

What College Students with Physical Impairments Say About
Discourses of Disability On Campus

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Dedication

To Claire, from whom I receive immeasurable support and encouragement. I am eternally grateful for her patience, cooperation, and ability to put up with my...we'll call them intricacies. When we began fifteen years ago I was a graduate student. She supported me a decade later when I resigned from my job, returned to school full-time and relocated in order to once again become a graduate student. I promise—*this is the last time*. I cannot begin to quantify her influence in this work and on my life. There has to be a stronger word than *Love*, and I will spend my lifetime trying to express it.

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Abstract of Dissertation

What College Students with Physical Impairments Say About Discourses of Disability on Campus

For students with disabilities, inclusion implies more than access as stipulated through the Americans with Disabilities Act (ADA) and its 2008 Amendments Act. It indicates the idea of a communal experience that attempts to develop a culture wherein the full participation of diverse students is established through proactive decisions and allows them to engage in aspects of campus life “in a seamless and real-time manner” (Huger, 2011, p. 5). The purpose of this study was to explore conversations surrounding disability, as understood by students with physical impairments, in order to make meaning of their lived experiences, the messages they receive, and their interpretations of those messages. Using discourse analysis as both a theory and method (Gee, 2011), seven students self-identifying with physical impairment were asked to discuss their college experiences; what factors impact their decisions regarding involvement; what it means to be “inclusive”; what they feel their institutions do to create and encourage inclusive campuses; and what they think non-disabled peers think of them.

Despite interviews designed to focus conversations on social involvement and engagement, participants often gravitated toward their educational pursuits and specific concerns based upon individual disability needs. Students de-emphasized extra-curricular involvement in favor of adherence to objectives for successful academic pursuits, often requiring they weigh the physical and wellness tolls such activities could take on their bodies. Considering how respondents speak of their university experiences, this paper argues the discourses of disability are understood as seriously academic and seriously medical or health related. Further, while participants stated overall positive experiences at

their universities, analysis of the conversations revealed encounters with physical access problems and difficulties with interactions and interpersonal relationships on campus. This suggests a deeper complexity to their initial assertions, perhaps highlighting the low expectations students with physical impairments hold toward true inclusion and the degree to which bad has to be sensed as bad enough to reach the level of being truly damaging to their view of the overall experience. Implications for this study are to help the university community—administrators, faculty, and students—understand the decision-making process for students with disabilities regarding campus involvement.

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CHAPTER ONE

INTRODUCTION TO THE STUDY

David, a freshman, agrees to join his roommates and their friends at the first home basketball game on campus. The others will show up at the gate and easily find seats in the student section, but David calls ahead because he uses a wheelchair. “We’ve a variety of handicapped seating for people showing they need it” says the box office manager. Upon arrival, David is given his options: directly behind the scorer’s table on the floor—seated amongst the administration and booster club—or in the second tier along the rail. Neither is in proximity to the student section, though David can clearly see his roommates across the court from his seat. After finding the accessible restroom closed for services, and 15 minutes spent searching for the next nearest facility, which no one seems to know where to find and is located back on the first floor, David decides to leave, and determines this will probably be his final basketball game.

Above all else, can we agree the world is constructed to be most inclusive for the able-bodied? Similarly, much in higher education and student affairs seems to indicate comparable assumptions “that all students entering (them) and all faculty teaching (in them) will be able-bodied” (Evans, Herriott, & Myers, 2009, p. 113). It stands to reason—a majority of us mobilize and interact without restriction. We experience little difficulty visiting friends’ apartments or dorm rooms; engaging with our friends at games, movies, and performances; entering, ordering, and dining at restaurants; and using public services such as buses, libraries, and computer terminals. When made aware of such difficulties as those experienced by David, we might rightfully assume (at least to a degree) it is not a deliberate act of discrimination on the part of those responsible for the university’s basketball arena, but a lack of recognition for the true impact of an environment’s design for those with particular impairments. At the same time, attributing

these practices to ignorance is an oversimplification of a deeper seeded and pervasive concern.

Our society has established a notion of the body's idealized form, and with a preconception of how one should look, behave, and communicate, we have also created *outsiders*—those who do not fit within the norm (Taub, Blinde, & Greer, 1999). Resulting from this categorization, people recognizing themselves as outsiders often are further debilitated when choosing to seek involvement (Taub, Blinde, & Greer, 1999). Within higher education the negative (or indifferent) attitudes toward those who challenge our concept of *normal* can be signaled through how a campus designs its programs, organizes its environment, disseminates its information, and speaks to and about its students. An integral piece in the investigation is analyzing the discourse, or the “ways of combining and integrating language, actions, interactions, ways of thinking, believing, valuing, and using various symbols, tools, and objects to enact a particular sort of socially recognized identity” (Gee, 2011, p. 29). In this particular case, the specific concern is college students with physical disabilities, and therefore, the discourses of disability which abound in higher education to influence these students.

An understanding of disability has many layers; it can speak to a medical condition, a limitation, an individual identity, and a social group identity, among others. Early discourses of disability mostly understand it through the language associated “with its history, reflected in medicine, psychology, sociology, and anthropology” as a way of conceptualizing “disability as a deviant individual experience within a dominant culture” (Johnstone, 2001, p. 5). Scotch (2009) suggests the institutionalized stigmatization of people with disabilities shares characteristics found in “experiences and characteristics of

other groups commonly recognized as minorities...prejudicial attitudes, discriminatory behavior, and institutional and legal constraints” (p. 174). The language employed follows the culture in its iteration of disability, reducing people through its vocabulary: *afflicted with, handicapped, stricken, suffering from, lame, misshapen, crippled, invalid*...and subsequently, making them invalid. People with disabilities were *disabled*, broken in a world in which they were not normal. Society viewed them as incapable (or at least less capable) of making decisions for themselves and performing work and social tasks independently, thus leading to a perception of necessary dependence (Scotch, 2009). A discussion of how disability is situated within post-secondary education in such a discourse is moot; by and large the populace had no place in the landscape of higher learning.

More recently there has been movement in the direction of consideration of “socio/political debates of disablement...disability as both an individual and a public, cross-cultural experience” (Johnstone, 2001, p. 6, citing Peters, 2000). Situating disability, and those with disabilities, in a larger community of diversity “does not need to present disabled people as more than or less than human but rather as ‘ordinary’ people coping with extraordinary circumstances” (Oliver, 1990, p. 68). Consideration is given to the ways in which environment, practices and policies, and language allow students with physical disabilities to move from an area of *otherness*, where their exclusion serves as a reminder of their physical difference and leaves some people with a perception they have no value or place in the able-bodied world (Morris, 1991, cited in Reeve, 2006), to a position of belonging and being allowed to pursue “learning, growth, and development” opportunities (Strange, 2000, p. 25).

Views of disability from an advocacy and social justice stance argue “reclaiming language and changing the ways in which we talk about disability can have a powerful effect on normalizing physical and cognitive differences” (Evans & Herriott, 2009, p. 29). The response to earlier expressions and characterizations of people with impairments was to urge the usage of a people-first language, whereby the emphasis returned to identifying the individual before the disability (e.g., *student with mobility impairment* rather than *disabled student*). However, while words and labels can be more easily adjusted, the underlying beliefs and stereotypes that lead to the behaviors and actions negatively impacting students with disabilities are more difficult to change. Further, it is difficult to speak to the influence language and “other stuff” (per Gee, 2011) has on students with disabilities without asking those individuals to share their lived experiences. In utilizing a discourse analysis study, I intend to provide an interpretation of interviews of college students with physical disabilities to, in a sense, craft their definitions of disability and their perceptions of how disability is further characterized by their college communities.

Context for the Project

In 1990, Congress approximated 43 million Americans had a documented disability, and found the population to be “the poorest, least educated, and largest minority in America,” (Burgdorf, 1991, p. 420). Approximately two-thirds of working-age persons with disabilities (PWD) were unemployed, 36% were dependent on government benefits, and of the working PWD, 20% lived below the poverty line—twice the rate for all Americans (Burgdorf, 1991). National Council on the Handicapped information detailed pervasive and documented discrimination against PWD, while a

survey found 75% of participants with disabilities supported enactment of civil rights regulations to shield them from discrimination (Burgdorf, 1991). Ethically and socially, protecting PWD from discrimination was a necessity.

Initially, increased access for persons with disabilities was by and large a product of mandated standards established through Section 504 of the Rehabilitation Act of 1973 (PL 93-112) and later the Americans with Disabilities Act 1990 (PL 101-336)¹. The intent was to prohibit discriminatory practices, remove architectural barriers, and limit exclusion from public services for people with impairments.

Understandably, at that stage, the common discourse surrounding disability was the language of legal compliance. Decades later, perhaps the time is upon us to examine where the discourses have steered, recognizing emergent conversations toward true inclusion through the social model of disability and the Theory of Complex Embodiment, wherein the dialogue expresses and values disability as diversity, rather than a strictly legal mandate. At the same time, it would be foolish to suggest we could entirely abandon thought of disability through a legal model. Social justice advocates must first comprehend the historical conditions under which calls for equity arose and be willing to adjust their expectations as the environment and situation changes (Fraser, 1997, as cited in North, 2008). When legal access became a minimal standard, it became the time for disability advocates to undertake examinations which may be valuable in “exposing the subtle ways that power moves through institutions and people” and “hold significant implications for educational endeavors aimed at social justice” (North, 2008, p. 1192).

¹ The Rehabilitation Act was reauthorized as Title IV of the Workforce Investment Act of 1998 (PL105-220), which in turn was superseded by the Workforce Innovation and Opportunity Act (PL 113-128) in 2014. The Americans with Disabilities Act was updated through the Americans with Disabilities Act Amendments Act of 2008 (PL 110-325).

For seven years, I assisted students with disabilities (SWD) at a public state university, and more often than not, they came to college with specific educational expectations and motivations. But even as students with disabilities presumably enter college with similar academic goals as other students, Hodges and Keller (1999) asserted the expectations for social acceptance they hold are frequently lower due to previous experiences, thus influencing them toward or away from seeking extra-curricular involvement. A tendency even exists for some students with physical disabilities (SWPD) to gather outside the general student body, thereby operating as a subpopulation and developing their own peer groups (Borthwick, 2002; Hodges & Keller, 1999). Numerous factors likely combine to cause SWPD to detach themselves; partially complicit might be the campus actions SWD perceive to be indicative of broader social attitudes (i.e., blocking ramps or disabled parking spaces, limiting when closed captioning is available in movies theaters, requiring special requests for lift-equipped buses, failing to provide or make known the availability of accessible publications and documents) (Denny & Carson, 1994; Hodges & Keller, 1999).

Ultimately, campuses may have a higher hurdle to clear in prompting students with disabilities to becoming involved because of their previous experiences. As it is, Hodges and Keller (1999) expressed concerns SWD may feel inhibited to engage even when they are equally aware of and interested in involvement opportunities. One such difficulty can be the heavy evening scheduling, typical of most colleges' involvement calendars. Nighttime events can be particularly difficult for students with a variety of disabilities, as they must consider the increased time and effort involved with returning to campus or leaving the dorm, especially if relying on others for transportation or personal

needs; arrange transportation assistance to campus for classes, the return trip to an apartment or dorm, and then to venture out later in the evening; and weigh the potential threat of vulnerability (i.e. personal safety) if traveling alone late at night. These are similar considerations all of us mull over, only exponentially more so for particular students with disabilities because of the environmental and behavioral barriers they can face on top of their impairments alone.

The suggestion by George Denny and Ellen Carson that even when true physical barriers are not present, “social distance or avoidance remains a problem so long as students with disabilities perceive barriers from other students and faculty/staff,” (1994, p. 5) is indicative of a further-reaching dilemma of isolation and a lack of social interaction and involvement for students with disabilities. Though students with disabilities on the island of Cypriot acknowledged to Hadjidakou, Polycarpou, and Hadjilia (2010) their quality peer-to-peer and student-faculty relationships, they were simultaneously cognizant of the insensitivity of their peers and faculty. The perceived tactlessness becomes more curious when viewed alongside findings which suggest SWD believe they form stronger faculty relationships than fellow students but remain substantially unsupported in seeking campus involvement (Hendrick, Dizen, Collins, Evans, & Grayson, 2010; Astin, Trevino, & Wingard, 1991; Junco & Salter, 2004). Further, even acknowledging those relationships, SWD are feeling isolated, ostracized, and devalued—presumably in part because the peers and faculty with whom they initiate relationships are the same people heard making derogatory comments about them (Astin, Trevino, & Wingard, 1991; Hodges & Keller, 1999; Perry & Franklin, 2006). As in the vignette involving David’s experience at his school’s basketball game, students involved

in Astin, Trevino, and Wingard's 1991 study reported few problems obtaining access to buildings and their courses but were able to recount numerous disparaging comments and discriminatory statements from their peers and, at times, their faculty. Their issue is not only accessibility in the legal (Americans with Disabilities Act) sense, but one of true inclusion in a social sense as well.

Perhaps, primary to efforts to encourage greater campus involvement for SWD is addressing the negative perceptions, or *stigma*, regarding these students. As an example, Reynol Junco and Daniel Salter (2004) found women generally held individuals with disabilities in higher standing than their male counterparts. Acknowledging their study was of technology's benefit more than attitudes of disability, their intervention—an online disability training program—gave indications men's attitudinal shift towards acceptance and valuing of SWD was more significant than that of the women in the study. While potentially a result of having more room for growth, the implications may be that a combination of exposure and information are key elements of adjusting the attitudinal barriers students with disabilities encounter.

Problem of Practice

Engagement and Involvement

According to George Kuh, an important consideration in seeking to comprehend the link between students' academic learning and the various activities filling their days and nights is acknowledging *engagement* and *involvement* as critical to college students' academic performance, retention, and matriculation, and in the creation of “a high quality experience” (2009, p. 686). Understanding environments in which we feel valued, accepted, and connected are most conducive to human development (Allen, 1992), our

recognition of how the college impacts the sense of belonging among students and, by association, their potential for academic success, is an imperative. Unfortunately, Kuh (2009) found equal levels of involvement are not occurring for all students. First, across demographics, students reported participation levels much lower than they had anticipated before enrolling in college. Second, at-risk populations (e.g., first generation, low socioeconomic status, minorities) were involved in activities deemed *High Impact*—for example, First Year Seminars, learning communities, service learning, study abroad, and internships—at lower levels than other students (though students with disabilities were not explicitly stated in the at-risk group by Kuh, those working with this population recognize similarities in tales recounted by SWD and the participation of identified at-risk populations). It is disheartening, especially as higher education advocates for SWD the benefit of the whole-student experience, to discover everyone is not gaining the same benefit from opportunities that should be available to them.

My objective to explore the conversations surrounding disability, as they are understood by SWD in higher education, required analysis of their lived experiences, the messages received, and their interpretations of those messages. When David was invited to join his peers at the basketball game, it appears his mobility-impairment was a critical determinant in how he experienced involvement. As a traditionally college-aged student, David has grown up in a world where the Americans with Disabilities Act of 1990 and the 2008 Amendments Act mandate access for people with disabilities. Yet, even in visiting a venue deemed technically compliant his experience was unique from that of his non-disabled friends, as he made the decision to call ahead, self-identify a need for particular seating, and then attend the game. When he finally chose from where to watch

the game, David was separated from the student section and his friends because of his impairment. We can easily connect students' with disabilities awareness of their social isolation with feelings of being ostracized from their peers. One potential meaning these students may perceive from such situations—while presumably not the intent of the institution—is how little value they hold at their campus or among fellow students. A technically compliant campus may not necessarily promote feelings within students with disabilities of integration and acceptance as valued, equal members of the campus community. Their and David's perceptions are increasingly important as we reflect upon our own programs, messages, and behaviors to determine how best to provide an enriching college experience and foster the growth of diverse students, and in this case, specifically students with disabilities.

Access and Inclusion

Disability in higher education is often discussed in terms of *access and inclusion*, especially with regard to university policies and mission statements. However, it may be that disability in higher education, instead, has **two distinct discourses** of *access* and *inclusion*. Often used as the single phrase, access and inclusion, we cannot presume either is dependent or inherent through the other. The first, access, calls upon the legal mandates of laws such as the Americans Disability Act and its subsequent 2008 Amendments Act (ADAAA), which stipulate no *otherwise qualified* person with a disability may be excluded from participation in, or receiving the benefit of, public services—including colleges and universities—based solely on a disability (PL 110-325, 2008). Individuals with disabilities have the right to an education (i.e., we do not have a right to restrict them from receiving an education), entry into environments for the

purpose of participation, and programs presented in such a way as those with disabilities can communicate/be communicated to as necessary. The legal language embedded in codes and policies obligates institutions to provide appropriate accommodation or support meant to ensure such access.

Inclusion, on the other hand, would seem to imply something quite different than one's right to be have access; it indicates the idea of a communal experience, or as Marianne Huger (2011) wrote, inclusion attempts to develop a culture wherein the full participation of diverse students is established through proactive, rather than reactive, decisions, and thus allows them to engage in all aspects of campus life "in a seamless and real-time manner" (p. 5). Further, it "implies that individuals are active members of a work and learning community...that is safe and welcoming" (Kalivoda, 2009, p. 3, 9). Considering David's story, the student was able to access the basketball game because the arena had ramps at the entrances, elevators to upper tiers, and accessible restrooms. The box office assisted patrons with disabilities in choosing among viewing areas set aside for fans with impairments in a variety of price ranges, just as other patrons could determine how much they were willing to spend on tickets and from where they wished to watch the game. Legally, David's college did what was necessary to provide access to the event. At the same time, we might argue the college failed David with regard to inclusion as a student attending his school's basketball game. His use of a wheelchair set him apart from his peers; while they were on one side of the stands he was among either campus administrators or the visitor's crowd. His need to use a restroom required he find the accessible location, and then seek out a second more inconvenient option due to maintenance being conducted during the event. Ultimately, the combination of separation

and inconvenience became too much to bear, and David's decision to leave was not determined by a lack of access but a failure of inclusion.

Problem of Research

Research related to people with disabilities often focuses on legal access issues, the meeting of minimal standards, and/or specifically academic concerns, rather than issues of involvement, adjustment, and establishing a setting that considers their overall college experience. Studies of campus climate often focus on diverse populations, yet the involvement of students with disabilities has not been prominently included among them. Of the studies conducted wherein disabled populations are the primary subjects, few specifically address students with physical impairments and their perceptions of campus or their place within that environment. This study intended to garner a better understanding of the lived experiences of students within higher education who identify with physical impairments. To this end, it was important the inclusion requirements maintained only students with physical impairments be considered as participants, though it was possible students may have co-morbid impairments (e.g., cognitive, psychological, or sensory) along with a physical limitation.

