussion of photographs, and 3. to reach policy makers" (p. 369).

2. Give a brief description of the most recent relevant research in this area (*cite sources*) and how your goals relate.

Individuals with physical disabilities are faced with stigma and stereotypes related to their limitations, resulting in a profound impact on a person's self-esteem, a major influence of identity development. A person's identity is defined not only by personal attributes, but through group membership, which contributes to shared similar experiences and offers a protective factor to potentially combat stigma (Nario-Redmond, Noel, & Fern, 2013). Students with physical disabilities must understand and accept their disability as part of their identity in order to self-disclose and self-advocate, two important elements of success at the university level (Adams & Proctor, 2010; Rothman, Maldonado, & Rothman, 2008). However, many students avoid seeking accommodations for their disability at the college level because it reduces their sense of independence, a major influence in identity development during young adulthood (Wang & Dovidio, 2011).

Students with physical disabilities, who feel a sense of belonging to their campus community, demonstrate: enhanced self-advocacy skills; greater levels of self-efficacy; and, meaningful relationships with peers (Vaccaro & Daly-Cano, 2015). Literature reveals that developing a sense of belonging within one's university is the "key to academic success and persistence" (Vaccaro & Daly-Cano, 2015) amongst individuals with disabilities. Cognitive, social, and psychological development transcends the classroom in higher education, with a strong emphasis on the social aspects of higher education and the development of one's identity and sense of purpose in young adulthood (Sachs & Schreuer, 2011; Trainor, 2008). Social inclusion among college students has been positively correlated with grade point averages, as it has been well documented that students who are involved in campus life earn better grades compared to students who feel isolated (Hadley, 2011).

While this literature provides helpful information about college students with disabilities, there is a scarcity of literature that focuses on the specific needs and challenges of college students with physical disabilities.

#### **B.** Participants in this Study

1. Identify all participant groups (e.g. undergraduate students, teachers, elementary school students, administrators, other groups). Describe the basic characteristics of each group (including anticipated number of participants from each group, age range).

This study seeks to recruit 7-10 undergraduate students, who are at least 18 years of age, as participants.

2. Describe any specific requirements for including or excluding individuals from participation (e.g. particular gender or racial/ethnic background) and the rationale for the exclusion.

Inclusion: Participants will need to be registered undergraduate students of the identified public university in northeastern U.S. and self-identify as having a physical disability in order to participate. Additionally, participants must have access to a digital camera or smartphone camera.

Exclusion: Social work students or any student enrolled in this researcher's current courses will be excluded from participation.

3. If this research involves vulnerable populations (e.g. minors, the mentally disabled, persons whose competency might be questioned, prisoners, pregnant women, or any others whose ability to give a fully informed consent might be questioned), justify their inclusion.

Participants will be adults (age 18 or older) and enrolled as undergraduate college students, therefore, there is no reason for this researcher to have concerns regarding level of competency to provide fully informed consent. Informed consent will be revisited throughout the research process to prevent participants from feeling coerced, due the vulnerability of individuals with disabilities.

4. Describe any relationship(s) between <u>any</u> researchers involved with this study and potential participants (e.g. professor-student, resident assistant-resident, supervisor-employee). Please note that existing relationships between a researcher and potential research participants create special concerns related to recruitment, informed consent and confidentiality of research data that must be addressed in subsequent sections of this protocol.

Due to this researcher's role as a professor in the social work department of the setting of the study, any student who is enrolled as a social work major, or is currently taking a course with this researcher will be excluded from participating.

# C. Identification and Recruitment of Potential Participants

Attach copies of ALL materials that will be used to recruit participants (e.g. letters, advertisements, flyers, posters, email scripts)

1. Describe how you will gain access to potential participants, how participants will be contacted, and what information will be given during the recruitment process.

Participants will be recruited via flyers posted throughout campus as well as through informational meetings conducted by this researcher in two residence halls that provide services for students with physical disabilities.

2. If participants will receive compensation in any way for their participation (e.g. money, course credit), indicate the type and the amount, the method of distribution of compensation and identify the source(s) of funds used for the compensation.

N/A

3. Will participants and/or data be accessed from a cooperating institution (e.g., school, university, business, agency)? If yes, a permission letter signed by an appropriate official (on the cooperating institution's letterhead) granting access to participants and/or data must be provided to the IRB committee.

Participants will be undergraduate students of Edinboro University of Pennsylvania, another, PASSHE school. Upon approval of this application through Kutztown University's IRB, Kutztown University's IRB is able to post the approved protocol through PASSHE IRB Sharepoint and request Edinboro University's approval.

# **D.** Interventions, Assessment Procedures and Other Sources of Data

Attach copies of everything that is being used for the purposes of this study (e.g. tests, surveys, observation recording sheets, interview questions, laboratory reporting sheets, debriefing materials).

1. Describe your procedure, including all testing, observations, interviewing, interventions, educational programs or laboratory procedures. Describe how data will be recorded (e.g. video or audiotape, notes). Give approximate amount of time needed from subjects.

There are six phases to the photovoice process, which includes:

- 1. an orientation and ethics training for participants in a group format (1.5 hours)
- 2. a period of time for participants to take photographs (4 hours over the course of 2 weeks)
  - a. Participants will submit up to a total of 20 photographs to this researcher
- 3. a focus group interview (2 hours)
  - a. data will be recorded via computer audio and some note-taking by this researcher
  - b. participants will choose 2 photographs to share and explain reasons for capturing image in relation to research questions
- 4. data analysis by researcher
- 5. respondent validation (1 hour)
- 6. a presentation of the photographs (1-2 hours). The researcher first conducts an orientation to photovoice for participants, which includes: an overview of photovoice; ethics and safety training; and, basic photography training (Wang & Burris, 1997).

Total time required of participants = 11 hours over course of 3 months

2. What data or information will be collected?

Photographs taken and submitted by participants will be collected via email. Participants will share images they choose and explain the photographs and their stories related to their identity and experiences in higher education, as college students with physical disabilities.

3. If this study is using archival data (data that has already been collected for other purposes than this study that has been on file), describe the nature of the data archive. Explain which data is to be accessed for this study and how it will be accessed. If data are publicly available, state this. If not, explain how you will get access to the data and attach documentation that you have authorization to do so.

N/A

4. Is the research involving the collection and/or use of health (physical or psychological) data from a healthcare provider (hospital, physician's office, health departments, etc.)? If yes, you may need to follow the guidelines established by the Health Information Portability and Accountability Act (HIPAA).

N/A

5. If this study is a qualitative or oral history project that involves unstructured or semistructured interviews or observations, provide a detailed description of the nature and scope of these procedures. Include the purpose of the interviews or observations, where they will take place, by whom they will be conducted, expected length of time, type of information and general areas of information to be covered and sample questions and/or behaviors to be observed.

During the orientation, this researcher will collaborate with participants to establish a time and location on campus to hold the focus group interview. With 7-10 participants, 2 hours will likely be necessary to provide each participant with an opportunity to engage. During the focus group interview, this researcher will provide participants with copies of their submitted photographs and ask each of them to narrow their collection down to one photograph for each of the research questions that they feel best capture what they want to share. The SHOWED method of Photovoice data analysis will be utilized as an interview guide to elicitation of information from participants in order to improve consistency and transparency of the focus group process. Participants will take turns sharing each photograph using through the researcher's prompts using the SHOWED method:

"S: What do you see?
H: What happened or is happening in the picture?
O: How does this relate to our lives?
W: Why does this happen?
E: How could this image educate others?
D: What can we do about it? (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009, p. 687).

6. Where will the study take place?

This study will take place at Edinboro University of Pennsylvania.

7. If deception is involved or if information will be withheld from participants, describe the type of deception or the information being withheld and explain why this is necessary. Describe your procedures for debriefing participants. Include a copy of the debriefing statement with this application.