While previous research provided a foundation for considering the degree to which students in general and students with disabilities interact and become involved at college, there were several limitations creating a void in the knowledge base. First, much of the research was done through survey methods (e.g., Kuh, 2001; Miller, 2001; Hendrick, et al., 2010), which primarily establishes a *degree* of student engagement and a numerical indication of perceptions regarding inclusiveness, but does little to help understand why they make their choices for involvement and what prompts students'

feelings regarding the climate. Second, though campus climate has become a well-studied area of the student experience, and while climate research routinely focuses on specific populations of students—such as female; African American; Hispanic; Lesbian, Gay, Bisexual, and Transgender (LGBT); and First-Generation—those with disabilities have not been represented sufficiently as a unique group.

In the recent literature of disability populations, additional limitations exist due to the heavy influence of larger populations with learning and cognitive disabilities. For instance, in Hendrick, et al. (2010), a mere 6% of subjects indicated mobility impairments. Miller's 2001 dissertation similarly shows she found 6.7% of her subjects with physical disabilities compared to 68% who disclosed learning disabilities. When study populations are heavily comprised of students with cognitive disabilities, the findings risk providing an inadequate reflection of the specific nature of interactions had by those with more obvious and potentially impactful impairments. Consequently, while some studies show no discernable variation in the inclusion of students with learning disabilities, and no significant differences between students with learning disabilities and their non-disabled peers in terms of self-concept, practitioners are left with a void in the knowledge of specific categories such as physical disabilities.

Third, the common practice in seeking a population for studying SWD is to utilize the campus office designated for disability services and support (Denny & Carson, 1994; Hodges & Keller, 1999; Miller, 2001). In so doing, participants are only drawn from the population of students who chose to self-identify in order to receive academic accommodation, and they may not be representative of the larger population. Presumably, of the disability categories on campus, those with mobility impairments might be among

the least likely to seek assistance through a disability services office so long as the physical environment of dorms, facilities, and classrooms meets ADAAA guidelines. Finally, even when research has been conducted at larger campuses, again using Miller's (2001) dissertation study at Florida State University as an example, the number of students with physical disabilities can be incredibly small. Therefore, limiting research to an individual campus—as further demonstrated by Denny & Carson (1994), Hodges & Keller (1999), Hadjidakou, et al. (2010), and Hendrick, et al. (2010)—while useful for that particular campus in considering how they meet the needs of their students, produces a small sliver of the experiences and perceptions of the participant group sought. While recognizing qualitative studies are rarely generalizable to a mass audience, it is still important to have significant feedback in order to establish a basis for constructing themes.

Significance of the Study

The study provides greater understanding and some perspective of the language and conversations surrounding disability, as portrayed through the discourse of students with physical disabilities. It gives voice to, and helps make sense of the perceptions shared by, a diverse student body in order to inform campus administrators and individuals seeking to create more inclusive environments—and offer greater opportunities for social engagement—to SWD. Findings highlight that which is done well to form welcoming, affirming campus communities, as well as illuminate negative or questionable attributes identified by SWPD in their understanding of disability within college, further aiding higher education institutions as they consider how to instill a sense of belonging for their students. This sense of belonging at the university links students

positively to their institution, creates a perception of being valued within the community, and can directly impact retention, persistence, and matriculation of students (Tinto, 1975; Schlossberg, Lynch, & Chickering, 1989).

Additionally, in the assumption of multiple discourses of disability operating within the institutions, it is important to recognize students' response to the different discourses. This study did not intend to be an indictment of particular discourses as much as it sought to understand the intertwining of them within the higher education environment. For instance, it may be that students find benefit in certain ways because of the legal or medical discourses but feel those understandings are detrimental at other times. Likewise, a social model proves useful in particular situations and a source of increased difficulty in others. After providing descriptions of the current circumstances for students with physical disabilities in college, however, it does stand to reason I turn a critical eye to how the impact and actions of the discourses allow or restrict the inclusion of SWPD within the campus community.

An important element in university administrators, faculty, and staff's ability to attract, retain, and foster the growth of diverse student populations is their ability to connect students' learning to their involvement and experiences. At this time, research suggests students with disabilities wish to be more involved, yet it has not established what factors encourage or restrict that engagement, or the issues students with physical disabilities are considering as they determine their level of involvement. More than simply pointing out the negative aspects of their experiences, the study highlights the positive factors, be it the individual's own past or the efforts of the campus to creating a

climate of inclusion. Through qualitative interviews, it gives voice to a population who, to large degree, has been held silent.

Conceptual Framework

According to Maxwell (1996), a primary component in any study is the conceptual context (i.e., “the system of concepts, assumptions, expectations, beliefs, and theories that supports and informs your research” (p. 25)). It serves to provide a basis of, and preliminary theories for, what is occurring and its causes. The notion of identity as a conceptual framework is based on the belief that all people have a multitude of identities, or ways of being recognized in particular contexts, which are supported by their roles in society (Gee, 2000). Such identities come to be established through interpretation, and are built upon historical and cultural views of nature; traditions, legacies, and rules in institutions; language, beliefs, values, and symbols (discourse); or the practices of like-minded groups (Gee, 2000). A study of the discourses of disability operating in higher education examines the identity creation of students with physical disabilities through these four distinct views: Natural, Institutional, Discursive, and Affinity. Greater discussion is provided in Chapter Three.

Research Question

This investigation explored what college students with physical disabilities said about how disability is constructed on their campuses. The objective of such inquiry was the betterment of the college experience for students with physical disabilities by revealing ways higher education institutions can better address the needs of a unique student sector. My end goal was to more fully understand students with disabilities’

perspectives, leading toward a critique of, as well as viable alternatives to, current practice. Therefore, the overarching question asked through this research is:

What do college students with physical impairments say about the discourses of disability on campus?

Specifically, participants were asked to reflect on what they:

- perceive to be factors impacting their decisions to engage in campus activities;
- think are key reasons for choosing to participate or not participate in activities;
- sense it means to have an inclusive campus;
- feel their institution does toward creating and encouraging an inclusive campus for students with disabilities;
- believe their non-disabled peers think of them.

Delimitations

Participants in this study were confined to students with physical mobility disabilities who have been enrolled at their college for a minimum of one academic year. The value of the findings rested in their ability to reflect thoughtfully on past experiences at the university. With this in mind, it was determined to speak only with students who have spent enough time at their institution to reasonably speak to their involvement there. The scope of the project was further delimited by considering institutions with residential student housing that were contacted to take part in the research. While nothing guarantees this particular group of students engages in on-campus activities, residential campuses—versus those more enmeshed in urban settings—are sites where students more-wholly work, play, and live. To discuss the perceptions of campuses, and not cities with colleges in them, this distinction was made by the researcher in considering research sites.

Because the purpose of this study was specifically to gain insight from students with physical impairments, those with learning, psychological, or other cognitive disabilities who do not also disclose a physical impairment were excluded from the desired population. Finally, it was an intentional decision not to focus on experiences and perceptions of the disability service offices the students may (or may not) utilize. These offices act as services providers and advocates for students with disabilities, but the intent of the study was to form greater understanding of the holistic experiences of the participants primarily as students of the university, not the provision of disability services.

Limitations

I envisioned various factors limiting the study as it moved forward. Key among potential limitations was gaining access to participants. Disability support professionals serve as the gatekeepers of confidential information and documentation provided by students to verify a need for accommodation. They were necessary allies in the dissemination of study invitations to potential participants. The recruitment process significantly relied on their assistance, and this made it a difficult task to control. There is a question of how large the population of SWPI on the campuses truly is. For the purpose of this project, students were asked to self-identify as having a physical limitation so the numbers on file with disability services may not reflect a true population available for participation. A plan was also made to recruit participants who chose not to disclose to their campuses' disability support offices, though this was a relatively unsuccessful effort. The very issue of my study, that past experiences and preconceptions may lead this population to shy away from involvement opportunities, might have been proven as a

constraint. The ways I established the investigation—from an invitation clearly designed to be inviting, to maintaining inclusive locations and environments within which to conduct interviews—were vital considerations in my research preparation. Additionally, in carrying out the study I encountered scheduling problems, issues with collaborator follow through, and difficulties attracting the number of participants initially sought. These limitations are discussed in greater detail in Chapter Five.

Participants

The sample was drawn from students self-disclosing physical impairments at selected four-year colleges in the United States. An invitation was created and dispersed on the campuses with assistance from school administrators. It described the intended project and asked students feeling they meet the criteria for participation and who would be interested in taking part to contact me. The announcement was to be disseminated through various print and text-based outlets—each with the identical message. School disability services departments agreed to provide assistance by distributing the invitation to all self-identified students with physical impairments registered through their office. However, as not all students with disabilities choose to register with disability services, the same call for participants was to appear through other printed avenues where students are likely to be informed of campus activities and opportunities (e.g., bulletin boards, fliers, news announcements). This was an attempt to represent the population most accurately, and not only students who need the support of a disability services office.

Research Design

My interest in this proposal was the perception students with physical impairments hold in relation to how disability is defined through conversations, customs,

practices, and behaviors present in their higher education communities, more than a true judgment of access or inclusion. Therefore, the paradigm of constructivism, which allows for truths to emerge based on the findings, seemed most appropriate. Constructivism holds that knowledge and truth are not so much discovered, as created by the investigator based on what emerges during research. According to Crotty (1998), our meaning of things develops through the interpretation of what we do and experience. Even our understanding of concrete scientific fact and objects is “developed and transmitted in an essentially social context” (Crotty, 1998, p. 42). Discourse analysis fits well with the constructivist epistemology as both believe one’s perspective and influences create unique meaning for individuals. While those meanings may at times be “true” for multiple people, they are often personalized, though inherently no more or less valid than the meaning generated by another individual. As the researcher I was obligated to analyze the responses received through inquiry and assign value to, and interpret meaning from, what had been expressed, with an expectation of finding the truths situated within those responses.

Invitations to take part in interviews were extended to a purposive group of those registered with Disability Services or self-identifying a physical impairment. Individuals had an opportunity to indicate their willingness to attend and were given options for the dates on which interviews were being held. Participants were asked to engage in a dialogue designed to elicit their impressions of the accessibility and inclusiveness of their campus communities for SWD. Transcripts of the sessions were analyzed, and the emergence of themes sought.

Researcher Bias

As a potential threat to the study's validity, researcher bias must be accounted for in the design (Maxwell, 1996). It is my responsibility to explain potential biases and account for how they might be minimized. Maxwell (1996), in citing personal communication with Fred Hess, indicates "validity in qualitative research is not a result of indifference, but of integrity" (p. 91). Recognizing my own perspective on the subject of this study may better inform readers as to my motivation for the investigation and what I hoped to learn as a result.

I have been intimately involved in supporting college students with disabilities as they seek accommodation, access, and success in the classroom and on campus. However, I fully understand how easy it is to be more or less oblivious to many of the concerns students with disabilities have in trying to integrate with their peers and community, because I lacked experience with disabilities during my own academic career or during my time teaching. Prior to entering the field of post-secondary disability support services I had been a 7-12 English/ Language Arts teacher and later, a graduate assistant operating volunteer tutoring programs for K-8 students in a parochial school district while working on a masters of Education in Special Education—Post Secondary Disabilities. But I had no direct knowledge of the life and intricacies of those with whom I would establish a career. It took students sharing their experiences with me for my awareness of the structural and attitudinal challenges which exist for students with disabilities to develop. Over time, my own recognition began to shift—I noticed how bikes chained to railings, cars parked in a crosswalk with their hazards blinking, and poorly designed signage were more than nuisances. Now, my first thoughts when viewing

buildings and facilities are: “Where is the ramp?,” “Can a wheelchair user get to the bathroom?,” and “Is this area usable for those with impairments?” My colleagues hear me speak of the concerns that may be present in how rooms and programs are set up, and in the best cases, they, too, begin to assess situations based on the concept of *universal design*, or creating settings not specifically for those with disabilities but that accommodate the most people possible without requiring additional adjustments.

Later, I came to question the extent to which messages and values a campus transmits may positively or negatively impact students with disabilities. It seemed the message pushed out to students, faculty, and staff is often about the legal concerns—ADAAA compliance, “mandatory minimum standards,” and “services provided upon request.” Typical oversights such as blocking walkways and ramps or not publicizing how to request accessible seating have the potential to leave a deep impression on individuals as they develop their sense of belonging and determine how to involvement themselves in the campus culture. Further, deliberately negative messages (i.e. derogatory comments by professors or other students toward those with disabilities) may be more damaging than mobility roadblocks. The attitudinal barriers created when we subtly mock others’ impairments—their speech, movement, and appearance—devalue people’s role within the campus community, ostracize those who don’t easily fit within our norm, and build an environment that defines itself as uninviting, unaccepting, and unwelcoming.

I believe that feeling valued by your community is one integral component of college student success. For those with disabilities, I do not think it comes just through accommodation and legal compliance. As the academe moves toward inclusiveness of diverse populations, it is imperative Academic Affairs, Student Affairs, facilities,

technology services, and the student population recognize how SWD find a home within their community—their peers, faculty and staff, and campus—and learn from it. My opinion in taking on this type of work is that it is not a *disability* issue to be dealt with by disability services offices, but a diversity concern that the entire campus is responsible for addressing. By identifying discourses within the campus communities that encourage and discourage meaningful academic and social involvement, institutions may more proactively devise conditions under which a greater population of their students may achieve success within their schools.

In identifying as someone who advocates the increased opportunities for involvement and engagement of students with disabilities I provide room for criticism by reviewers who may presume the work is presented so as to advance an agenda. An explanation of how I sought to avoid imposing bias and therefore maintain the validity of this investigation is included within the research design, presented in Chapter Three.

Key Terms

Key terms, and an expansion of common words which hold further meaning within the higher education, student affairs, and disability studies community are defined in this section. Though a number of the words identified have generally understood meanings, some readers may find it useful to consider alternative definitions employed within the particular fields as they read the following study.

Chilly climate. Beilke and Yssel (1999) attribute the term *chilly climate* to Hall and Sadler (1982). It reflects a setting that can be considered unwelcome for a particular population. Three categories of behavior were identified as being responsible for causing the chill: devaluation, evaluation, and doubt. The original article, “The classroom

climate: A chilly one for women?,” was published by the Association of American Colleges, through sponsorship by the Fund for the Improvement of Postsecondary Education, Washington, DC.

Disability. WHO determined disability as “any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being” (Johnstone, 2001, p. 10); the Americans with Disabilities Act (ADA) indicates it as a physical or mental impairment that substantially limits one or more major life activities.

Engagement. George Kuh identified engagement as “the time and effort students devote to activities that are empirically linked to desired outcomes of college and what institutions do to induce students to participate in these activities” (2009, p. 683). In her foreword to Harper and Quaye (2009), Estela Mara Bensimon indicates productive engagement as “an important means by which students develop feelings about their peers, professors, and institutions that give them a sense of connectedness, affiliation, and belonging, while offering rich opportunities for learning and development” (p. xxiii).

Impairment. The World Health Association (WHO) considers impairment “any loss or abnormality of psychological, physiological or anatomical structure or function” (Johnstone, 2001, p. 10). Yet, other descriptions of it might prove more worthwhile in understanding how impairment may impact an individual. For instance, Evans and Herriott (2009) further express impairment also as “a weakness or quality of reduced effectiveness,” and more importantly, “any condition that results in a way of functioning or results in behavior that differs from the expected level of performance in any given area” (p. 29).

Impairment, Disability, or Handicap? Distinctions in the terminology can be a challenge to those outside the field of disability. For my purposes, impairment is established as the physical quality causing an individual to function in the way they do. Disability can be understood as the way in which impairment causes restrictions to the person's life. Finally, handicap is best recognized as "a disadvantage resulting from an impairment or disability that restricts or prevents the carrying out of a role that is considered normal for that individual, depending upon other factors such as age, gender, social status, and culture" (Evans & Herriot, 2009, p. 29). Evans and Herriot actually delineate the differences even more simply: impairment is the "lived, bodily experience of an individual," disability is "the way in which the impairment is perceived by the larger society," and handicap indicates the "way in which the person with a disability interacts with the environment" (2009, p. 29).

Involvement. According to Alexander Astin (1999), involvement is the "amount of physical and psychological energy that the student devotes to the academic experience" (p. 518).

Physical impairment/disability. ADA articulated physical disability as a "physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary (reproductive organs or urinary system), hemic (blood) and lymphatic, skin, and endocrine." Definitions of physical impairment or disability are often utilized in making determinations for disability verification; therefore, a standard generally must be met showing the impairment impacts day-to-day activities and major life activities.

However, for the purposes of this study, individuals will be self-determining their inclusion in the category of physical impairment and will not be asked to reach the ADAAA's threshold for consideration as protected under the law.

Stigma. Stigma equates to “an extreme form of labeling...usually identified with a variety of socially inferior attributes, that, in their turn are assumed to be associated with a group or an individual. The term concerns deviance from a supposed norm and tends to be ascribed as a permanent attribute” and “buttresses and maintains a status quo in a system where one stratum of society can continue to oppress another” (Johnstone, 2001, p. 8).

Additionally, acronyms throughout will be used indicating:

- persons with disabilities or impairments (PWD/PWI),
- people with physical disabilities or impairments (PWPD/PWPI),
- students with disabilities or impairments (SWD/SWI), and
- students with physical disabilities or impairments (SWPD/SWPI).

It is worth noting that a particular point I attempt to make throughout this work is how language is important, and the choices we make in determining what words to use carry value. At the same time, I have the burden of employing the language as it is commonly understood in order to most clearly communicate my purposes. Therefore, though I might have preference for “impairment”, situations may dictate I instead write “disability.” This is a struggle I balanced in trying to articulate my own value system while maintaining clarity for the reader.

Summary

Knowing individuals develop best in environments where they believe they are valued and accepted, it is imperative we recognize how campuses impact not just students' sense of belonging, but by association their academic success. These perceptions become increasingly important when determining how to foster the growth of diverse students such as those with disabilities. While legislation has led to requirements for greater physical accessibility, concern as to whether the campus' extracurricular and social environments are equally inclusive, both in general compliance and in being seen as inclusive, now becomes a prominent issue.

This study gives voice to a population not previously heard, helps highlight what has been done well to form welcoming, inclusive campus communities, and may assist colleges as they seek to instill a sense of belonging in their students. Knowing the reasons why students feel positively linked to their institution, or for that matter why they may not feel connected, can only serve those making campus and programming decisions on college campuses.