N/A

# E. Potential Risks to Participants and Procedures to Minimize These Risks

- 1. Discuss any physical, psychological, financial, social/economic or legal risks, or harm from breaches of confidentiality that might result from participation in this study and assess the likelihood and seriousness of these risks. Explain why it is necessary to expose participants to potential risks.
  - 1. As with any focus group, confidentiality cannot be fully guaranteed.
  - 2. Photographs can potentially give away participant identity
  - 3. Potential a social risk involved with the presentation of photographs.
- 2. For each risk identified, describe actions that will be taken to minimize the risk.
  - 1. Confidentiality- The importance of confidentiality will be explained during the ethics training and reiterated throughout the study.
  - 2. This researcher will explain during the orientation how photographs will be utilized (focus group, publication, educational conferences, presentation), which will be outlined in the informed consent. Participants will be reminded throughout the study that, as owners of the photographs, participants can decide at any point to retract their photographs, with the exception of photographs that have gone into publication.

Ethics training will be conducted as part of the orientation training in order to educate participants on obtaining consent from individuals in order to capture other individuals within photographs. Safety measures will include: taking photographs in familiar places; and, avoiding anything or anyone that could "indict, stigmatize, embarrass, or shame individuals or groups" (Burgos, Frazo, Fitzgerald, True, Adachi-Mejia & Cannuscio, 2014, p. 2). Participants will be required to complete a "Photovoice Ethics Agreement Form" after completion of the Ethics and Safety Training.

3. Social risk- This risk will be minimized, as participants will decide the platform in which to present the photographs and will also be reminded that participation in the presentation is voluntary, just as participation is voluntary throughout the entire study.

# F. Benefit/Risk Assessment

1. What are the potential benefits of the research? (Please note – if participants will not benefit directly in any way from their participation, state this. Compensation, including course credit, is not considered a benefit.) Do benefits outweigh potential risks?

Photovoice is a form of Community-based Participatory Action Research (CBPAR) designed to provide a voice to vulnerable, marginalized, and oppressed groups (Hergenrather, Rhodes, Cowan, Bardoshki, & Pula, 2009). Photographs, taken by participants, offer visual images that transcend language barriers, producing a powerful form of communication that can empower individuals and communities (Holtby et al, 2015). Specifically, this study has the potential to help college students with physical disabilities engage in critical discussions and advocacy efforts improve the representation of students with physical disabilities in higher education. The benefits to participants and of the research study outweigh the minimal, potential risks involved.

2. If benefits do not outweigh risks, explain why this project is justified.

N/A

# G. Procedures Used to Protect the Anonymity and/or Confidentiality of Participants and Records Management

Records (including consents) must be maintained for as long as applicable regulations require.

1. Explain how data will be recorded (describe any coding procedure). Will anyone besides the principal investigator and co-investigators have access to the raw data or any other form of data (please describe)? How will data be reported if presented or published (particularly important – will identifying information be masked)?

Photographs will be saved to a computer drive with a password known only to this researcher. Interviews will be audio-taped and along with some note-taking. The audio-tape will be transcribed by this researcher into a Microsoft Word Document and saved to a computer drive with a password. The audio-recording and interview protocols will be secured in a locked filing cabinet. No one beside the principal investigator or co-investigators will have access to data.

Photographs of persons who can be identified must have a consent form from the person in the photograph. Data from the focus group interview will be void of any identifying information, including the names of participants.

2. Explain any limits to confidentiality (e.g. child abuse reporting laws, individuals besides the researchers who will have access to data).

As a mandated reporter, this researcher will be required to report any concerns regarding child abuse. As a licensed social worker, this researcher must also report any concerns of a participant who is at risk to harm themselves or others, as well as any concerns of elder abuse or other vulnerable populations.

3. If Internet or Web-based surveys are being used, describe procedures for ensuring that confidentiality is protected.

N/A

4. How will records be stored during the study? What will happen to records at the conclusion of the study? (Please refer to the IRB website for policy and procedure on record retention.) What will happen to data at the conclusion of the study?

Computerized records will be stored via a password protected computer drive. Paper records will be stored in a locked filing cabinet of the investigator. All records relating to the approved research (e.g., consent forms), will be retained by the investigator for at least (3) three years after completion of the research.

5. If audiotaping or videotaping is conducted, describe how tapes will be stored and what will happen to them at the conclusion of the study?

Computer audio recordings of the focus group interview will be stored by this researcher and protected by password. Audio recordings will be maintained for at least 3 years per federal regulations.

6. Describe how records (e.g. consents, survey, tapes, notes) will be destroyed. If records will not be destroyed, please explain why not. Until records are destroyed, they must be kept in a secure place, accessed only by the investigator, co-investigators or sponsor/advisor.

Paper records will be shredded and computer storage files will be permanently deleted.

7. Expected length of time for study to be completed (data collection and analysis)?

9 months

# H. Informed consent - Attach consent and assent forms and/or script for oral explanation (if any).

More information about what is required and templates of informed consent / assent are provided on the IRB website. All forms should be readable and must be presented in age and developmentally appropriate language.

1. Describe the process involved in obtaining informed consent (e.g. when, where, who, and how)

Informed consent will be explained by this researcher to each participant, in person, the setting of the study. The consent form will be explained verbally and this researcher will give participants an opportunity to ask questions or voice any concerns. Participants will be required to sign a consent form. A copy of the signed consent form will be provided to the participants. Participants will be reminded throughout the study that participation is voluntary and they can withdraw at any time.

2. If subjects include members of vulnerable populations or are vulnerable because of their relationship with the researcher, explain what special procedures will be followed to ensure informed and voluntary consent.

Participants are identified as having a physical disability. This researcher will revisit the voluntary participation and consent throughout the study to decrease concerns about coercion.

3. If potential participants are minors, describe procedures for obtaining their assent to research and procedures for obtaining parental or guardian consent.

N/A

4. If you believe your project requires a waiver or alteration of informed consent, or a waiver of the requirement to obtain a signed consent, you must request a waiver. Complete the appropriate form provided on the IRB website and attach it to the end of this application.

N/A

# **TYPES OF REVIEW**

Please indicate which category you are applying for review. Please note that the IRB Committee will make the final determination for type of review. If applying for an exempt or expedited review, you must indicate the category number. The category numbers are located on the IRB website located at <u>http://www2.kutztown.edu/about-ku/administrative-offices/grants-and-sponsored-projects/institutional-review-board.htm</u>, under Types of Review.

Exempt Review (Indicate category number 1a – 1f)

X Expedited Review(Indicate category number 2a – 2g) 2g Full Review **SIGNATURES** - All student applications and applications submitted by non-university personnel must have a Kutztown University advisor or sponsor.

# The principal investigator, co-investigators and the advisor/sponsor must sign the application. By signing and submitting the application to the IRB, all parties listed agree that they have read and agree to the following statements.

I understand that I have responsibility for the protection of the rights and welfare of human subjects and the ethical conduct of this research project.

I agree to comply with all Kutztown University policies and procedures, applicable federal, state and local laws, and the ethical principles of my profession.

I have completed the required IRB training within the last three years.

I understand that if any revisions/changes are made in the project I must obtain IRB review and approval prior to implementation of changes.

I understand that IRB approval is only for one year (except exempt applications). If my research will continue beyond one year, I will file the yearly review form with the IRB prior to the expiration date. I understand that failure to file may result in termination of the project and require resubmission as a new project.

I will immediately report any adverse events or unanticipated problems to the IRB.

I understand that no part of the proposed research described in this application may be carried out until I have received final approval from the IRB.

Additional statement for advisors/sponsors - I understand that I am the primary responsible party for legal and ethical performance of this project. I certify that I have read and approved this protocol and I agree to meet with the principal investigator(s) on a regular basis to review project progress and help resolve any problems which arise. I also certify that I will provide written approval of all revisions and additions to this protocol.

Principal investigator:

Name (please print)

Signature

Co-investigators (if applicable) (copy and paste additional signatures lines as needed):

Name (please print)

Signature

Date

## Appendix B

#### **CONSENT FORM**

#### Photovoice Research Study:

#### **Understanding College Students with Physical Disabilities**

You are invited to participate in a research study being conducted through Kutztown University. During this research study, you and other participants will be asked to take photographs and discuss strengths and concerns about being a college student with a physical disability. This type of study is known as Photovoice. This study will provide you with an opportunity to let others know what it is like to be you.