CHAPTER TWO

REVIEW OF THE LITERATURE

The purpose of this chapter is to establish a literature foundation for studying what college students with physical impairments say about the discourses of disability on their campuses. The review is organized with three main intentions. First, it discusses literature used to establish what has been previously called a *chilly climate* for students with disabilities. Research discussing perceptions and reactions to disability on campus utilizes individuals with impairments, as well as non-disabled students, to set a backdrop for studying the constructed disability discourses within higher education settings. Second, it reviews literature related to the involvement of college students with physical disabilities, and discusses some general themes found throughout the studies, the methodologies employed in researching the particular population, the authors' main ideas and findings, and my own conjecture on what is influencing the previous work. Third, the chapter gives a broad review of how disability has been constructed in higher education as well as the idea of how disability has been rendered by a range of disciplinary vantage points. In so doing, an understanding of physical disability from the Disability Studies (DS) perspective, specifically an iteration of the social model and Theory of Complex Embodiment, is established in order to ground the dissertation study proposed.

A Chilly Climate for Students with Disabilities

In 1999, Beilke and Yssel published *The Chilly Climate for Students with Disabilities in Higher Education*, a study in which they investigated students' with disabilities perceptions of faculty attitudes and campus climate at their institutions. Through heavily structured interviews with 10 students registered for disability services

at the university wherein the study took place, they came to the conclusion students with disabilities were analogous to a minority group, and their issues of access had further reaching implications with regard to students' right to opportunity. A prominent opinion students held of their faculty was their being dismissive and annoyed by students with disabilities. Their behavior was judged contradictory to any stated willingness to accommodate or support students with disabilities. Faculty appeared "cool," or unreceptive, to stated needs, instilling students with feelings they were being blamed for requiring assistance. Additionally, participants acknowledged instructors who had singled them out during class and the additional stress burdening them because of the extra responsibility they had been led to believe was placed upon faculty.

Participants stated faculty of whom they spoke "were exemplary in part due to the egregious behavior of other faculty" (Beilke and Yssel, 1999, p. 365). By and large students trusted faculty would provide what was required, though it did not seem to translate to them developing a sense of a welcoming environment. The authors suggest a possible disconnect between faculty objectives and institutional missions—the former with a focus on their subject and scholarship without regard for, or an interest in, the broader university aims—and did not anticipate a change to that asynchronous relationship soon. The number of students with disabilities enrolling in higher education continues to increase but so too does the frequency with which academics must implement accommodations. Too often, it is believed support comes at the detriment of academic rigor and accountability, and Beilke and Yssel leave reviewers with an acknowledgement that "until faculty can be assured that opportunity does not come at the

expense of academic integrity, it is likely that students with disabilities will continue to encounter chilly classrooms in higher education” (1999, p. 369-370).

The chilly climate sensed by students with disabilities is reflected in Denny and Carson (1994) who undertook a study of similar focus five years earlier than Beilke and Yssel, though through survey methods rather than interviews. Forty-one, out of the 192 students with disabilities registered for disability support services at the University of Arkansas, returned a completed instrument to gather perceptions of how faculty, staff, and students view them. Similar to Beilke and Yssel (1994), the findings may not all be seen as negative. For instance, 100% of respondents believed they were a person of worth, and a majority felt the response received when peers learned of their disabilities was either supportive or such that it didn't matter (28% and 58%, respectively), and 54% indicated their peers viewed them as equally capable to other students. At the same time, negatives were identified as well—15% of subjects felt rejected upon disclosing their impairments to other students and 19% believed they were regarded as less capable than others because of their disability. Perhaps their finding that the greatest misconception working to aid the sense of otherness is the nearly half of respondents who think peers assume all students with disabilities have learning problems. This is particularly relevant, as academics were seen as the greatest obstacle, with physical environments and the social/psychological engagement following in that order.

Given the opportunity to suggest ways their institution might assist in increasing acceptance of students with disabilities, one belief was if faculty were better in accommodating students, it would lead to improved acceptance by peers. Respondents also felt more opportunities to engage in equal relationships, such as learning

experiences, would be beneficial. Concrete examples for improving the campus centered on themes of improved physical environments and efforts of continued disability education, though more telling may be the suggestions for greater open-mindedness, friendliness, and cooperation—concepts suggesting clues as to the culture students with disabilities encounter throughout their higher education experiences. Subjects also recognized the role of disability in their lives: as a continuing challenge (27%); a fact of life (17%); an inconvenience or frustration (15%); and as an opportunity (7%) or source of strength (5%). What they resoundingly understood was how, while looking to the university to create a culture and climate of acceptance and valuation of individuals, it has absolutely no business facilitating social contacts for students. Elaboration on students' feelings is not present but many possibilities exist, whether it might be seen as pandering, the minimization of their equal personhood, or simply outside the realm of the college's responsibility. Students completing the survey overwhelmingly rejected the idea of institutional involvement in this regard.

Insomuch as the studies of Beilke and Yssel (1999) and Denny and Carson (1994) have been assistive in establishing perceived climates and faculty attitudes in the United States, Holloway (2010) helps make the case that the previously detailed experiences of students with disabilities is not exclusively a problem within our borders. Her study from the United Kingdom sought an in-depth exploration of the higher education experiences of six students with disabilities. In many ways, participants mirrored the responses from other studies, and at the same time, specifically went on to justify a key area of concern for additional lines of study.

Most compelling in Holloway's findings is the difficulty students with disabilities felt seeking access to even basic academic support services, and the elevated stress and anxiety sensed as a result. Participants perceived a wide range of faculty attitudes, from "highly supportive and aware" to "cynical, unhelpful, and non-consultative in decision-making" (Holloway, 2010, p. 605). Students acknowledged support was ultimately available and provided, either by the faculty or through an informal, unofficial network (e.g., professionals within a given department able to work around the system on the student's behalf). The interviews highlighted positive experiences shared by interviewees. Participants indicated such things as access, advising, test accommodations, learning supports, and knowledgeable staff willing to help with adaptations to be adequate. Yet the important point was how experiences such as those shared provide a context for students with disabilities as they come to develop impressions of a campus climate and their place within it.

Students were burdened by increased stress and worry. They shared the difficulties faced with time requirements to complete tasks, their feelings of uncertainty, frustration, and financial burden inherent in being students with disabilities. Holloway (2010) articulates the basic problem of higher education's interaction with students with disabilities: "...the moral intent is to provide equality of opportunity. However, much of the students' experience fell far short of this" (p. 606). Students with disabilities sensed the lack of true systems of service, lack of consistency and continuity of support, and an overall lack of a clear message of inclusivity. It was not just that the difficulties faced were burdensome; it was the implication of those encumbrances, that "in spite of the

appearance of inclusiveness implied by admission (to the institution), students experienced marginalization and disempowerment” (Holloway, 2010, p. 612).

Holloway’s 2010 study, though primarily addressing academic concerns, has implications which can be used in examining how campuses serve students with disabilities in other, non-academic, pursuits. She calls on institutions to establish clear and efficient systems across departments and programs which would benefit a variety of students. Similarly, it is suggested rather than only thinking of inclusion through the lens of a medical model, we would be better served to consider the needs of students with disabilities on a continuum of the (learning) needs of all students.

Criticism, Limitations, and Short-comings

Beilke and Yssel (1999), Denny and Carson (1994), and Holloway (2010) were single-site studies, and as a result represent investigations of individual universities more than a shared experience of students with disabilities in the broader community. The outcome of said research, in my opinion, is primarily useful in two ways. First, as single studies each is assistive to campus administrators and those working toward more inclusive climates at that particular site because it informs them about how students in that university perceive the faculty, their peers, and the setting. For instance, the Dean of Students and/or Academic Dean at the University of Arkansas might utilize Denny and Carson (1994) to inform efforts to improve experiences for students with disabilities. In light of the findings it leads the campus to reconsider the transportation and pedestrian systems, and perhaps discuss development of a comprehensive assessment effort aimed at addressing views held by the campus community toward students with disabilities (as well as diverse populations as a whole). Second, the research can be grouped together and

interpreted as if each site is itself a participant in a larger study. That is, I can consider how each of the institutions has built a climate which leads its students to develop certain perceptions. Then, through an analysis I would be questioning the commonalities in each case or at each institution.

On first glance, it appears as if two studies, Beilke and Yssel (1999) and Denny and Carson (1994) are relatively outdated while Holloway's research is more current. But that is misleading; in the final notes Holloway indicates the study occurred 13 years prior to publication, situating the work in approximately 1997, firmly between the other studies. Conjecture leads me to believe the interest existed in the mid to late 1990s as a result of newly established laws in the U.S. and UK, The Americans with Disabilities Act of 1990 (ADA) and the Disability Discrimination Act of 1995 (DDA), respectively. ADA and DDA emphasize the responsibilities of higher education institutions to meet the access needs of individuals with disabilities, though to different degrees. Regardless, in the wake of that legislation it may have been that some researchers believed ideas of access were only a single element in meeting the needs for this population.

These studies, while helping advocates and practitioners gain a bit of understanding about students with disabilities' perceptions of individual around them, were primarily useful for me in how they highlight what is still not known. They share a similar limitation in that research participants come with a wide spectrum of disclosed impairments, making it difficult to determine particular experiences of any subpopulation, such as those with physical impairments. For instance, Beilke and Yssel (1999) identified six individuals—three with neurologic/cognitive impairments and three with physical impairments—yet do not discuss sufficiently the findings in detail or as

consolidated themes for students with physical (or cognitive) impairments. Instead, a paragraph is devoted to each of the six students, beginning with a demographic description of the student followed by just a key item or quotation taken from the heavily structured interview.

In the same way, Denny and Carson (1994) is representative of much disability research; the population is heavily weighted by participants with learning disabilities and the discussion does not recognize variation in subjects' impairments. I acknowledge there are undoubtedly shared experiences of students with disabilities, but without parsing the intricacies of subgroups, or at the least distinguishing between some variables (e.g., hidden vs. visible, cognitive vs. physical/sensory impairments) one may come away with an assumption what is true for one type of individual with impairment is applicable for all persons with impairments. Of course similar criticism is valid even within a study of students with physical impairments (there are, after all, many ways one can be impaired and how that impairment operates in one's life), but as the researcher I sought and discussed findings speaking to the broader discourse of disability as it exists for the individuals and on whole, rather than reporting on participants individually.

Non-disabled Student Attitudes Toward SWD

Though we still question what specific factors influence attitudes of able-bodied (sometimes called physically well, "average", or "normal") college students toward their peers with disabilities, prior research suggests that a perception of disability may impact attitudes of some students regarding relationships between themselves and others with impairments. Meyer, Gouvier, Duke, and Advokat (2001) explored changes in the attitudes of able-bodied students as a result of the social context in which they encounter

people with impairments by creating an experimental condition wherein students were organized into groups and specifically situated while completing the Attitudes Towards Disabled People Scale (ATDP-O) and a Likert general measure of ease scale. Thirty undergraduate students at Louisiana State University (n=30), ten of whom had a disability necessitating use of a wheelchair, were separated into three groups based on *disability* or *non-disability* status. One of two “confederates,” one in a wheelchair, were embedded in the clusters as they sat in the following combinations: confederate with no disability and non-disabled participants (ND/ND), confederate with disability and non-disabled participants (D/ND), and confederate with disability and participants with disabilities (D/D).

They predicted non-disabled participants would exhibit higher levels of discomfort when in proximity to the individual believed to have a disability, though results contradicted their hypothesis. In fact, group D/ND showed more favorable attitudes of disability than group ND/ND, leading investigators to consider how proximity to individuals with disabilities may be beneficial to improving attitudes, rather than a source of increased discomfort. Of particular interest were findings related to D/D that led the investigators to suggest people with disabilities may also exhibit a level of discomfort around other individuals with disabilities. The authors do not draw particular conclusions as to why this may occur, though they question whether it stems from a lack of prior experience interacting with other individuals with impairments or the degree to which some people are comfortable with their own disability identity.

Unfortunately, the findings in Meyer et al. (2001) are speculative, mainly because of the study population. Sample size (n=30) and locale (single site) were not sufficient to

draw conclusions, and while the researchers consider proximity to peers with disabilities beneficial to increasing one's comfort in such situations, they offer the possibility of false responses in order to appear more tolerant, and acknowledged almost all items can be faked.

Upton and Harper (2002) sought to address the attitudes of non-disabled students toward educational accommodations and their perceptions of a particular set of accommodations for a determined group of disabilities. A sample of undergraduate and graduate students without disabilities (n= 852) at a large Midwestern university completed a demographic survey and the Scale of Attitudes Toward Disabled Persons (SADP Form R). Specifically, Upton and Harper were interested in determining the general attitudes of their subjects toward academic accommodations and the deservedness of students with specific disabilities to receive accommodation.

A key finding for university professionals may be that the sample's year in school had a significant impact on their attitudes with respect to disability. Graduate students indicated a view of people with disabilities most favorable among respondents. Those at the junior and senior level were also found to hold individuals with disabilities in higher standing than sophomores. Further, college year seemed connected to the students' evaluation of *equitable accommodation*, though it showed no impact on general attitudes of accommodation in the broader sense. Again, graduate students responded most positively, followed by juniors/seniors and freshmen/sophomores. An assessment of *accommodation deservedness* concluded that from a predetermined group of disability categories, students with visual impairments, cerebral palsy, brain injuries, and hearing impairments were considered most deserving of academic accommodation, while the

least deserving were those with spinal cord injuries, manic depression, depression, and spina bifida. Coinciding with those results was the conclusion that the same group, seen as most deserving of accommodation, was also more deserving of a greater number of accommodations.

Upton and Harper (2002) conclude females consistently hold a more positive opinion than men in their attitudes of persons with disabilities. Yet one must be cognizant of limitations in the study. The sample was comprised primarily of Caucasian, female subjects who volunteered as a result of faculty soliciting participants during class, which impacted the generalizability of the findings. Limited information as to the exposure of respondents to people with disabilities offers little additional support, but generates questions and areas for further study. Again, as with the previously discussed study, it is difficult to assess the sample's truthfulness. There is the potential that subjects gave socially acceptable responses, lest they be seen by others, or admit to themselves, a bias against disabled populations. Though they are without a method by which to verify the truthfulness of results, investigators used an instrument that had been applied across a variety of settings to various populations and had proven to be a reliable measure. Therefore, equipped with what is known from the study, one can make conclusions and then consider methods by which to gain greater depth and breadth of information to extend our understanding even further in future studies.

Though Upton and Harper (2002) studied accommodations and related perceptions within academic settings, the implications might extend into the social realm of higher education, to consider how non-disabled students perceive students with disabilities and their need for additional provisions or effort to gain access to programs or

opportunities for engagement. Students seemingly develop greater awareness and heightened attitudes of peers with impairments over the course of their years in higher education. Knowing the factors leading to this change could provide considerable benefit when seeking increased accessibility and inclusiveness on campuses.

Hergenrather and Rhodes (2007) investigated whether students felt differently regarding students with disabilities based on the context of their potential interaction. Researchers administered an adapted version of the Disability Social Relationship Scale, removing the four specifically identified categories of impairment in favor of a tool to assess the more general classification of disability, to undergraduate students at a large southern university (n=1031). The new instrument, the Disability Social Relations Generalized Disability Scale (DSRGD), was an anonymous paper and pencil measurement of individuals' attitudes regarding students with disabilities within the social arenas of Work, Dating, and Marriage. Researchers sought to quantify differences in attitudes within each social context and discover potential variables impacting changes across setting or participants.

Hergenrather and Rhodes (2007) hypothesized attitudes are multidimensional and vary by the context of the relationship and by the participants' gender. They found each hypothesis offered held true, with varying degrees of articulation and association. Significant differences existed in attitudes concerning people with disabilities with regard to dating, marriage, and work—variations aligning to conclusions drawn in prior studies and confirmed within the context of their sample. Work settings offered the most positive attitudes toward PWD, followed by marriage, and finally, dating. Also as Upton and Harper (2002), and Hergenrather and Rhodes' own prior research suggested, women

possessed more positive attitudes of individuals with disabilities than male counterparts. Yet, despite the differences across contexts and between genders, they asserted their findings suggest an overall positive attitude with respect to PWD, which within the context of the statistical information presented in this particular study, is valid.

The authors identified some relevant limitations, such as a homogeneous study population comprised primarily of white females located in commonly utilized settings during times determined to be the norm. The findings, then, lack generalizability—something researchers self-identify as a concern. Second, students may express a higher ideal than they truly hold, *faking good* as Hergenrather and Rhodes (2007) called it. Third, because disability was simply one large group, we are left knowing little about the intricacies of attitudes about actual people with disabilities. One's feeling of a peer who uses a wheelchair potentially varies substantially from another with a hearing impairment, learning disability, psychiatric disorder, HIV/AIDS, etc. Fourth, the measure only asked participants to indicate their current or past interactions with people with disabilities as one of two options, yes/no. The significant information lacking, and of benefit moving forward, is the degree to which subjects interact, how often, and in what contexts. As recognized by the authors, if staying in the realm of a quantitative study, a Likert scale providing varying levels of engagement would help establish a better indication of differences in the participants as give context as their responses are interpreted. The bigger limitation of their study was that by creating a disability scale without categories, the constructors left it to those participating to generate their own inferences as to what *disability* entailed. Knowing how participants define it in the study would be a compelling investigation.

Rojahn, Komelasky, and Man (2008) replicated a study previously undertaken by Man, Rojahn, Chrosniak, and Sanford (2006) who found disability did not reduce the stated romantic attractiveness of opposite sex peers, as per the Romantic Attraction Scale (RAS), a tool comprised of 16 black and white pictures with accompanying vignettes of male and female individuals with and without disabilities. Though the 2006 study seemed to provide clear results, Rojahn and colleagues had a feeling the results were not accurate, and sought an opportunity to validate or challenge the findings. Their 2008 investigation again used the RAS but paired it with a second instrument, the Implicit Association Test (IAT), an online measurement designed to address participants' implicitly held attitudes and perceptions of groups of people. By pairing the RAS and IAT, Rojahn et al. (2008) wished to determine whether reported attitudes toward a particular set of people were consistent with an embedded evaluation of the physically-well versus individuals with disability. Further, researchers wanted to determine if females held more favorable attitudes about entering relationships with people with disabilities than similar males and whether significant differences exist in responses generated by students who report family members with disabilities versus those without impairments in the family.