We ask that you read this form and ask any questions you may have before you decide whether or not you want to participate in the study. The University requires that you give your signed agreement if you choose to participate.

This study is being conducted by Kimberly Hardner, MSSA, LSW, DSW Candidate

#### Title of the Study:

Understanding College Students with Physical Disabilities

#### Purpose of the Study:

The purpose of this study is to understand what it means to be a college student with a physical disability

#### **Procedures:**

If you agree to participate in this study, we would ask you to do the following things

- 1. Participate in an orientation and ethics training (1.5 hours)
- 2. Sign an ethics acknowledgment form at the completion of the ethics training
- 3. Take photographs of your life experiences over the course of two weeks, using a digital camera or smartphone camera that you have access to
- 4. Email up to 20 total photographs to this researcher
- 5. Participate in a focus group with participants to share your photographs and experiences (2 hours)
- 6. Follow-up with the researcher after the focus group to ensure accuracy of researcher's analysis
- 7. Participate in a presentation of photographs to be determined by participants (this may be a brochure, a poster presentation, an informational session with or without participants)

#### **Risks and Benefits of Being in the Study:**

The likelihood of risk to participants is minimal and this researcher will make every attempt to minimize risk through the orientation and training; however, the following risks must be considered:

4. As with any focus group, confidentiality cannot be fully guaranteed.

- 5. Photographs can potentially give away participant identity
- 6. Potential a social risk involved with the presentation of photographs

The benefits to participation are

- 1. Empowerment of participants
- 2. Meet new community members
- 3. Opportunity to identify strengths and concerns among students with physical disabilities, and increase awareness of strengths and concerns
- 4. Engage in social change

#### **Compensation:**

Participants will receive a \$50 Amazon gift card as an incentive for participation in this research study.

#### **Confidentiality:**

All information will be handled in a confidential manner to the extent provided by law, so that no one will be able to identify you when results are recorded. During the focus group, full names will not be disclosed. The focus group will be audio recorded for the sole purpose of this researcher to transcribe the interview and analyzing data.

The records of this study will be kept private. Any documents stored on a computer will be protected by a password. Any paperwork related to the study will be kept in a locked filing cabinet.

In any report or presentation, we will not include any names or identifying information. Participants will be instructed to minimize identifying information that may be visible in photographs.

This researcher is a mandated reporter, and is required by law to report any information related to related child abuse or neglect that may be disclosed by participants. Additionally, as a Licensed Social Worker in Pennsylvania, this researcher would also need to break the rules of confidentiality if a participant threatens to harm themselves, someone else, or discloses information related to abuse or neglect of elderly or other vulnerable persons.

#### Voluntary Participation:

Your participation in this study is completely voluntary. There is no penalty for not participating. You may discontinue your participation and withdraw from the study at any time without penalty.

#### Photographs:

You will decide what photographs are taken and which photographs to share. The photographs you submit for this study will be of your choosing, and will be shared with other participants during the focus group interview of this study. You may be asked to share your photographs for a public presentation. Photographs may also be used in research publications, conference presentations, and trainings.

You are the owner of any photographs that you take during this study. You can decide at any point to retract your photographs, even after the completion of the study up until the point when photographs have gone into publication.

#### **Contacts and Questions:**

The researcher conducting this study is: Kimberly Hardner, MSSA, LSW, DSW Candidate 814-732-1521 <u>khard972@live.kutztown.edu</u> Dissertation Chair: Dr. Juliana Svistova Kutztown University of Pennsylvania Assistant Professor, Social Work Department Old Main 339, PO Box 730 Kutzown, PA 19530 610-683-4330 svistova@kutztown.edu

You may ask any questions you have now. If you have questions later regarding the research study, you may contact the researcher listed above. If you have any questions or concerns about the rights of research participants, please contact the IRB Committee at Kutztown University at 484-646-4167.

Your participation is completely voluntary. Signing this paper means that this form has been explained to you and that you are interested in participating in this research study. You can change your mind at any point once the study begins, and decide not to participate. If after reviewing this form, you choose not to sign and not to participate, that is okay as well.

Thank you!

#### **Statement of Consent:**

I have read the information described above and have received a copy of this information. I have asked questions I had regarding the research study and have received answers to my satisfaction. I am 18 years of age or older and voluntarily consent to participate in this study.

Print Name of Participant \_\_\_\_\_

Signature of Participant

Date

**Researcher Signature** 

Date

# Appendix C

# Photovoice Orientation, Ethics and Safety Training, and Basic Photography Training (1.5 hours)

Understanding College Students with Physical Disabilities Photovoice Research Study

- I. Obtain Informed Consent from all Participants
- II. Welcome
- III. Ice-breaker
- IV. Photovoice Orientation
  - a. What is photovoice?
  - b. Goals of photovoice
  - c. Advantages and Limitations of Photovoice
- V. Ethics and Safety Training
  - a. Informed Consent as a Participant
  - b. Obtaining Consent from Individuals in Photographs
    - i. When to obtain consent
    - ii. Pass out and review consent to photograph forms
    - *iii.* Role-play/ Examples
    - *iv. Review Photovoice Ethics Agreement Form and obtain signatures from participants*
  - c. Participant Safety
    - i. Role-play/examples
- VI. Basic Photography Training
  - a. Basics of Photography
  - b. Tips and Tricks
  - c. Role-Play

#### Appendix D

"Understanding College Students with Physical Disabilities"

#### Photovoice Research Study

#### PHOTOVOICE ETHICS AGREEMENT FORM

Participant's Name

In this photovoice study, you and other participants will be taking photographs about your identity and experiences as a college student. The photovoice project and study is an opportunity for you to teach others what it is like to be a college student with a physical disability.

By signing this ethics agreement form, you are agreeing to the abide by the ethics of photovoice as taught to you by this researcher, Kimberly Hardner, MSSA, LSW, DSW Candidate.

Please read each of the following statements and sign your initials next to each statement to confirm that you have read and understand each ethical statement.

\_\_\_\_\_ I will not intrude into an individual's personal space both publicly or privately.

I will not take any photographs that may "indict, stigmatize, embarrass, or shame individuals or groups" (Bugos, Frasso, Fitzgerald, True, Adachi-Mejia, Cannuscio, , 2014, p. 2)

\_\_\_\_\_ I will not place individuals in false light with my photographs.

- \_\_\_\_\_ I will respect confidentiality of the stories discussed during the focus group interview.
- \_\_\_\_\_ I will obtain the permission and signature from any individual represented in my photographs.
- \_\_\_\_\_ I will not reveal the name(s) of any subject(s) in my photographs, and will not use them when creating captions for my photographs or when discussing my photographs.

Signing this ethics agreement form means that you have read, understand, and agree to

respect the ethics and privacy of this photovoice project. If you fail to follow these

principles, you will not be able to participate.

Print Your Name Here

Sign Your Name Here

Date

# Appendix E

Debriefing Form for Participation in a Research Study

#### Understanding College Students with Physical Disabilities

Thank you for your participation in our study! Your participation is greatly appreciated.

#### Purpose of the Study:

We previously informed you that the purpose of the study was explore and understand the identity and experiences of college students with physical disabilities. The goal of our research is to explore what it means to be a college student with a physical disability. This knowledge has the potential to shape practices and policies to promote and improve inclusion among individuals with disabilities in higher education.

We realize that some of the questions asked and the discussions that occurred within the focus group may have provoked strong emotional reactions. As researchers, we do not provide mental health services and we will not be following up with you after the study. However, we want to provide every participant in this study with a comprehensive and accurate list of clinical resources that are available, should you decide you need assistance at any time. Please see information pertaining to local resources at the end of this form.

#### **Confidentiality:**

You may decide that you do not want your data used in this research. If you would like your data removed from the study and permanently deleted please contact Kimberly Hardner, MSSA, LSW, DSW Candidate by email or phone:

khard972@live.kutztown.edu or

814-732-1521

#### Final Report:

If you would like to receive a copy of the final report of this study (or a summary of the findings) when it is completed, please feel free to contact us.