Results from their population of undergraduate students (n=41), ranging in age from 17 to 23 years old (mean of 27.3), indicated no difference in favorability as a result of gender. However, subjects with a disabled family member rated persons with disabilities as more attractive than the non-disabled photos and vignettes when completing the RAS, yet showed an overall preference for the physically-well when measured by IAT. Researchers concluded the explicit attitudes (RAS) may have been a result of participants feeling pressure to respond in a socially acceptable way. Thus, in

order to seem appropriately accepting, subjects may overstate their positive attitudes. The findings of the IAT, then, provide a more accurate portrayal of their implicitly held attitudes. While the conclusions drawn by Rojahn et al. (2008) were speculative, utilizing both the RAS and IAT within one study provided evidence for their suggestion the explicit and implicit attitudes students hold about people with disabilities may significantly differ. This leaves us to inquire about where and under what conditions people with disabilities believe opportunities for personal, and potentially romantic, relationships exist.

Miller, Chen, Glover-Graf, and Kranz (2009) created the Relationships and Disability Survey (RAD) to examine the willingness of non-disabled people to engage in personal relationships with persons with disabilities and to answer questions as to whether the willingness of non-disabled students to engage in relationships is impacted by the type of relationship, category of disability, or severity of disability. They also queried if there was an interaction between these three variables and the readiness of subjects to create relationships with peers with impairments. Along with a 12-item demographic survey, the RAD contained a 24-item Likert scale with possible scores ranging from 1 (very unwilling) to 6 (very willing), and a checklist of characteristics from which to select those which might make the participant most likely to extend beyond disability status in determining whether to form relationships. An additional tool, the Marlowe-Crowne Social Disability Scale Short Form-C, was completed to assess whether the responses were the product of self-deception or another forms of deceit, possibly to avoid being judged harshly for how they answered the assessment. Undertaken at a predominantly Hispanic serving public university in the southwestern

U.S., the study was similar to many others reviewed, in that the sample (n= 305) was heavily comprised of female students (83%), though was dissimilar to a majority of the literature in that 90.5% of respondents identified as Hispanic.

Results of the RAD indicated variation in participants' willingness to enter relationships with disabled peers. Friendships were deemed most agreeable, followed by closer acquaintances, marriage/partnerships, and finally dating situations, though all scores appeared relatively positive, ranging from somewhat to very willing to engage in relationships. Miller et al. (2009) found as the severity of the impairment heightened, the initial openness to build relationships decreased. Particularly, students appeared more willing to engage with students presenting physical, sensory, and health conditions, and were considerably more hesitant to enter into relations when people had psychological disabilities. Overall, participants' willingness to engage with people with physical impairments was second only to sensory-impaired individuals, followed by those with cognitive limitations.

Severity of the impairment also proved significant, as the sample seemed most willing to begin a relationship when a mild disability was present and less open as the condition's severity increased. Subjects were most willing to create friendships with peers who had mild health impairments and least likely to consider marriage to someone with a psychological condition. Little distinction was found in the scores for interaction of relationship and category or severity of disability in regard to being friends or acquaintances with peers with sensory, health, and physical impairments, but showed small discrepancies when cognitive or psychological disabilities were introduced. As the degree of the relationship became more romantically focused (dating and marriage) a

considerable difference emerged, especially for psychologically and cognitively impaired individuals. When the severity of the disability elevated, the response differences also increased; variation was smallest for entering into friendships and was greatest for dating and marriage.

Based on these results, we might conclude people are willing to generate friendships and acquaintances when opportunities exist to engage people with disabilities (even severe impairments) but are essentially unwilling to consider the prospect of dating or marrying the same individuals. However, certain personal attributes were impactful in changing the willingness of non-disabled parties to consider relationships with impaired parties (Miller et al., 2009). The top three characteristics—intelligence, kindness, and humor—are indications people were more agreeable to looking past their initial perceptions of an impairment when a person is intellectually stimulating, provides an impression that they are important and cared for, and has a good sense of humor.

Social Involvement and Physical Disability in Higher Education

Establishing a clearer understanding of the specific experiences, opportunities, and trials for students with physical impairments presented a challenge of its own. A dearth of published literature pushed me to utilize the pool available which is primarily in the form of doctoral dissertations. Rather than continually drawing the reader's attention to that point and away from the context in which information contained therein assists in driving my argument for the proposed study, I choose to identify upfront the following unpublished doctoral dissertation studies: Alling (1999), Borthwick (2002), Hodges (1997), Hurst (2006), Leatherman-Sommers (1999), and Kane (2009). In some respects the heavy reliance on unpublished work proves encouraging as it suggests an

investigative avenue full of opportunity. To the best of my knowledge these studies—having occurred between 1997 and present—represented the current research of college students with physical impairments and their social involvement within the landscape of higher education. I believe, in viewing the body of literature en masse, one can interpret a renewed interest in studying the access and involvement for students with disabilities.

Students with physical disabilities have acknowledged an interest in, and perceived benefit from, the opportunity to become socially engaged and to build relationships with their non-disabled peers at college (Kane, 2009; Hurst, 2006; Borthwick, 2002). In this way, they are more like their peers than different. Undergraduate SWPD in the research of Hodges and Keller (1999) reported similar factors in decision-making related to involvement as are generally associated with other students. At the same time they also appeared to be influenced by concerns such as the perceived acceptance of peers and whether there were potential opportunities for them, as students with disability, within traditional extracurricular activities. SWPD acknowledged being aware of opportunities, but awareness was not enough to influence the decision alone, as they overwhelmingly expressed a hesitation to engage.

A Lose-Lose Situation: The Impact of Past Experiences on Future Inclusion

The prior life experiences of students with physical disabilities can have a bearing on their future interaction and engagement in college, with various factors weighing on them when considering whether to seek involvement. Hodges and Keller's (1999) participants with early onset impairments—those present or which occur prior to high school—exhibited lowered expectations for becoming socially engaged because past encounters informed them opportunities for inclusion were not theirs. At the same time,

students with late onset impairment—occurrence post-high school—were in no better position, anticipating negative feedback from peers. Due to their limited experiences as individuals with impairments, those with late onset impairments were hesitant to approach new situations for fear of the unfamiliar challenges they may encounter as they continue to develop an understanding of their post-injury or impairment selves.

Apprehension and conflicted feelings of whether to interact with non-disabled peers as a result of past experiences was further evidenced in a Canadian study undertaken by Borthwick (2002). In research to measure the self-esteem differences between university-age persons with and without physical disabilities attending post-secondary schools and those not enrolled, participants with physical impairments recounted elementary and high school situations in which they were treated differently or ostracized. Peers taunted and teased them; at other times school officials were the problem, which proved limiting in a variety of ways. Teachers acted as if the physical impairments were accompanied by cognitive difficulties, restricting students with physical disabilities' opportunity for inclusion with their peers. They felt faculty and staff were poorly prepared or lacked knowledge to assist in providing support for students with disabilities, and as a result individuals and their families were left to sort out for themselves assistance required for access to academics and extracurricular activities. Opportunities for inclusion inside and outside the school environment were denied; if rooms or buildings were inaccessible, SWPD stated they were sometimes left elsewhere while the majority went about their activities. When appropriate transportation was not available they found themselves staying at school while other students took field trips.

Lived experiences such as those described in both Hodges and Keller (1999) and Borthwick (2002) cannot help but to create a sense of outsider status for SWPD. Upon arriving at higher education institutions, despite legal compliance mandates, those feelings come with them. Then, individuals discover physical barriers may still exist, and even though not necessarily rising to levels of noncompliance, they can impact SWPD inclusion. Kane (2009) identified obstructions such as blocked ramps, poorly maintained pedestrian walkways, and ADA-compliant but difficult entrances (i.e., malfunctioning mechanisms or obstructed entryways) contribute to feelings of otherness, further inhibiting SWPD as they make decisions regarding involvement.

Contributing Factors of Disablement

Other factors not wholly dependent on, but at times related to the physical environment motivate SWPD in decision-making. Studies indicate aspects of having a disability, though not the disability itself, hold students back. Time constraints associated with maneuvering and transitioning around campus can be particularly restrictive, leading some SWPD away from engagement (Borthwick, 2002; Kane, 2009). For instance, with only minimal time between classes, rather than join peers in campus dining facilities and then attempt to get back in time for their next class, SWPD might opt out of such opportunities to interact socially with classmates to ensure they are not late getting to their next course.

Additionally, a key stressor for some SWPD has been establishing reliable and convenient transportation to and from campus and activities (Hodges & Keller, 1999; Borthwick, 2002; Hurst, 2006; Kane, 2009). Many participants in the previously identified studies lived off-campus, and depending on their transportation arrangements,

it may have been not only inconvenient but also restrictive to spend the day on campus for classes, leave, and return in the evening or on non-class days to attend extracurricular programming or social opportunities (Hodges & Keller, 1999). One can imagine a financial impetus to not make multiple trips to and from home, but for students with physical impairments, barriers are also created by the additional time and effort involved with transportation to and navigating within the higher education setting, thus inhibiting what might be considered the college experience (Kane, 2009). Further, depending on the severity of impairment, some individuals with more involved impairments sense barriers to extracurricular opportunities because of their need for attendant support (Hodges & Keller, 1999). In that regard, SWPD are limited due to availability of their assistance, while the mere presence of personal attendants draws attention to the difference and needs of SWPD, further creating a distinction of otherness from their peers.

Hurst (2006) indicated similar findings when questioning the differences between students with and without physical disabilities in their perceived support, coping and self-efficacy, and college adjustment. Utilizing a mixed method design combining a series of questionnaires with interviews, the researcher sought to identify potential differences between SWPD, SWPD in intercollegiate athletics, and students without disabilities. Hurst drew the conclusion that restrictions SWPD often encountered were disability-related but not specifically due to the impairment itself. Instead, participants lacked appropriate support and internal characteristics which aided their coping and feelings of an ability to perform satisfactorily (Hurst, 2006). In place of positive traits, students with disabilities acknowledged feeling burdened by high stress caused by limitations encountered as a result of their impairments.

Based on scores from the *Coping Inventory for Stressful Situations*, SWPD engaged in intercollegiate athletics more often indicated characteristics aiding their management of stress, while the other groups of students frequently embodied attributes considered to add to their stress (Hurst, 2006). Involvement in athletics proved beneficial in various aspects of college life--broadening SWPD social experiences, building their positive social skills and increasing self-confidence, creating feelings of accomplishment as they grew to recognize their various abilities and potential, and generally helping them connect interpersonally to other students and athletes with whom they had come into contact. Additionally, findings from the interviews hosted by Hurst suggested the group involved in athletics perceived fewer adjustment issues during their freshmen year, compared to students with and without disabilities not in athletics who indicated they had found it difficult to establish social connections on campus.

Difficulty Establishing Peer Relationships

Studies by Leatherman-Sommers (1999) and Kane (2009) revealed SWPD perceived difficulties forging connections to peers. Employing the *Inventory of Parent and Peer Attachment* and *Student Adjustment to College Questionnaire*, Leatherman-Sommers investigated the attachment of students with physical disabilities to their parents and peers. She suggested SWPD have significant disadvantages in establishing peer relationships, compared to their able-bodied classmates. One consideration based on the findings was that in order to maintain strong bonds, parents of SWPD over-compensate so the disability did not negatively impact the relationship. Friendships with fellow students, however, may have suffered due to the stereotypical ideas and preconceptions they *and* students with disabilities brought to the situation. As a result, the

relationships between SWPD and non-disabled peers are potentially bonds with significantly lower attachment compared to their peers' relations to one another.

Through a series of three in-depth interviews with eight participants, Kane (2009) examined the impact physical disability has on the college experience of students and established how barriers at the institution were impacting the college experience for the SWPD. As in other research, physical accessibility continued to influence involvement. Subjects detailed how they struggled in efforts to utilize university “buildings, bathrooms, the bookstore and other campus shops, dining halls, dormitories, and classroom” and experienced difficulty due to signage which did not serve them effectively (Kane, 2009, p. 39-40). In assessing the quality experience of SWPD, it was telling that though Kane’s participants shared generally positive interactions with both faculty and students, they still felt distant from their peers without disabilities. They believed non-disabled classmates had difficulty knowing how to associate with SWPD due to the impairments. SWPD received messages that hindered their decisions to form relationships, such as when students stared or completely avoided making eye contact as the individual approached with a wheelchair (Kane, 2010). A similar sentiment was echoed in the 2010 study by Hadjidakou, Polycarpou, and Hadjilia on the island of Cyprus, where students with physical disabilities felt they had overall positive relationships with other students yet also felt their peers and faculty lacked sensitivity in associating with SWPD. Likewise, Hodges and Keller (1999) found their participants believed that as SWPD, it was their responsibility to instigate conversations and interactions with other students. These students felt that over the course of time and

contact, non-disabled peers would eventually grow more comfortable with them in social settings.

For these and other reasons, college students with physical disabilities find it difficult to “fit in” despite desires to mix with peers. Unfortunately, the ostracism they feel pushes them to the fringes leaving them lonely and left out—even when at events or gatherings (Borthwick, 2002). Instead of college helping SWPD increase their social, emotional, and interpersonal development, the researcher found students who experience low levels of self-esteem related to their social acceptance, appearance, and potential for romantic relationships. SWPD acknowledged they felt more comfortable in specialized events and activities for individuals with disabilities—a sentiment shared in Hodges and Keller (1999) who concluded SWPD might be forming their own subculture, and the affiliation with a group of peers similarly impaired is still a positive move toward social integration. It may be true--perhaps this accomplishes the aim of allowing SWPD to experience social connections seemingly unavailable otherwise, though it could also prove a negative as it assists in helping them further isolate even more from the larger society. Yet, arguably, the social support SWPD receive through this engagement is an important contributing factor in creating a sense of belonging, as Hurst (2002) found for athletes with disabilities.

Constructing Disability

It is contended disability has been construed so as to establish those with impairments in strikingly different ways, based on the construct employed. This section discusses the medical and legal models of disability in order to present the competing construct underlying my study, the social model of disability. At that time, the Theory of

Complex Embodiment is also discussed to illustrate the continual advances and complicated intertwining of different models within social theory of disability studies.

Medical Model

The medical model of disability interprets those with impairments as being afflicted by an illness, as unhealthy or unwell (Johnstone, 2001). This view situates disability firmly within individuals, causing them limitations (Oliver, 1996). It supports the idea of “impairment as abnormality...disability as not being able to perform an activity considered normal...and handicap as the inability to perform a normal social role” in the world as it has been constructed (Oliver, 1990, p. 4). Under this interpretation society attempts to create a medical condition, giving it a classification or name; diagnose the problem (i.e., disability); and prescribe a treatment or cure for it (Johnstone, 2001). The locus of disability is then within those *afflicted* by their conditions which necessitate appropriate *treatment*—lest they remain *unfit* (Siebers, 2008).

Critics of the medical model argue rather than finding relief through this process, individuals with impairments become dependent on their labels, needing them in order to receive assistance, financial support, and even protection under the law (Johnstone, 2001). In one sense, the battle against a purely medical model arose as a legal construction of disability came into being. Citing a 1986 Louis Harris survey in which 54% of 18-44 year old subjects with disability viewed people with disabilities as a minority group, Longmore (2009) suggests individuals were pressing for social acceptance and inclusion rather than needing to be fixed or cured.

Legal Construct

Longmore (2009) identifies the first stage in the American disability movement as the establishment of individual rights. He asserts the main problem for a large percentage of people with disabilities is not their impairment but the discriminatory attitudes, actions, and practices encountered, or what he cites as the “institutionalized oppression of disabled people” (Longmore, 2009, p. 143). In some ways the legalist view of disability combats the “bias and discrimination evident in such actions as the mistreatment and arrest of Nadine and Steven Jacobson,” who had been arrested (though later acquitted) for their refusal to give up their exit row plane seats because of blindness (Longmore, 2009, p. 143).

Primary in the establishment of Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990², is “a policy commitment to the social inclusion of people with disabilities” (Scotch, 2009, p. 174), and a goal to “avoid or cease acting in a discriminatory manner” (Simon, 2011, p. 95). In contrast to a medical construction of disability, the push in the direction of equality of access and legal protection seeks to change the conversation from one of fixing individuals’ problems to creating opportunities for people with disabilities (Longmore, 2009). President George H. Bush declared the Americans with Disabilities Act (ADA) to be an “historic new civil rights act...the world’s first comprehensive declaration of equality for people with disabilities” (Burgdorf, 1991, p. 413-414). Yet even in so doing, the legal model continues to perpetuate the otherness inherently created by the medical classifications of

² The Rehabilitation Act was reauthorized as Title IV of the Workforce Investment Act of 1998 (PL105-220), which in turn was superseded by the Workforce Innovation and Opportunity Act (PL 113-128) in 2014. The Americans with Disabilities Act was updated through the Americans with Disabilities Act Amendments Act of 2008 (PL 110-325).

disability. This is evidenced clearly within much of the language establishing the ADA and ADA Amendments Act (ADAAA), which provides a list of *prohibited actions* including, among others: denying access; providing unequal or less effective services than available to others; failing to provide supports or assistance required for access; utilizing “methods of administration that result in discrimination;” screening or limiting the acceptance of people with disabilities; and failing to provide reasonable accommodations (Simon, 2011, p. 96).

Still, it is difficult to argue against the ways the ADAAA has influenced the United States and also U.S. higher education. The establishment of a mechanism protecting people with disabilities from discrimination created a momentous shift in the college demographic and brought an increase in the number of students with disabilities entering higher education. Institutions, obligated to provide reasonable support and modifications ensuring physical access to facilities used on and off-campus for courses or extra-curricular events; programmatic access to organizations, services, clubs and university transportation, for example; and reasonable accommodation when provided notification, continue to experience growth in the population of students identifying as having disabilities. Information from the 1996-97 and 1997-98 academic years show 428,280 students with disabilities enrolled in postsecondary education (Lewis and Farris, 1999) while a publication from the National Center for Educational Statistics approximated 645,000 students with disabilities enrolled at two and four-year degree granting postsecondary institutions in academic year 2008-09 (Raue and Lewis, 2011). Further, according to a 2008 United States Government Accountability Office Report to the U.S. House of Representatives Committee on Education and Labor, almost 11% of all

postsecondary students had disabilities, and the number figures to be increasing (GOA, 2009).

Opponents of the early disability rights movement characterized the push for greater “rights and self-determination” (Longmore, 2009, p. 150) as an expectation of special treatment, and showed difficulty reconciling these new interpretations of *equal* and *fair opportunity* (Longmore, 2009). Adherence to such beliefs and characterizations of people with disabilities are held over from the more medical construct of disability, and are very much present today, as evidenced in the current push back from the hotel industry to ADAAA requirements mandating accessible lifts in their pool areas. Despite having known for years of the upcoming—now overdue—date of compliance, they argue accessibility requirements are burdensome and question whether the disabled even use pools. Similarly, as has already been suggested in the literature of college students with disabilities, the perceptions held within broader society can prove detrimental and counterproductive to the pursuits of equal access and opportunity of people with impairments.

The legal model may prove to be the beginning to a social model of disability, with its purpose driven by a legal right to equal inclusion, while acknowledging people have differences requiring various degrees of assistance (Longmore, 2009). Yet it is likely too ambitious to expect the Americans with Disabilities Act Amendments Act to end disability discrimination since “stigma associated with disability is so embedded and reinforced within our culture and social structure that it will take tremendous effort to root out” (Scotch, 2009, p. 180). Instead, we legislate a minimum level of compliance, guidelines to avoid penalty or court proceedings, and bar acts of overt discrimination, but

must acknowledge, as Scotch (2009) does, the ADAAA's goals of "rooting out discrimination and improving the social position of people with disabilities" (p. 179) are unlikely to be realized through political intervention. Instead, establishing equal access is the ensuing call for *affirmation*—"a celebration of who we are, not despite disability (or deafness), but precisely because of the disability (and deaf) experience" (Longmore, 2009, p. 150).

Social Construct

"Whatever legal protection from discrimination has been gained, it would be very difficult to argue that people with disabilities have achieved social or economic parity as a result of ADA, or that having a disability is no longer a relevant factor in the life chances of many individuals" (Scotch, 2009, p. 179). If the first phase of the American disability movement proposed access and inclusion through adoption of civil rights legislation, the second phase, establishing a "collective identity" through self-determination leads us into the formation of a social model of disability (Longmore, 2009, p. 141). In as much as legal constructs identify people with disabilities in need of protection, the field of Disability Studies (DS) challenges the discourse of dependency and care in favor of one built upon enhancing independence and inclusion (Johnstone, 2001). Disability is experienced by individuals and society; it is who we are more than medical ailments to be classified, labeled, and treated (Peters, 2001, as cited in Johnstone, 2001).

The social model grew in popularity and acceptance because it spoke to people with disabilities and connected directly to them through their experiences (Oliver, 1996). The focus shifted away from an interpretation of disability as an "individual defect" in

favor of a view that it is a “product of social injustice, one that requires not the cure...but significant changes in the social and built environments” (Siebers, 2008, p. 3). Key to such a theoretical model is acknowledging disability as a “product of social organisation (author’s spelling) rather than personal limitations” (Oliver, 1996, p. 1), created by “disabling environments” (Siebers, 2008, p. 23). *Disablement*—barriers to inclusion—is then our creation; people design physical spaces which impede access for those with some impairments, and formulate beliefs and stereotypical assumptions as to their (in)abilities, wants, and needs (Johnstone, 2001).

Disability, in this sense, is not a physical or mental impairment, but a:

social construction shaped by environmental factors, including physical characteristics built into the environment, cultural attitudes and social behaviors, and the institutionalized rules, procedures, and practices of private entities and public organizations... (which) reflect overly narrow assumptions about what constitutes the normal range of human functioning (Scotch, 2009, p. 173).

It is experienced when students face created barriers in facilities and programmatic design, and can be understood as a problem endangering the potential to benefit for both the individual with an impairment and the community as a whole (Johnstone, 2001).

By situating “disability in the environment, not in the body” (Siebers, 2008, p. 73), the social construct of disability refutes a view of people with disabilities as defective, focusing on societal factors as a large cause of difficulties they may encounter. The negative assertions, exclusionary attitudes, and discriminatory practices separating some people from the *able-bodied, well, or healthy* (Bury, 1996, as cited in Johnstone, 2001) provide evidence for DS proponents who argue the battle being waged is more similar to struggles against the historical discrimination of African-Americans and

women—fights won in policy change (legal equality) but not in cultural shifts (e.g., inclusiveness) (Oliver, 1990). Belch (2000) cites numerous examples of instances in which diverse population encounter discrimination, insensitivity, and a lack of opportunity despite legal rights. Within the postsecondary environment is the call to create a truly inclusive campus—one “prepared for and welcoming to a diverse population” and striving to be inclusive from the start rather than acting reactively as instances of exclusion become apparent (Huger, 2011, p. 4). Presumably higher education, and particularly those in Student Affairs, emphasizes the full inclusion and involvement of diverse students, including students with disabilities, as they call for valuing “community, human dignity, and equality” (Belch, 2000, p. 9). Oliver (1996) argues against efforts to *normalize* people with disabilities by retrofitting them to society as it presently exists, instead, “demanding acceptance...as we are, not as society thinks we should be” (p. 37). Higher education advocates seemingly embracing a social model of disability suggest colleges “commit to a cultural shift to facilitate the full participation of all students, including those with disabilities” (Huger, 2011, p. 3). Such a move away from a culture of accommodation is dependent on people within it embracing their role in establishing such an environment (Huger, 2011).

The difficulty in this proposal may be engaging allies who accept the shared responsibility in promoting a culture of inclusivity for people with disabilities. A campus-wide commitment to both accessibility and inclusion likely requires a reconsideration of the work, goals, and missions driving disability service offices, which to a large extent continue as departments charged with legal compliance far more than broader objectives of inclusion on a comprehensive scale (Huger, 2011). Unfortunately, “most of the world

still thinks of disability as an individual, intensely personal problem” (Oliver, 1996, p. 3). Employing precepts of the social model, however, aligns smoothly with *The Student Personnel Point of View*, published and revised for over seventy-five years by the American Council on Education, which “emphasized the obligation of educators to consider the student as a whole, unique individual—not only his or her intellectual development but also emotional and physical development, social relationships, vocational skills, and moral and religious values” (Roberts, 2012; Belch, 2000, p. 9). A campus community with a mind toward the social model considers how students with disabilities struggle to gain a sense of belonging and value as individuals who add to the student body with their uniqueness, experience, and personal cultures (Belch, 2000), and strives to allow students to engage in all aspects of campus life “in a seamless and real-time manner” (Huger, 2011, p. 5).

At such time as this were to ever truly occur—that impairment was no longer disabling—the transferal from an accommodation model would be complete. Unfortunately for proponents of the social model, this is precisely what critics suggest limits it. They claim the social model cannot be used exclusively, expected to provide understanding and do it all with regard to explain disability precisely because the model does not allow for aspects of impairment to themselves be disabling (Oliver, 1996). It denies the impact of pain, sickness, and chronic relapse of debilitating conditions associated with the disability. Further, critics argue a social model is far too inclusive, and only those who are truly sick or unwell should receive support, while people with disabilities should be looked upon to adapt to fit in, not force society to suit them (Scotch, 2009).

Such criticism is both short-sighted and indicative of why a *more* social model is warranted. First, DS advocates generally would agree the social model—let alone any model—cannot be employed exclusively. It is, after all, a model and not social theory. What it is capable of doing, however, is connecting to the lived experiences of people with disabilities and it may, if appropriately considered, then assist professionals reflect upon their practices (Oliver, 1996). Second, the very idea of someone needing to be sick enough to warrant assistance hints at the oppressiveness of the medical model of disability—by and large a philosophy used to establish people with impairments as unfit, and thereby contributing to a class of people being deemed less-than the normal, healthy majority. This viewpoint operates as a stigmatizing notion, adding credence to exclusionary perspectives of “us and them.”

What the social model allows people with disabilities to do, according to Siebers (2008), is challenge their identity, though not all scholars are open to recognizing disability as an identity. Some feel because of the broad variations within disability it would be difficult to subcategorize appropriately. Yet, a challenge to identity is exemplified by the Deaf community of Martha’s Vineyard throughout the 19th century. At that time and place, the prevalence of deafness led to a hearing community who learned sign language in order to function along with their deaf neighbors (Siebers, 2008).

The Social Model in Higher Education

On college campuses application of a social model of disability is evident in universal design elements that allow participation and access for all constituents, not only people with impairments, without assistance, modification, or accommodation. Unlike

perspectives situating disability within the individual, a social view, one embracing inclusiveness, benefits more than the individual alone. Individuals do benefit, of course, as easily navigated systems increase academic and social integration, and freedom to “explore the opportunities available at the institution” (Huger, 2011, p. 5). All parties can expect increased opportunity to interact and coexist with diverse individuals, which arguably works to lessen “discrimination, prejudice, and marginalization” of those minority populations (Huger, 2011, p. 6).

The University of Syracuse, led by the Beyond Compliance Coordinating Committee (BCCC), utilizes a similar model to create a dialogue around disability and instigate changes at the university. Cory, White, and Stuckey (2010) provide a case study of the formation and impact of BCCC at Syracuse, and through it highlight an argument for how Disability Studies and a social model of disability can propel the actions of the university forward on its way to greater inclusivity for students with disabilities. The BCCC platform includes an objective for challenging the typical conversation of disability as often served through disability service departments which tend to stress accommodation, legal compliance, and issues of participation and access. The group advocates a perspective of *disability as diversity* and is specifically concerned “that as long as the University was meeting just the minimal standards...there was no possibility of equality of opportunity and meaningful participation” (Cory, et al., 2010, p. 30).

BCCC had a clear objective of appealing directly to Syracuse’s own ideals, their own “reputation for teaching, and acting on, inclusion” by proposing “there was even more of a need...for the campus to live inclusion” (Cory, et al., 2010, p. 32). The committee became vocal, calling on improved disability service provisions, and an

increased role of those with disabilities to become active participants in (rather than passive receivers of) the development of policies impacting people with disabilities. The case study at Syracuse illustrates how Disability Studies and the social model of disability are “intimately tied to action” (Cory, et al., 2010, p. 34). The authors stipulate applying these principles across campus highlights the university’s commitment to the inclusion and valuation of students with disabilities as a diverse student population. They conclude a key element of inclusion is *empowerment*, the opportunity to have a role in decisions impacting them as individuals and as a group. Such philosophical shifts emphasize a move away from discourses of disability entrenched in medical and legal constructs. Though, clearly “this shift does not signify a denial of the presence of impairments, nor a rejection of the utility of intervention and treatment. Instead (it) has been developed to...disentangle impairments from the myth, ideology, and stigma that influence social interactions and social policy” (Simi Linton and colleagues, as quoted by Longmore, 2009, p. 148-149).

Much like the calls by BCCC to see increased funding for the Disability Studies program, a better disability accommodation model, and increased hires of people with disabilities (Cory, et al., 2010), Longmore (2009) sees the goals of DS as trying to connect the disability community to researchers in such a way as to take advantage of each sides vast experience. The disabled experience, he argues, is integral to proposed research as it should serve to inform the direction such investigation takes. He, too, stresses a need for increased research funding and affirmative action to seek out students and faculty with disabilities who can help develop the research field and a richer, more supportive and active, disability community.

A Move Toward Complex Embodiment

An argument persists among disability theorists and scholars that:

1. The medical model focuses too heavily on the individual embodiment of disability; and
2. Social models refuse to acknowledge it at all (Siebers, 2008).

In Stephens' (2011) study of her disabled father, she contends a social model is developed through rhetoric, and that for people with disabilities (her father) "rhetorical construction of a disabled identity is necessary and provides evidence for the need to step beyond the social model as it is currently conceived" (p. 1). Echoing Siebers, Stephens is critical of a rigid social model because she finds an important element of disabled people's identity is their disability, and she contends *disability* is a combination of a social construction and an understanding of impairment as part of an individual's disability.

We are led to a new consideration, "a theory of complex embodiment that values disability as a form of human variation" (Siebers, 2008, p. 25). The Theory of Complex Embodiment acknowledges the impact of the environment to disabled people (social model) but recognizes as well the various factors affecting disability which originate in the body, such as ongoing health concerns or chronic pain (Siebers, 2008). Unlike the origins of the social model, which were arguably connected to a political movement for basic civil rights and valuation, complex embodiment belies a stance that people with disabilities are not attempting to make politicized statements, but only pronounce that their:

Challenge is to function...to live with their disability, to come to know their body, to accept what it can do, and to keep doing what they can do for as long as they can. They do not want to feel dominated by the people on whom they depend for help, and they want to be able to imagine themselves in a world without feeling ashamed (Siebers, 2008, p. 68-69).

Stephens details in her father's construction of his disability identity an argument that individuals do not have one identity or operate in only one discourse, but that many identities and discourses operate simultaneously. Despite being confusing and complicated—and at times contradictory—disability is a necessary identity. As she explains, a disability identity can be a positive source of strength and unique knowledge, yet may at other times serve as a negative, such as when it impairs the individual or disrupts an identity he or she formerly held that may be unsustainable at this stage. While small in scope, Stephens' argument helps establish the importance of investigating the language people with disabilities employ in discussing their personal identities because their expressive and complex understanding of the world “contains much information about how they perceive themselves... (and) can reveal complex yet precise discursive constructions of identity and can contribute to our understanding of disability” (Stephens, 2011, p. 3).

CHAPTER THREE

METHODOLOGY

The purpose of this study was to explore the conversations surrounding disability, as they are understood by students with disabilities in higher education, in order to make meaning of their lived experiences, the messages they receive, and their interpretations of those messages. Such discernment may prove useful to those who seek to improve the inclusiveness and campus climate and of their institutions. Additionally, it may inform students, administrators, and the broader community of their role in establishing a community in which diversity in its membership is a valued commodity. The research was driven by the question:

What do college students with physical impairments say about the discourses of disability on campus?

This chapter details the research design, including my epistemological decisions; theoretical perspective and subjectivity; data methods, analysis, and management. It concludes with a discussion of the ethical precautions, informed consent procedures, and efforts to minimize risk to participants.

Research Design

Epistemology

I approached this study with an eye toward the constructivist epistemology and a goal of “understanding the complex world of lived experience from the point of view of those who live it” (Schwandt, 1994, p. 118). My intent was providing an analysis of individuals’ experiences in order to understand them. Participants in the study likely interact with the surrounding environment of a college campus in distinct ways—

sometimes coming to similar conclusions, and sometimes creating distinctive perspectives. From a constructivist perspective, I judge the personal meaning-making to be equally valid to any collective understanding, as well as to any other individual discernment (Crotty, 1998). The meaning created by an individual expresses the “unique experience of each of us. It suggests that each one’s way of making sense of the world is valid and worthy of respect as any other” (Crotty, 1998, p. 58). I committed, as the researcher, to a principle that knowledge and truth, often concrete idioms, are fashioned through one’s perspective (Schwandt, 1994), and rather than serving to discover or uncover truth, I become an interpreter of multiple meanings so as to present an understanding of the experience(s) (Denzin & Lincoln, 2003; Krathwohl, 1998).

With an acceptance of multiple *truths*, constructivists suspend belief in the existence of *one-true truths*. Consequently, reality is “pluralistic and plastic...stretched and shaped” (Schwandt, 1994, p. 125), and entirely dependent on one’s frame of reference, thinking process and symbolic language (Bruner, 1986, p. 95, as cited in Schwandt, 1994). I wish to understand how individuals engage, make sense, and come to know the world, while acknowledging findings are localized and entirely bound by the situation of my participants (Krathwohl, 1998). One cannot hope to know the *real world* as a static entity (Bruner, 1986; Von Glaserfeld, 1991, as cited in Schwandt, 1994) because it is constantly being further developed as people construct, reconfigure, and revise their knowledge through new and changing experiences and engagements (Schwandt, 1994; Crotty, 1998). In the end, I serve as a sense-maker—constructing meaning and accepting these constructions as significant, all the while retaining the

knowledge they are incomplete and malleable as new material challenges and changes prior experience (Guba & Lincoln, 1989).

Theoretical Perspective

In his text, *An Introduction to Discourse Analysis*, James Paul Gee (2011) encourages us to consider discourse analysis as both a theory and a methodological approach to research. With that spirit in mind, I utilized and relied heavily upon Gee's views of discourse analysis in a similar manner. The first step was to be familiar with the function of language and Discourse; then we could grasp the intent of discourse analysis.

Language and Capital "d" Discourse

Language, as iterated by Gee, serves specific motives. More than merely the way we deliver information to each other, language "allows us to do things and to be things," (Gee, 2011, p. 2)—"to enact activities, perspectives, and identities" (Gee, 1999, p. 4-5). Our ability to participate in particular activities and events often is dependent on language whether we engage in a debate or discussion; conduct a meeting or negotiation; or engage in religious or spiritual observations (e.g., pray) (Gee, 2011).

Additionally, language allows us to take on "different socially significant identities" (Gee, 2011, p. 2). Individuals establish themselves in a variety of roles such as professionals in a field of study/practice (doctor, contractor, lawyer, mechanic, professor), members of certain identity groups, whether it is 'one of the guys,' parent, and/or student. The use of "and/or" is intentional as our participation in one activity, or membership within a particular assemblage, does not preclude our role in any number of others; instead, language gives us access to a variety of identities simultaneously *and* at different times in different settings.

Recognizing what language can do, we are positioned to explore what it can mean, for the same language is not able to do the same thing at all times, in all places. There is a necessary connection between what I (as the speaker) want you (as listener) to know by “what I am trying to do and what I am trying to be” through my language (Gee, 2011, p. 2). That connection linking what I say, do, and how I identify is what provides an understanding to language. None of this is possible simply because we know a standard definition of a word. Without context a definition “only tells us the range of meanings a word has, it does not really tell us how to use the word appropriately in real contexts of use” (Gee, 2011, p. 4). Gee proposes practices in which we engage, or what he calls *games*, are the source of language’s meaning. As speakers and receivers of language our understanding is a product of perception and perspective. Only through clear knowledge of “*who* is saying it and *what* the person saying it is trying to do” (italics by author) can full comprehension be grasped (Gee, 2011, p. 2). He argues as meaning comes from games we play, those games “are always ways of saying, doing, and being” (2011, p. 5), and ultimately we want to win these games, wherein winning may as well be equated to being received as “‘acceptable’ or ‘good’” (2011, p. 6). Accepted, we become eligible for the things wanted and valued in society: “money, status, power, and acceptance on a variety of different terms,” otherwise recognized as *social goods* (Gee, 2011, p. 7). Gaining social goods becomes very much political—a fight over who is eligible to receive them and how much gets distributed to whom. Because winning brings victors the benefits, in using language “social goods and their distribution are always at stake,” leading Gee to conclude that “language is always “political” in a deep sense” (2011, p. 7).