#### Useful Contact Information:

If you have any questions or concerns regarding this study, its purpose or procedures, or if you have a research-related problem, please feel free to contact the researcher(s), Kimberly Hardner, MSSA, LSW, DSW Candidate by email or phone:

khard972@live.kutztown.edu or

814-732-1521

If you have any questions concerning your rights as a research subject, you may contact the Kutztown University Internal Review Board at (484) 646-4217 or Jeffrey Werner, Director of Kutztown University IRB at <u>werner@kutztown.edu</u>

If you feel upset after having completed the study or find that some questions or aspects of the study triggered distress, talking with a qualified clinician may help. If you feel you would like assistance please contact

Counseling and Psychological Services (CAPS) of Edinboro University at **814-732-2252** (Monday-Friday 8am-5pm) or

In case of a crisis or emergency, call (814) 732-2911 on campus or 911 otherwise.

Telephone Helpline services are available from outside agencies after hours:

- in Erie County Crisis Services (Safe Harbor Behavioral Health) (814) 456-2014 or
- 800-300-9558
- in Crawford County Crisis Hotline (Stairways Behavioral Health) (814) 724-2732
   or 800-315-5721 Help Line/Meadville Medical Center (814) 373-2345

In a serious emergency, remember that you can also call **911 for immediate assistance**.

Further Reading(s):

If you would like to learn more about college students with disabilities or Photovoice, please see the

following references:

# Appendix F

# Recruitment Flyer



Are you a college student with a physical disability? Are you interested in photography? Would you like to change your community?

# To participate, you must:

Be at least 18 years of age

Be a registered undergraduate student

Have a physical disability

Have access to a digital or smartphone camera

Be willing to take photographs and take part in a group discussion

Be willing to share pictures with the public

For more information, Contact: Kimberly Hardner, MSSA, LSW, DSW Candidate 814-732-1521 khard972@live.kutztown.edu

# LOOKING FOR RESEARCH STUDY PARTICIPANTS

# Appendix G

# Interview Protocol

Participant Initials \_\_\_\_\_ and Participant #\_\_\_\_\_

Understanding College Students with Physical Disabilities Photovoice Research Study

| Participant #                           | Focus Group Interview Notes  |  |  |  |  |
|---|--|--|--|--|--|
| Interview Details                       |  |  |  |  |  |
| Research Question: (identity)?          | What does it mean to be a college student with a physical disability |  |  |  |  |
| Photograph #:<br>Photograph<br>Caption: |  |  |  |  |  |
|   |  |  |  |  |  |
|   |  |  |  |  |  |

# **SHOWED Interview Notes**

S: What do you see?

## COLLEGE STUDENTS WITH PHYSICAL DISABILITIES

H: What <u>happened</u> or is happening in the picture?

O: How does this relate to our lives?

W: Why does this happen?

E: How could this image <u>e</u>ducate others?

D: What can we <u>do</u> about it?"

Research Question: How has your physical disability influenced your experiences (academic and social) in college?

| Photograph:<br>Photograph<br>Caption: | <br> |      |  |
|---------------------------------------|------|------|--|
|                                       | <br> | <br> |  |
|                                       | <br> | <br> |  |
|                                       |      |      |  |



S: What do you see?

## COLLEGE STUDENTS WITH PHYSICAL DISABILITIES

H: What <u>happened</u> or is happening in the picture?

O: How does this relate to our lives?

W: Why does this happen?

E: How could this image <u>e</u>ducate others?

D: What can we <u>do</u> about it?"