It can be theorized, as Gee does, that language is “integrally connected to matters of equity and justice” because through it people have access to different identities and different practices “connect(ed) to different sorts of status and social goods,” and it is, therefore, the “root source of inequality in society” (Gee, 2011, p. 30). Of dire importance in reaping social goods is to establish oneself as the right person (identity) in the right place(s)—that is, to pull off a Discourse (Gee, 2011). Capital “d” Discourse is:

a dance that exists in the abstract as a coordinated pattern of words, deeds, values, beliefs, symbols, tools, objects, times, and places and in the here and now as a performance that is recognizable as just such a coordination (Gee, 2011, p. 36).

Being this *who* involves embodiment of the type of person one wants to be seen as in the right *what*, or “a socially situated practice or activity” (Gee, 2011, p. 30). Establishing how to communicate various aspects of ourselves is achieved through a utilization of various acts of language as we speak and write, leading (we hope) to our being recognized *in the Discourse*. But how might one “do” a Discourse? It requires more than our ability to speak the language. Doing Discourse means personifying the *who* that should be recognizable in whatever identity is being attempted—the process is not just about our doing but about social acceptance of that Discourse by others who are already in it. Gee identifies four components of how we locate ourselves within a Discourse:

- a) “situated identities;”
- b) “ways of performing and recognizing characteristic identities and activities;”
- c) “ways of coordinating and getting coordinated by other people, things, tools, technologies, symbol systems, places, and times;”

- d) “characteristic ways of acting-interacting-feeling-emoting-valuing-gesturing-posturing-dressing-thinking-believing-knowing-speaking-listening (and, in some Discourses, reading-and-writing, as well)” (Gee, 2011, p. 40).

Discourse Analysis, then, is ultimately a theory of language-in-use, “about saying-doing-being” wherein meaning comes from the “‘game’ or practice it is part of and enacts” (Gee, 2011, p. 11). It recognizes all language is political because all language is about the allocation of social goods such as power, money, and other resources which cause inequities of some individuals and groups, raising the status and authority of some while minimizing the position and possibility of others.

Method

Discourse Analysis as Method

As a research method, discourse analysis aims to investigate language-in-use, what Stubbs (1983) characterized as “language above the sentence or above the clause” (p. 1). Gee (2011) identifies two forms of discourse analysis—descriptive and critical. Descriptive is just that; it depicts language-in-use so it might be better understood. Researchers employing discourse analysis in a purely descriptive study seek “deep explanations of how language or the world works and why they work that way” (Gee, 2011, p. 9). The product of such work is an interpretation of what is found but without particular consideration for applying it to a recognized problem or issue.

Critical discourse analysis moves beyond a descriptive approach, though one element en route to criticism is first locating an understanding of language. Instead, it seeks to “speak to and, perhaps, intervene in, social or political issues, problems, and

controversies” (Gee, 2011, p. 9). This theory of discourse analysis stipulates all language involves the distribution of social goods, and is therefore always political, and even acts describing language-in-use speak to issues. As such, one might argue that because we have the tools and skills to analyze discourse, we are responsible for both examining how language operates and intervening in the issues to which it contributes. This is why Gee expresses the opinion all discourse analysis “needs to be critical, not because discourse analysts are or need to be political, but because language itself is” (Gee, 2011, p. 9). And in truth, as “global citizens” we do have an obligation to contribute to the betterment of our society, tackling problems acting to deprive and minimize the possibility of some members gaining social goods (Gee, 2011, p. 12).

Interviewing

Residing on a continuum between highly structured interviews, with rigid questions and protocol, and unstructured interviews, wherein a topic is discussed but neither questions nor an order has been devised, the semi-structured interview incorporates a mix of the formal and informal approaches (Merriam, 2002). Semi-structured interviews were used in this study to garner information from participants which would likely not have surfaced unless they were specifically asked (Patton, 1990). Some questions were devised to ensure all participants discussed certain information, but the conversation was driven by a general topic and a set of questions or prompts, though they were not expected to be recited verbatim or in a predetermined order (Merriam, 2002). The researcher initiated discussion of an issue and was able to guide the conversation with various inquiries (Rubin & Rubin, 1995). At the same time, interviews

of this nature have the potential to go in other directions based upon where the participant leads the conversations through his or her responses (Slavin, 1992). Because the researcher intended to follow a line of inquiry but wished to allow the discussions to deviate as a result of what emerged as participants respond, the semi-structured interview seemed most suitable. It provided necessary organization at the onset, yet remained flexible enough that as participants touched on a topic not anticipated prior to questions being devised, the investigator could adjust appropriately.

Interview Protocol

Individual, one-to-one interviews were scheduled with each study participant. The nature of the study invited students with disabilities to openly discuss their experiences in a way that has not been available to them in the past. For that reason, it was conceivable interviews would last upwards of one hour, though efforts were taken to allow participants an “out” if it appeared as if interviews might last longer than ninety minutes. As the time threshold appeared to be nearing, I brought it to the attention of interviewees and allowed them to leave or continue as they chose.

While the goal was creating an environment which lent itself to an open discussion more than a question and answer session, an outline of the interview process was established to assist me in maintaining a level of consistency from conversation to conversation (Appendix A). An introductory statement reiterated the goals of the study and verbalized it was within the participant’s control to choose what questions to answer or when to stop the interview. Organizing, or pillar, questions guided the interviews, with additional questions or prompts situated under them. Use of individual follow up

questions was dependent on the direction each conversation took, and it is understood they may or may not have been employed regularly.

Within one to three days subsequent to the session, a second meeting was arranged with participants to follow up on any lingering thoughts they had about the interview experience. However, whereas the prior appointment took place in a location designated by me, students were invited to select a different setting on campus to talk. I envisioned this being highly unstructured so as to allow the students to express reactions once they had an opportunity to reflect upon the questions. Possible areas for inquiry included:

- Why the student selected the location they did;
- Questions or topics participants anticipated I was going to ask about that I didn't;
- Questions or topics participants wanted me to bring up that I didn't;
- Lingering thoughts or reactions participants had to the experience after given time to reflect on the interview.

It was believed this second meeting would provide valuable data, especially given that students participating in the interviews may have taken part in prior studies either of disabilities or students in general and have developed an expectation of what they thought was wanted of them in my study. The opportunity to come back together, after they were given time to digest the experience allowed me to gain insight not unearthed during the initial interview session.

Participants

Participants for this study were selected through purposive sampling students with physical impairments at three separate participating four-year institutions, and who have been continuously enrolled in their school for at least one academic year. Whether called purposeful, purposive, information-rich cases (Patton, 1990) or criterion-based selection (LeCompte & Preissle, 1993, as cited in Maxwell, 1996), the goal in such sampling is the same--to include individuals' with the ability to provide the information required to answer the research question (Maxwell, 1996; Merriam, 2002). In this case, the investigator chose to target participants best positioned to reflect upon their experiences after substantial time and exposure to the higher education setting. It is possible, though by no means a certainty, that freshmen and recent transfer students are still actively engaged in learning to navigate relatively unfamiliar college environments; therefore, they may be ill prepared to contemplate their experiences in relation to the bigger picture of inclusion.

Intentionally, those with learning, psychological, or other cognitive disabilities, as well as sensory and other types of disabilities who do not also disclose physical impairments, were excluded from the desired population. This was done with a recognition that within "students with disabilities" exists significant variation in impairment, ability, and situation. A study incorporating the broad category of disability would likely lead to a great many findings, yet it would be an undertaking without specific focus. By limiting the population to only students with physical impairment, the research more adequately honors the truths of this particular population of students.

A decision was made to undertake this study on multiple campuses so as to not come away with findings that suggest too much about only a particular setting. While qualitative investigation rarely can be generalized to larger populations, it was the purpose of this study to uncover similarities or variations across unique settings rather than across students within one site. In this way, the researcher had access to perspectives related to how campuses construct disability and not what occurs within a singular location.

To locate collaborating institutions I utilized my professional network, established through years working in higher education disability services. Informal e-mail letters were sent to approximately 25 former colleagues—including those met through professional projects and organizations such as American College Personnel Association (ACPA), Association of Higher Education and Disability (AHEAD), Illinois-Iowa AHEAD (ILLOWA AHEAD) and North Carolina AHEAD (NCAHEAD), and Student Affairs Administrators in Higher Education (NASPA). Many of these individuals are employed in a disability support office, while some work in other student affairs or academic areas. My primary interests and concerns were in locating professionals who would view the research as beneficial at the macro and micro levels; provide assistance in participant recruitment (i.e., identifying appropriate outlets for, and then dispersing invitation-type messages to their student population); and shared my perspective in this study, namely, that disability need be viewed as a diversity issue as well as the more established and accepted legalistic concern. Based on the response I received from these individuals, we began a dialogue of additional topics including logistical issues, for

example, assistance coordinating appropriate and accessible space for interviews to occur on campus (preferably NOT in the disability service office) and parking permits.

Cooperation from each school's disability services department was meant to greatly assist in recruiting students with physical impairments to participate in this study. Due to Family Education Rights and Privacy Act (FERPA) regulations regarding the disclosure of information pertaining to students with disabilities, invitations were to be forwarded through the disability services offices on each campus rather than directly by the investigator. Additionally, because not all students with disabilities choose to register for accommodation or support through a disability services office, it seemed useful to determine where, on each included campus, students on the whole are likely to get their campus information and notices. An open invitation was created to be dispersed throughout the institution using a variety of methods. Such methods included campus announcements, publications, and university websites. Advertisements described the intended project and population sought, and asked students interested in participating to contact the researcher. This was an attempt to represent the population most accurately, and not only students who needed the support of a disability services office. Respondents meeting the delimiting criteria who were available during the researcher's time frame were considered for participation.

The goal was identifying multiple students for each of the campuses involved, though a specific number of total participants was determined to be less important due to the potential length and great depth of each individual interview. However, the maximum sought was between five and seven participants per institution, with a total not to exceed twenty students.

Data Management

Interviews with all participants were digitally recorded and downloaded to the researcher's external hard drive for the express purpose of ensuring accuracy. Participants were aware the interviews were being recorded, having been informed and given written consent prior to participation. Still, each was asked to give verbal approval at the beginning of their recording. Word for word transcripts were generated based upon the digital recordings.

Data Analysis

In a discourse analysis it is difficult to establish at the outset the analytic questions guiding the investigation. That is, I could not determine what to ask of the data without knowing what data is available. However, based on the research question, I employed identity, particularly focusing on the Natural Identity (N-ID) as an analytic lens as an initial step to analyze what students with physical impairments say about the discourses of disability. Discourses are ways of being certain types of people, both how we wish to be seen and also in how others may choose to recognize us. The act of establishing an identity is dependent on being recognized in the appropriate context (Gee, 2000). Consequently, Gee proposes the “notion of identity...can be used as an analytic tool for studying important issues of theory and practice in education” (2000, p. 100).

Identity as Analytic Lens

Gee (2000) indicates four ways to view identity. In reviewing the data (interviews with participants) I considered how it spoke to the various perspectives of identity. The first, Natural (N-ID), is indicative of the state a person is in without any relation to something done or accomplished. For instance, an N-ID could be female/male,

Caucasian, or blind. Society has not influenced the identities existing, except in how each might be seen as “meaningful in the sense that they constitute the “kind of person” I am” (Gee, 2000, p. 102). The second, the Institutional Perspective (I-ID), is established because of a position supported by an authority. Gee provides the example of himself as a university professor. The identity is given, or granted, because of criteria determined by the authority figure. I-ID can be positive such as the earned place of a college faculty, or an imposition, as evidenced by a student labeled as disabled by the university. In that instance, the individual has not changed, but an authorizing body has determined a set of criteria that now recognizes this person as a type of *something*.

The Discursive Perspective (D-ID) is achieved through the “discourses and dialogue of other people” (Gee, 2000, p. 103). It potentially is an identity a person wants to be seen as, or it can be an identity thrust upon them. As is often true, many Institutional Identities only hold up because the discourse of others sustains them. An individual with an impairment may not wish to be seen disabled, but “because other people treat, talk about, and interact” with the individual as if they are disabled they *are disabled* through the Discursive Identity. Therefore, it raises the question: Can a person with a physical impairment at times not identify as disabled but establish a D-ID “because other people treat, talk about, and interact” (Gee, 2000, p. 103) with the individual as if they are disabled?

Finally, people can identify with one another or a group through a set of common interests, beliefs, and practices and create the Affinity Perspective (A-ID). Though they may share little or no other direct connection, the common interest links them. We see this exemplified at Comic Con, where hundreds of thousands from around the world

gather because of an interest in comic books, science fiction, and pop culture, as well as through the various club and organization opportunities on college campuses.

It is imperative to recognize that while separate, each of the four perspectives of identity operate in concert, interacting rather than being established void of influence from the others. While an identity, such as physically-disabled, can be associated with any of the four perspectives, only when others recognize it does an identity hold. Hence, a student may wish to achieve another identity but be thwarted because people do not see them as such. Comparably, it is also possible for an identity to dominate an individual regardless of a desire for different recognition. For instance, while someone may wish to be viewed as a biology tutor, student government officer, or *anime* (Japanese animation) fan, if students otherwise identify them as disabled that identity will be what sticks. The analysis of this study focused heavily on participants' self-authorship—the ways they view themselves and make meaning of their own experiences—that is to say, the Natural Identity (N-ID) of a student with a physical impairment. In so using identity as an initial tool of analysis, conversations of students self-identifying with physical impairments (N-ID) indicate the ways in which discourses of disability are established and fostered in the campus community.

Validity

The very nature of discourse analysis is providing interpretation. Its validity is not judged by whether it proves something true or untrue, but in how the researcher can establish the interpretation as more or less valid (Gee, 2011). Beginning with an idea or hypothesis, an investigator sets about developing an argument for it through in-depth scrutiny of the discourse being interpreted. Gee (2011) offers four elements which

constitute discourse analysis' validity: convergence, agreement, coverage, and linguistic detail.

Convergence—The more an analysis “offers compatible and convincing answers” to the 42 questions developed through Building Tasks and Tools of Inquiry (p. 123);

Agreement—The more other analysts, researchers, and “natives” are convinced by the argument(s) offered, or agree with the conclusions;

Coverage—The more an analysis relates to other data, making “sense of what has come before and after the situations being analyzed” and predicts what may occur in similar situations” that follow (p. 123);

Linguistic Detail—The more an analysis ties to accepted grammatical rules and how well they establish the appropriate norms as judged by “native speakers.”

A discourse analysis can claim to be valid based on these elements:

“Because it is highly improbable that a good many answers to 42 different questions, the perspectives of different “inside” and “outside” observers, additional data sets, and the good judgment of “native speakers” and/or linguistics will converge unless there is good reason to trust the analysis” (Gee, 2011, p. 124).

That said, validity is a context issue, or what Gee has called *The Frame Problem*. An analyst must continue to broaden the context until such widening shows the increased scope no longer influences a new interpretation. At that point it is acceptable to assert validity, though acknowledging later findings may act to falsify those interpretations (Gee, 2011). Therefore, as researcher, my claims for validity were dependent on my skill and diligence in providing thick description and evidence supporting my suppositions.

Avoiding Researcher Bias

My experiences and bias is only detrimental if it was allowed to color my analysis in such a way that I do not present a fair account of the information. However, I am not

trying to prove or disprove particular phenomena as much as understand the discourses of disability, as recognized by students with physical impairments, which already exist. Several steps were taken to account for and minimize the impact of my own beliefs when entering the study. First, interview questions and prompts were created so as to be non-judgmental, imposing no expectation upon the student to respond in a particularly positive or negative way. At the same time, I acknowledge that, due to the conversational tone I hoped to create, participants may perceive my role in the conversation leading them in a particular direction. It is important I remained cognizant of such instances, made note of those occasions, and sought to decrease such situations moving forward. Second, I attempted to identify evidence which disproved my own ideas and caused me to consider whether it was plausible to modify or maintain the conclusions being drawn through my analysis, and report such cases, allowing “readers to evaluate this and draw their own conclusions” (Maxwell, 1996, p. 93, citing Wolcott, 1990). Third, by utilizing individual student participants at three separate universities I was able to perform some degree of triangulation, as each interview was conducted independent of any other student’s interview, both at their home institution and at the alternate sites (Maxwell, 1996). Finally, feedback on my process and analysis came from my research chair and committee throughout the investigation. Each came to this study with a unique background and level of familiarity with particular aspects of the research.

Human Participants and Ethical Precautions

Informed Consent and Minimizing Risk

The investigator received consent from The George Washington University Institutional Review Board (IRB) prior to conducting research or solicitation of

individual participants. Upon approval by IRB, the researcher forwarded the approval to each individual campus where the inquiry is to take place. As a contact in either disability services, student affairs, or a school of education or disability studies is cooperating at each institution, I was able to receive support in navigating their own IRB processes, as necessary. However, as an outside researcher with no direct tie to those institutions, The George Washington University approval was allowed to stand, rather than requiring I submit separately to each review board.

Prior to beginning the inquiry, participating students were given an opportunity to read, or have read to them, the informed consent which detailed the objectives of the study and any possible risks, of which none were anticipated. However, because this investigation asked individuals to consider aspects of their experiences as people with disabilities that they may not have reflected upon in detail, it was important consent involved both an understanding of the study and an explanation that participants could refuse to answer or stop the interview at any time. Additionally, the investigator answered any questions brought forward by participants in an effort to guarantee they were taking part with a clear indication of the nature and focus of the research, and the potential exposure of deeply held feelings and experiences which could cause them distress. With this in mind, the researcher was prepared with information from the particular campus as to accessing support through disability services and campus counseling centers, so that when the study concluded for the participants they were not left feeling unsupported with any lingering concerns or feelings as a result of their reflection.

Study participants were given the opportunity to establish for themselves a pseudonym used from the start of the interview through the analysis and written dissemination of the study. Following the interviews, participants were able to contact the researcher and request removal from the study group if they had a change of heart for any reason; no such requests were made.

CHAPTER FOUR

RESULTS

The purpose of this study was to explore conversations surrounding disability, as they are understood by students with physical impairments in higher education, in order to make meaning of their lived experiences, the messages they receive, and their interpretations of those messages. Gee's theoretical views of discourse analysis stipulate all language involves distribution of social goods, and for that reason is always political (critical analysis). This chapter discusses findings which have come about after close examination and subsequent interpretation of transcripts and the actual audio recordings of semi-structured interviews with seven students self-identifying as having a physical impairment.

As previously stated in Chapter Three, in a discourse analysis it is difficult to establish at the outset analytic questions to guide the study because one does not know what to ask of the data without knowing what data is available. Driven by the research question, "*What do college students with physical impairments say about the discourses of disability on campus?*," identity was initially employed as an analytic lens when seeking meaning from the data. The avenues by which this compilation of lengthy and, at times, intimate conversations could be analyzed are numerous. It is likely my decision as to what to ask of it was equally telling of me, as was the choice made in creating a conversation with the reader. Results, then, are not presented with reference to specific and pre-determined interview questions, but instead as they came together to develop arguments for the questions that emerged. Importance is not to be determined based on the order of themes presented or the amount of space dedicated to one versus another.

In a discourse analysis, the focus of a review is akin to a college-level literature course in which students seek to understand what an author is saying both explicitly and implicitly. Walt Whitman wrote in *Song of the Open Road*, “You road I enter upon and look around! I believe you are not all that is here; I believe that much unseen is also here.” The words of participants—my conversation partners—illustrate and give a basis for arguments being made. However, the words alone give only part of the story. To the degree possible (and necessary) the reader is guided toward, and gains insight from, the *other stuff*—be it a look, a marked pause, a fidget, or a noticeable inflection.

For clarity, and assistance in establishing the dialogue so as to be truthfully shared, formatting techniques were employed throughout the transcribed portions of this chapter to provide visual cues:

1. **Bolded** font indicates the speaker increasing volume and stress on particular words.
2. *Italics* (except as used to indicate pseudonyms of participants) identify a speaker’s rising pitch and a more quiet emphasis.
3. Ellipses (...) represent speech that trails off, unfinished thoughts, long pauses, or a jump from one idea to another. At times parenthetical notations will provide additional assistance in understanding an ellipse.
4. Dashes (—) show statements of clarification, additional thoughts, or where the speaker digresses within the dialogue.

For instance, this statement from *Robert* which appears later in the chapter:

I mean...when you **inflict** this type of injury—**on yourself**—because of *alcohol*...(nodding) you kind of get a good wake up call.

Introduction of Participants

Research participants were given an opportunity to establish for themselves a pseudonym to be used from the start of the interview through the analysis and written dissemination of this study. They are presented below alphabetically by their chosen names, without indicating the campuses from which they came.

Andrew: *Andrew* is a Computer Science major with a rare progressively degenerative disorder which impacts the growth and development of muscle tissue. *Andrew* identified himself as an artist, a Christian, and someone who tries to give of himself and his time, volunteering at organizations and camps serving both children with disabilities and for those interested in the arts. When asked specifically to think about where his identity of “disability” falls in his understanding of self, *Andrew* stated that he ranks it lower than the other characteristics but admitted, “...definitely, it’s part of me, but I don’t let it influence any major part of my life.”

Claire: *Claire* recently concluded her freshmen year at college. *Claire* was diagnosed with a unique form of Muscular Dystrophy when she was approximately 8 years old. “Basically it is muscular weakness throughout. It is progressive...so I do get worse all the time.” Specifically, *Claire* is affected with weakening in her legs and core muscles and has restricted movement throughout most of her body, as joint stiffness and a curvature of the spine are common with this disease. *Claire* characterizes herself first as a musician and performer, and then (perhaps because of the age at which she was first diagnosed) she strongly identifies as her disability. “It shaped a lot of who I am.”

Dante: Following a traumatic accident post high school graduation, *Dante* is quadriplegic with minimal use of his hands and arms, but no fine motor skills. With a laugh, he explains his chosen pseudonym, *Dante*, is an homage to *Clerks*, the 1994 Kevin Smith movie, “with a little “circles of hell” *Dante* thrown in, too.” He will graduate soon and is currently applying to MFA programs far from home and family. We return often to the oft-quoted line from *Clerks*, “I’m not even supposed to be here today!” It is not lost on either of us how that phrase and the course of *Dante*’s injury and life is a recurrent theme throughout our discussion.

Dick: As a young man *Dick* was injured in an event resulting in chronic and debilitating pain in one leg and ankle. He describes himself as someone who had always been athletic and on-the-go, but now is challenged to find other outlets for his competitive and active nature. He has suffered through surgeries, the recovery periods, and ultimately, the failure of treatments to correct his impairment. *Dick* has a difficult time walking for any distance, and has recurrent pain which can require him to stay off his feet for several days at a time until the pain resides. His impending graduation has taken several semesters longer than planned due to medical withdrawals and the need to request incompletes from instructors.

Lauren: *Lauren* is a graduate student with a degenerative muscle disorder that progressed quickly throughout her teen and college-aged years. While she is often able to mobilize on her own, *Lauren*’s condition is characterized by varying degrees of fatigue and muscle weakness. As a result she has found it safer to use a wheelchair when on campus and in public areas, though prefers to walk as much as she is able when at home or in more

protected environments such as at friends' homes. Her approaching wedding is both a highlight and worrisome event of the next year in *Lauren's* life.

Robert: It was just days before Christmas in the mid-1990s, and *Robert* was being released from the hospital rehabilitation center in which he had stayed since his car accident the previous September. After a night on which he says he clearly had been drinking too much, *Robert* was thrown through the windshield of his car and severed his spinal cord. Now paralyzed from the chest down, he is grateful to have almost complete use of his arms, "with a big exception of my triceps and my wrists, hands and things...they are not functional." Less than a year later, *Robert* returned to college a "changed man"; he changed majors, recognizing he would no longer be able to complete the physical rigor of his initial intention, and graduated with his BA in Psychology. He is now working towards a Master's degree and has the goal of becoming a substance abuse/rehabilitation counselor.

Susan: *Susan* chose not to identify her disability (and it was not asked of her); instead she offered to discuss its impact and the manifestation of her disease on her daily life. College has taken longer to finish than she anticipated, and her self-identified stubbornness at times hinders her progress because she might not come to accept the limitations she has. Her impairment causes difficulty walking, and though her doctors have repeatedly told her to use her wheelchair on campus, so far *Susan's* preference is to get around with crutches. The influence of this choice became more evident to her as we spoke, and she recognized her logic was less an issue of mobility and more about the perception a wheelchair would display to fellow students. "With so many people, confinement with it (wheelchair) was very unnerving so I kind of belong...I know they're

probably...it will turn them off.” With her college career ending soon, *Susan* is in a position of reflecting on her experiences and those opportunities not explored.

Analytic Question 1: Is the Discourse of Disability on Campus Serious?

Despite interview prompts heavily focused on social involvement and engagement, by their own choosing responders gravitated in the direction of their education and specific concerns based upon their individual disability needs. Considering, then, how participants discuss their own university life, it can be argued the discourses of disability are understood as seriously academic and seriously medical or health related.

Seriously Academic

Participants entering college with physical impairments, whether present from birth or acquired later in life, recognize their decisions of involvement, major selection, and career aspirations are heavily defined or limited due to the nature of their disabilities. They view higher education as their effort to achieve greater independence. For participants it involved establishing a pathway to be independent from family and caregivers, government assistance programs, and inactivity. A major hurdle for SWPI was rationalizing college in relation to their physical limitations and the potential for autonomy. They weighed many factors—both academic and social—in determining the schools to which they would apply. Participants were not unlike the majority of students in this aspect of the process, though greater implications must also be factored into the decision.

For these students with physical impairments, seeking independence meant viewing college with a critical eye toward potential difficulties. Participants have a

responsibility to proactively seek out would-be pitfalls, rationalizing the likely outcome of such problems versus their needs and goals. For *Dante*, going to school at his university was the goal before he'd ever set foot on campus because the program in his intended major is highly regarded. He thought about his biggest fears:

Will he get where he needs in his chair?
What accessible housing options are available?
How will the school work with his personal care requirements and his need for home health nurses?

“It was a distinct goal and when it got closer and closer, it became more achievable, but you realize you set that goal...but then logistically (trailing off)...” The statement, and the uncertainty with which *Dante* concludes his thought, epitomizes the discomfort and uncertainty felt in making a dramatic transition. Luckily, after thoroughly reviewing and communicating with the institution, *Dante* felt comfortable the school matched his academic and personal necessities. He found the degree program best for his future goals; housing and facilities addressed his questions around accessibility needs; and campus offered the opportunities to mobilize easily, both independently and utilizing campus transportation. Further, it was close enough to his family (350 miles away) that his parents felt at ease in case there were emergencies, but far enough away for *Dante* to feel safe they would not hover and thwart his efforts at learning to live independently as an adult with quadriplegia.

Prioritizing Education Over All Other. An overlooked aspect of being a college student with a physical impairment can be the degree to which the disability cannot be ignored or “worked around.” With guidance from designated disability support offices, SWD may be entitled to accommodations designed to assist them in gaining appropriate access to facilities, services, programs, and education. However, accommodations

alleviate none of the responsibility students have for proving their proficiency with their work, or the timeliness of completing their work, and they will be evaluated on the quality of their work without regard for disability. If writing a paper takes a SWD three hours for every hour it takes the majority of students to produce the same essay, the onus is on the individual to account for and manage the time appropriately. “I am focused on doing what I needed to do, being here, **being a student**” (*Dick*). Managing the work, their accommodations, and their energy were determining factors in the choices participants made with their time. There was a finite amount of time and energy, and when *Dick* reached a point where he felt that he could not physically handle anymore he realized he must “prioritize where you’re going to spend your energies.” *Robert* shared a similar sentiment of “having too many other things to deal with to worry” about involvement or being part of the social crowd.

Yet, this prioritizing did not come without consequences, though how great of a cost may be based on who was speaking. *Dick* had intentions of not letting his impairment impact his education or college experience, figuring any physical hardships or discomfort would be made up for with perseverance, a positive attitude, and self-management. It was during his junior year, when finally involved with mostly courses within his major, that he experienced complications which forced him to take medical leave and repeat all the courses from that semester at another time. Field placement classes required he stand for long periods of time while on location, often carrying or setting up equipment several times during a given day. Rather than coordinate accommodations, he felt obligated to perform his tasks without support, worrying classmates might perceive his effort as unequal to their own. Simultaneously, students

from his class were beginning to gather more frequently after work for social activities. *Dick* had been trying to explore what might be considered the college life and came to realize his own abilities would not account for the physical rigor and strain his body was unable to manage. For personal wellness, and faced with the prospect of requiring additional procedures as a result of the damage done by the past semester, *Dick* adjusted his expectations and purpose.

“I kind of had to reinvent how I did everything...I know that there are certain things that I can't do--like go out to the woods (he stops, taking a deep breath)...and go camping...that's going to be asking a lot.”

The process of recognizing disablement (*Dick's* characterization) or one's need to consider implications of an impairment caused a recalibration not without drawbacks:

It becomes **frustrating** that for, you know, years and years (short laugh) **years** I cooked in a kitchen...and ...there's so much pain that I can just barely walk...they don't see that I crawl around my house after work because it hurt so much to walk...So I have to come back to where I can't stand anymore. It hurts too much.

Such recognition ultimately proved positive, as he defined his purpose or objectives, but the lack of “involvement” can be misconstrued as a failure in accessibility rather than self-determination or management.

I would have liked to be involved more. I would have liked to go to a lot more things but me not going wasn't a result of timing or whether it was promoted, or accessibility or anything like that. It was more, I don't know...It was more personal choice that I'm tired. I need sleep. I'm like an old man” (*Dante*).

The expectations participants have established for themselves indicates a dedication to the academic aspects of college life, and while not meant to be taken to mean a true

comparison, a more singular commitment to the educational purposes of college than may be generally assumed for the majority of students.

Well, the thing is, I am just really here for the academics. I'm really here for my degree. I am not here for—if I was here to meet more people...I would hang out with them. I know it would be good for me (to engage with other students) (*Dick*).

A de-emphasis on social aspects of the university experience is a meritorious behavior; participants determined their goals, established priorities, and incorporated a plan through which they might achieve these objectives. Therefore, the minimized role of social involvement is an intentional component in their academic success.

For *Susan*, her self-professed reluctance in embodying the disability identity was overridden by the importance of completing her education because “growing up I wasn't physically able to go to school.” The difficulties she encountered earlier in her academic career made an impression on her in more ways than one; it solidified for her the idealized aim of education, and it forced her to consider herself, and her disability, in relation to achieving that aim.

Involvement, then, was NEVER a priority.
FUNCTIONING is a priority, so now I'm going to do this,
and I'm going to do it right.

But what might it mean, “to do it right”? *Susan*'s disinclination—but eventual decision toward—coordinating support through her school's disability service office was rationalized by her awareness “education is why (she's) here, and (she) has to ‘get’ (i.e., come to understand) that support is key to being most successful.” *Doing it right* means setting priorities for how one goes about organizing time and effort, and *Susan* determined since reentry to her program that she would choose to apply those energies to staying in school fulltime over “the extra stuff—games, involvement...”

As some other participants also detailed, *Susan*'s emphasis was clearly, and knowingly, on the academic nature of her college life. Her impairment has affected the speed at which she is able to complete her degree, having forced a series of withdrawals and semesters attended in a part-time status. There was a concern, or what she calls a fear, the stress and expectations of school would be too physically demanding and force either another temporary withdrawal or her worst-case scenario—a permanent dropping out from school. To that end, *Susan* appeared to struggle in our conversation to discuss her college life without the eventual return to academics as her primary point. When speaking of places to relax, she talked of a particular café inside the bookstore because it was an easy area for her to maneuver with crutches and she needed to spend her time studying. Pushed to think of a location she would go during free time, she told of the quiet rooms in the library where she would camp out for hours each day before, in between, and after classes. As I initiated talk of on-campus relationships and with whom she spends time, *Susan* told of the faculty and department administrators she trusts to know about her difficulties and who assist her in the stressful times of the semester if her impairment causes complications. Finally, confronted by my realization she has this pattern of returning each conversation to academics, she allowed herself a prideful moment, “Doctors told me I should just give up” going to school or complete the degree.

Claire represents a difference from some other participants, in that she highlighted a distinct goal of college being “enjoying yourself...being here for more than education...to be able to mature, and make friends.” But *Claire* also benefitted from a support network prior to college emphasizing her physical and emotional development along with a value of higher education, highlighted in the explanation as to why she

mobilizes in a more upright device rather than a scooter or wheelchair. There had been a discussion of her present abilities, the changing nature of her impairment, and how best to maintain her current mobility. She and her support system—parents and the doctors—had an attitude that with the more upright device she would

be standing more rather than just sitting, so I could use the muscles that I have for as long as possible...also some psychological as far as like, I am up higher, even on conversations. I am sitting on that (points to the fold away bench on her device). I am much higher than the others (students with wheelchairs).

Yet, *Claire* was realistic about her prognosis, knowing despite her best efforts she would eventually experience further deterioration and have little choice but to seek other, more traditional options such as a wheelchair. It was important for her that she maintain her mobility and health the best she could, as long as she could, and use the time to complete her degree.

The Building/Rebuilding of Self. Contributors entered higher education with some understanding of who they were, the expectations they were placing upon themselves, and what they wished to accomplish for themselves and through college participation. More recent experiences, whether directly related to impairment and injury, or academics and campus encounters, caused a shift in their interpretations of the *self* they embody. For some, such realizations led to reconstructing and reshaping expectations. For others, it instigated serious shaping of expectancies for the first time. In either case, their single-mindedness toward a college education was helpful in initiating their building or reconfiguring of the individuals they were to become.

During introductions to one another, I often found myself speaking about how I came to study the experiences of people with disabilities. This invariably steered us into talking about what we thought when we were young about what our lives would be like and the types of jobs we might have. There were goals of being musicians and artists, veterinarian, chef, and nurse. But participants were weighing aspirations with the realities of their physical capabilities and the security provided by those decisions.

In one way or another, each participant self-identified as both a person with a disability, and a person. Their college educations serve as the bridge between the disability identity thrust or born upon them and independence in adulthood. Following *Robert's* accident came an initial period of adjustment and rehabilitation. He was shoved into a phase of shedding some aspects of the person he once was, while simultaneously learning to cope with the realities of his present self. The initial focus was on learning how he would take care of daily necessities, for instance, eating, hygiene, and mobilization. Soon, however, *Robert's* attention returned to his future, and the realization he was “a changed man.” It led him to question what was important to him and what he might do for a profession if given the opportunity. The same sense of urgency felt in developing his care routines and establishing what he could and could not do for himself was applied to his metamorphosis into a student with a disability. His trepidation, and the anxiety of those closest to him, eased as he came to recognize himself as *disabled* at times, but not in his mental capacity or in “being a learner, a scholar.” Academics were—are—part of the rebuilding process *Robert* undertook following his paralysis. From the early realization his body would not allow him to participate in a physically challenging field, the new goal “has been: ‘Keep the Ball Rolling.’”

But—what does that mean? *Robert* identifies as a helper. Prior to impairment, his plans involved moving toward a civil service career, most likely law enforcement. Post-injury, his experiences and abilities led him to consider where to utilize the same instincts. Rather than dwelling on what had been subtracted from his experience, *Robert* came to his education looking for a way to adjust and still reach a similar destination. “It’s (disability) not my concern. It’s not something that I have a problem with saying— ‘Yeah, I have a disability.’ I’m a quad. I’m a **person** with a disability.” Emphasizing his personhood is reflective of that sense of humanity *Robert* feels. Identifying as an individual drawn to law enforcement, health care, and psychology, *Robert* sought what would allow him to be his best whole self. Unable to proceed one way as planned, the negative experiences that contributed to his disablement, alongside his being “healed by the people who have always been with me (through his rehabilitation),” informed his decision to become a substance abuse/rehabilitation counselor. “I just kind of combined the two after all the post injury.”

Andrew and *Claire* each found themselves also reconsidering early aspirations, though for much different reasons than *Robert*. Growing up they dreamed of careers in the performing arts, goals determined to be unfeasible as they grew cognizant of implications related to their progressive impairments. Still, before choosing *disability* or *student* or an affinity group, each identified as a *musician*. For *Andrew*, he had been learning self-sufficiency from an early age, the good and bad of a difficult upbringing only heightened by a challenging physical disorder. To date, his musicality has so far been relatively unaffected, but he employs a personal care assistant, and sustaining the

energy and movement to play for extended periods will contribute to the impracticality of the performing arts as a viable occupation.

Actually, at first, **my plan** was to go to another school and to major in Music and...I just started to look at some things that they had and I was also thinking that maybe music would not be the best course like finding a career that will...

In building for the future, *Andrew* encountered decisions forcing him to think of himself both in his current state and as he may likely present as soon as a few years later. The college experience was the embodiment of *Andrew's* personal ambitions as an artist coming face-to-face with the knowledge he will continue to grow physically weaker, less mobile, and dependent on others. In choosing a course of study and a focus for his college experience, *Andrew* determined to highlight other strengths and focus on what will offer the stability and security required with his health concerns and progressive limitations.