# Appendix H KUTZTOWN UNIVERSITY GRADUATE STUDENT GRANT APPLICATION FORM

| Student Name Kimberly Hardner, MSSA, LSW, DSW Candidate Date 08/07/1 | . <u>7</u> |
|--|------------|
|--|------------|

Address 6053 Larch Dr., Fairview, PA 16415 Email khard972@live.kutztown.edu

Telephone Number <u>814-873-7030</u>\_\_\_\_\_

Program of Study \_\_\_\_\_\_ Doctor of Social Work\_\_\_\_\_\_

Faculty Member Supporting Application <u>Dr. Juliana Svistova</u>

REQUEST IS FOR (*please check*)

X Research/Creative Project
 Travel Expenses (to present a paper at a professional conference)

Graduate Credits Completed 30

AMOUNT REQUESTED (*The maximum grant award is \$1,500. Reviewers may elect to fully fund, partially fund, or not fund a request.*) <u>\$1,300</u>

TITLE OF RESEARCH, CREATIVE PROJECT, OR PAPER PRESENTATION <u>Understanding College Students with Physical Disabilities</u>

## STUDENT STATEMENT

If a Graduate Student Grant is awarded, I agree to the following conditions:

- Complete the research, creative project, or paper presentation as outlined in my proposal.
- Submit a brief report and short biography at the completion of the research, creative project, or paper presentation.
- If applicable, present the results of the research or creative project at a regional, national, or international conference.
- Submit budget expenditures.

Student Signature

Date \_\_\_\_\_

**ATTACH NARRATIVE DESCRIPTION TO THIS FORM** (refer to Graduate Student Grant Application Guidelines)

I. Relevance and Significance of Research Topic

Understanding vulnerable populations, such as college students with physical disabilities, can provide significant contributions toward both leadership and education within the field of social work. As a particularly vulnerable population on university campuses, students with

physical disabilities deserve attention, support, and advocacy from university leaders, faculty, and staff. Affording students with physical disabilities the same opportunities for inclusion and success within higher education aligns with social justice, one of the core values of the social work profession (NASW, 2008). Access to postsecondary opportunities should be equally available to all individuals, regardless of race, ethnicity, gender, sexual orientation, and in this argument, physical ability (Espinoza, 2007).

II. Description of Research Design

The purpose of this dissertation research study is to explore and understand the identity and experiences of college students with physical disabilities at a public university in the northeastern United States, through the implementation of Photovoice. This knowledge has the potential to shape practices and policies to promote and improve inclusion among individuals with physical disabilities in higher education. Photovoice can be utilized with diverse groups and communities, and provide a venue for individuals and communities to share their stories; enhance community cohesion; and, facilitate advocacy efforts to shape public policies that increase parity (Agarwal et al, 2015; Sethi, 2016; Teti, Rolbiecki, Zhang, Hampton, & Binson, 2016; Wang & Burris, 1997). Through Photovoice, college students with physical disabilities will have an opportunity to share their experiences with others through photographs, as well as through their shared narratives and the dialogue that will transpire through the focus group. The focus group will be audio-recorded and transcribed verbatim to increase transparency and validity.

The IRB process through Kutztown University is under review, which will subsequently determine the feasibility of the study to be conducted at Edinboro University of Pennsylvania. The sample population will emerge from Edinboro University of PA, a university well-known for providing support services to students with physical disabilities. Upon completion of the orientation and ethics training (which has been prepared and includes an ethical agreement for photography, beyond the participant consent form), participants will be tasked with taking photographs and then returning for a focus group. During the focus group, participants will explain their photographs and determine an appropriate venue to showcase their strengths and challenges related to being a college student with a physical disability.

#### III. Budget

The tentative sample for this study will be 7-10 participants. Each participant will be expected to contribute at least 11 hours to the research study over the course of 3 months, therefore, a \$50 gift card to Amazon would be ethically responsible to reward them for their time. The orientation and ethics training (1.5 hours) would be worth \$10 in incentives; the data collection and focus group (6 hours) would be worth \$20 in incentives; while the showcase (2-3 hours) would be worth \$10.

| Participant Incentives      | \$50 Amazon gift cards                  | up to <b>\$500</b> |
|-----------------------------|---|--------------------|
| Transcription Services      | up to \$250 per hour of audio-recording | up to <b>\$500</b> |
| Printing of Photographs and |   | \$150-300          |
| Creation of Poster Displays |   |                    |

**Total Budget** 

\$1150-\$1300