Within the building/rebuilding process are phases or stages, as individuals do not operate with the same understanding. For instance, *Andrew* said disability “definitely, it’s a part of me but I don’t let it influence any major part of my life.” Yet throughout our conversation significant influences appear to exist, though *Andrew* may fail to process these influences even in speaking of how impairment made him reconsider his major and the future implications of his condition. Whereas *Andrew* was still building his sense of self, *Robert* seemed to have greater self-awareness—perhaps the result of the immediacy of *Robert's* disablement and subsequent confrontation with his changed self.

Similarly, *Dick* neither grew up with an impairment nor did he slowly transition into it. As it may have been inferred from his previous experiences, *Dick* was set to make

a life for himself in a professional kitchen. He worked, in one fashion or another, in a restaurant since before graduating high school. He was cultivating a career, not a job—a sentiment expressed on multiple occasions throughout the interviews. Then came the injury, and at least for the career he had intended, disablement.

“There’s no way I’m ever going to move in the kitchen, you know? And all I have was a high school degree at that point.”

With the recognition of his kitchen life no longer a viable option, *Dick* felt his future stability vanishing. Complicating his situation was when “Disability (Social Security disability office) denied me, and ‘you are not disabled.’” *Dick* was impaired as it related to performing the responsibilities of his current job but not to a degree that he was considered permanently disabled by government standards, and he was left seeking a new path.

In retrospect, as *Dick* considered this “rebuilding” of his professional and future self, he was not rebuilding so much as “building.” Though he speaks of the kitchen and cooking as a vocation, the degree to which he emphatically asserted how he was in flux without this known quantity begins to lessen, and ultimately *Dick* stops, and laughing, shakes his head, “That’s not really my bag anyway.” Whereas one might ascertain the impairment has thwarted *Dick*’s plans and forced him into finding an alternative, the truer statement may be that the ongoing process for *Dick* was recalibrated post-injury, and the future he had decided for himself was, in fact, his settling for a safe and known entity. Challenged with a disruption in this path, *Dick* is learning more about his other interests and aspects of himself not explored since gaining his impairment.

I know that I'm not an **athlete** anymore although I've *been told* I'm an athlete. (Interviewer: It's hard to get rid of it sometimes.) And so I found different ways to be...*competitive*. (Interviewer: How do you compete now?) Well, like with music.

His cognizance of his physical health did not diminish his psychological identity as a competitor, though it has driven him to reconsider it with respect for his present impairment. "That's really one thing I like about a competitive spirit (and his approach)...it's more...more...in a **constructive way**." As he delved into a description of the sort of "dueling guitar" contest he and his friends challenged one another with, each expected to play something better than their competitor, a visible change comes over *Dick*. Now, moved forward in his chair, sitting upright and more actively speaking with his hands and body, he talked of music and his initiation into the local comedy community.

The changed status *Dick* embodies first forced, and then allowed him space to visit the other areas in which he had strengths and interest. While initially outlets for his competitiveness, they served as accomplices in leading *Dick* into his communication and broadcasting field. His academic life was enhanced by replacing his need for competition, and he was rewarded by having it help define the person he ultimately wanted to be—with or without impairment.

Seriously Medical/Health Related

"There is a whole other element of my life that I have to factor in. **You** want to take the class, you take the class...**You** want to go to the game you know—*go to the game*."

There may be an assumption, right or wrong, the only concern in evaluating how students with disabilities engage with an environment, such as a college campus, is

physical accessibility (e.g., electronic doors, wheelchair ramps, appropriate walkways/doorways) and ensuring ADAAG (American with Disabilities Act Architectural Guidelines) standards as the legal requirement. In examining the experiences of study participants, there is an aspect not associated with ADAAG inaccessibility, but other factors, such as consideration for medical and health-related issues. Participants brought into their conversations the health and medical needs that become central to understanding their lived experiences as college students and their interactions with the community of peers, faculty, and staff. Individuals—whether impaired through chronic condition or injury—are heavily dedicated to a strict routine, established for their care and wellness.

Similar to several participants in the study, *Robert* took time off from his education while he rehabilitated and aligned his personal support needs. His separation from college only lasted an academic year, in which time his entire college expectation and experience was altered. Admirably, he completed his undergraduate degree only one year later than he had been planning prior to the accident. Initially in his return post-injury, *Robert* found the impairment playing a significant role in aspects of decision making he had not considered during his rehabilitation and reintroduction into school. He felt susceptible to environmental factors and people, who while not knowingly creating hazards for him, were raising the risk factor associated with his being a campus community member. University life became a game of logistics, carefully orchestrated maneuvers established to ensure his safety and preserve his health. “I think about (time)—the schedule. There comes...there are certain times that I know I would (encounter a critical mass of movement/students).” *Robert* is aware many of the concerns

he had (and has still) are real and not imagined or magnified by his insecurities, yet he is grateful of the good-naturedness of those around him. People are, he believes,

“accommodating and helpful but are hesitant and unsure what to do.”

I suppose for everybody (unintelligible recording)...I can just act *normal* and...everything will be...*fine* but **they're** afraid. That ‘I don’t know what to do with this person’... ‘**Oh my god, he’s got a disability**’ you know?

People’s insecurities, coupled with his own, were leading to situations in which either nothing was being done on *Robert’s* behalf or people were coming at him with multiple questions, suggestions, and concerns they thought were important. But to *Robert*, instead of helping establish a safety net, their well-meant intentions heightened the risk he felt.

“In layman’s terms—I (was) afraid.” Fear combined with *Robert’s* new embodiment to transform him into “a bit of a recluse.”

It was not automatic, but over time, *Robert* saw how problematic this behavior was to his psyche and personal health. Someone who described his past self as “outgoing and gregarious” had transformed into a marginal student who did not get out, withdrawing to the security of what was familiar because of fear, possible risk, and the perceived reactions of those around him. “It took, I don’t know, probably at least one good semester of going around to different classrooms...going around to different places on campus. Finding out where I can get *independently*.” Now “disability is not even in my vocabulary” or at least he believes he does not knowingly dwell on his impairment. “...I’m just one of the...(exhales) I’m **just a student**.” But *Robert* acknowledged without prompting he does filter decisions through a disability lens.

I don't know... (approximately 5 second pause, he begins to drum his hand on the arm of his wheelchair)... This is very difficult for me because I'm the type of person that my focus on things is "Well, I'm here. We're going to have to do this. I'm **going** to be included." And people get that from me... they get that vibe as well.

Robert has a self-described *stubbornness* and seeks to challenge his concerns regarding involvement, participation, and social activities. He is acutely aware of the risks, but opts to approach situations head-on. In so doing his concerns are not alleviated, though he does think people around him come to own the unease as well and help preserve what he needs to be safe and unscathed. Still, an important deterrent to entering potentially risky situations has been clear memories of his earlier college experiences and behaviors.

Drinking. Partying and all that stuff. I mean... when you **inflict** this type of injury—**on yourself**—because of *alcohol*... (nodding) you kind of get a good wake up call.

Robert avoids such settings now, knowing they create bad situations for him, situations which are often uncontrolled and therefore hold increased danger. Additionally, recognizing the dark places he has gone emotionally, to engage in similar practices (whether he were to drink or simply be in attendance) is to relive the physical damage he has done to himself, and only drives his psyche into a spiral of regret and depression—something he has spent significant effort to pull himself from once before.

Entering the final stretch of his Master's degree, *Robert* is finding balance in weighing his campus and life opportunities versus the considerable, very real, and permanent personal health factors involved with his day-to-day. Where *Robert* exists now, physically and mentally cognizant, was not an immediate turning of the corner for him. There were steps to his determining expectations for himself and his experience. Along the way have been positives and plateaus:

I switched. I had to reassess my career goals due to (his physical limitations). And I didn't have **anybody** to **drive** at that time. I couldn't drive **myself**. Umm....so I had to find people.

I've *never wanted* to go (to the campus movie theater). Probably because it is so far away. It will take a *year*...it's a pretty long haul.

But there have been several milestones that had helped...keep me motivated and generated—and led up to and *precipitated*—the attitude that I have now. You know, I started back driving again. Moved into **my own** apartment.

Dante was not only transitioning to college, but also was a transfer student and was working to re-establish services such as Vocational Rehabilitation and Social Services following the move to a new city.

You get your mind set and decide you're going away to college and start recognizing this goal is achievable and then (pause) then you start to realize all the issues...transferring medical records to doctors you still have to **find**, lining up your funding that is tied to where you are living—and that pays for doctors, CNAs, therapy, specialized equipment, health services...it—was just—**erratic** for the first couple months. **I mean erratic**. Seeing everything and...you...just wanted to have some...**control** about the situation.

The responsibility *Dante* confronted was securing his health needs before he was able to be a student. He hadn't arranged a class schedule, chosen a food plan, or learned his student ID number, but was tasked with lining up the people on whom he would rely for his essential daily care and well-being. Once arranged, the care routine and CNA appointments determine the rest of his day and night. Life is dictated by a very strict schedule of CNAs coming in the morning and at night. He is, for lack of a more delicate term, confined to his wheelchair or bed until such time as an assistant arrives to transfer him to another location. His disability is an adherence to a schedule, a plan, and logistics.

As someone with quadriplegia, *Dante* is aware, “hyper-vigilant,” about “conditions impacting your ability to maintain. Cold, heat, sun, safe transportation...” His body is susceptible to variations in temperature since his body no longer regulates hot and cold, like his internal thermostat does not adjust to the conditions around him. With compromised feeling throughout his body he has to remind himself when he has been away from home or a bathroom for too long because he will not sense a full bladder and is dependent on a catheter. If it is full or malfunctioning, it can lead to a urinary tract infection, incredibly dangerous for an individual such as *Dante*; by the time he would be aware of a problem the UTI likely would be a significant infection. His younger brother, also a student at the university, has been a positive addition to *Dante*’s final years in school. They live separately, and live separate lives, but it does afford *Dante* an opportunity he missed out on because of his initial injury, the recovery, the rehabilitation, and the transition into a local community college while living at home under the care of his parents. He “gets to be the big brother... buy him food, help when he (laughing) loses stuff or has questions and problems. (Long pause and he scratches his chin) But sometimes I have to ask (younger brother) for help—like with a catheter.” *Dante*, visibly affected, has become fidgety, shifting his weight back and forward, and appears to redden in the face. “I really never worry about whether I have people to go with” (to movies, games, events, etc.). Instead, *Dante*’s concern is his body.

There is a whole other element of life that I have to factor into things. I mean, I’m used to it, but a lot of the things I would do other people would not think much about...

Does it work with my CNAs?
How long will it take to get there and back?
How long will I be there and *how* will I get back?...

A lot of times, things will be scheduled at times that just won't work (club meetings, class gatherings, parties, sporting events or performances).

Living in on-campus housing was an important milestone, and a benchmark, for *Dante*. His aim is to eventually live independently in an apartment—*alone* the apt term only in the mind of someone who has gained comfort with the necessary cycle of caregivers coming and going. In order for this goal to become reality, *Dante* has to learn and then trust the system lined up in his college housing, and carry it into his future life.

We have a plan...because once I'm in bed, I'm in bed for the night until (the CNA) gets me out. It's like—the fire alarm is going off, right? 'Uh, sir, we need you to go outside.' 'No, no I can't.' 'Sir, we need—' 'I'm quadriplegic. **I can't physically get out of bed.** I'm in room ____."

Dante is expected to perform as any other student in his coursework. But too frequently people do not adequately comprehend how his impairment impacts every aspect of his life.

People see you and they see the wheelchair and they understand **the wheelchair**. But there's no thought past that into what is all the *behind-the-scenes* stuff—what it takes for me to get in the wheelchair in the morning with my CNAs...like, there are so many **levels** that others don't see.

An example he shared involved a class project in which student groups were tasked with developing a script, a filming schedule, and scouting a shooting location. As the group worked through where they wanted to film their project, *Dante* felt he had to continually ask questions and trust his peers to look out for his safety. They wanted to use a house, and he had to inquire if there were stairs. "Only a small one" he was told, "we'll just lift you." "But my chair weighs like **500 pounds!**" Additionally, the rest of his team found the early mornings most manageable, but for him, "in order to get there, if I skip a lot...it'll still take me two hours!" Nothing is a simple task when working with a physical

impairment. Most things are doable, but it is never simple and it is more often “overbearing,” with considerable thought and planning necessary for even the most routine and basic of activities. And when something has to give, it can’t be the routines necessary to maintain his health, and that means nurses and care-givers are the constants-bookends to a day no matter what comes between.

Dante’s reaction when speaking to the social aspects of college life exemplifies how the seemingly simple thought of *doing involvement* can actually be far more detailed. Determining action—whether to engage in extemporaneous learning or social activities—is a process for a student such as *Dante*. Significant thought and planning is necessary and even then, he must decide if the time spent would be equivalent to the work and the potential drawbacks.

I’m just not sure that it would really be *worth it*. There were things I wish I had gone to, but it wouldn’t have been for lack of **feeling like I fit in** or anything **like that**. It would more have just been on the lines of...*you know*, I’ve got a scheduled CNA coming tonight.

The autonomy of choice, an individual’s freedom to simply choose to participate, to watch, to join in, battles the necessity for self-care with students such as *Dante*, *Robert*, and *Andrew*. Similar to *Dante*, *Andrew* adheres to a CNA schedule but has the additional support of a full time caregiver or aide with him at all times. With daily living tasks he has little autonomy; his life as a student with a disability who has another adult with him at all times arguably has even less. *Andrew* said his impairment is not his most important identity or aspect of *him*, “it’s just like any other character trait or something.” But the impairments related to his disability require he begin and end each day with

assistance from his CNA and he was aware his schedule is dictated by their arriving and leaving,

Typically (the CNAs) have to leave at midnight. And so there are certain things that I **have to get done** before they leave. And so sometimes that does keep me from being involved with certain things. I just take that as something I have to do...(he stops, then begins again) and go on with it.

Within the hours of his day, *Andrew* navigates campus with fulltime support. *Andrew* performs with various groups at school, and he left the interview to get to one such practice, with his aide walking in front of him. He sensed this does not impact him to any real degree, though it may require a bit of explanation, telling people someone extra will be with him. “Sometimes, they might, like, sit a bit further, right or something?...or just be where they can be there if I need something,” but they have also learned to give him some space.

As *Andrew* is always accompanied by support personnel, one may question the degree to which choices center only on his wants, versus having assistants who also must be present. He is never just a student; rather, he is always a *disabled* student and his aide. Does this make it tougher to integrate? Are choices then about want, or about considering that the aide will be in tow, and therefore *Andrew* can never be just “student”? His presence is always as the student AND caregiver.

Due to a serious adherence to a routine focused on medical issues and health, participants may lack a certain kind of autonomy and self-determination. So often, college is painted as an experience where students are figuring out who they are and with whom they fit; that requires self-discovery, introspection, and a type of freedom (of movement, exploration) that may be hindered by the presence of their aide. On the whole,

Andrew said very little about having an aide or caregiver—positive or negative—though stated on multiple occasions that his impairment was a non-issue. How much that was influenced by the constant presence of this individual in the room during the interview is debatable. His impairment prohibits him from driving, and if his daytime aide was not available he would need a variety of other measures to “function.” The campus housing he has been assigned is designed for a single, but because of “the Medicaid system or whatever there has to be a primary caregiver in place before they’ll provide services.” Therefore, *Andrew* found his decisions further limited because without this person he would also be without significant financial assistance. The degree to which he recognized choice in the matter is difficult to ascertain. Describing the arrangement:

I have (someone from home) that is just staying, like...just... he’s...**living** on campus with me...He’s sleeping in *my living area*. My first year I was in one of the rooms for RAs (resident assistants). It’s made for **one person**.

In correcting himself, *Andrew* emphasized this person is not a visitor, not a roommate, and certainly not an invited guest. It is his apartment that has been co-opted; he pays for the apartment while his designated caregiver lives in it because without the individual he also cannot live there. Yet to hear him discuss the day-to-day, *Andrew* is adamant—his impairment does not impact the decisions and opportunities available. In saying this, he glances across the room to the corner in which his aide is sitting, watching and listening to our conversation. *Andrew* holds eye contact with this person for several seconds before returning to the conversation.

(Interviewer: How does that, or has it had an impact, with interacting, or student activities or things like that?)
Andrew: No. Not...really.

In concert with the demonstrative manner through which *Andrew* held, and then broke, his gaze with the aide accompanying him this day, his answer may be much more complicated than what was given. His words and demeanor suggest a mild defiance—his making clear to the third party in our room (and himself) that he will have “normal” experiences in spite of what is obviously, based upon our majority perspective, their nonstandard arrangement. The stare, and *Andrew*’s countenance, foretell what could be mistaken for anger if taken in isolation from the rest of the conversation. Instead, there is a signal of persistence. He is, in one regard, the dependent, relying upon this person for crucial aspects of his daily functioning and safety. At the same time *Andrew* is the client, the controlling interest in making determinations, and unwilling to relinquish the reins. Together, they create a violent tension--the tug to have freedom to choice and the pull of being guided in ways deemed necessary or in his best interest by his employee.

Though different from *Andrew* in most regards, *Claire* shared a similar, though not the same, experience when it came to campus housing. Whereas *Andrew*’s fulltime caregiver fills any extra room in his residence, *Claire* lives alone because of the substantial space taken up by equipment needed for her therapies and health. She does have suitemates, but she chose not to have a roommate because her health and the devices necessary to maintain it had to take precedence over the “roomie experience.” Like *Dante*, she recognizes the need to be hyper-aware of her body. “My condition is progressive, and it changes,” necessitating she consider the implications of situations based upon the physical stresses put on her, and how they may potentially compromise her long-term health. As such, she is constantly adapting to a changing body in an environment that does not. Because the progression of impairments related to her

diagnosis has been gradual and slow developing, it may be that it has been easier for *Claire* to understand and adjust to:

If I—immediately upon diagnosis—if I was the next day where I am *now*...it would've been **much harder** to accept. Whereas, this kind of gradual, you know...(she smooths her hair back behind her ears) I can gradually kind of *discover*?...what I'm getting into and...be able to understand (she gestures toward her body and looks down over herself, then returns eye contact) **this**.

Recognizing how quickly she fatigues keeps *Claire* from situations in which she would need to walk long distances or stand for extended periods because there has to be a constant (healthy) fear for personal safety. Forgetting, or trying to live in denial of her limitations (as she states to have witnessed in others) places her in peril that is avoidable. Unlike what some others have said, *Claire* interpreted her identifying as a student with a disability as “show(ing) that you kind of *accepted* it.” She has developed a keen understanding of the boundaries and hurdles she may encounter and is cognizant of how her mobility has greater implications than simply changing how well she gets from place to place. Were she not to be thoughtful in this manner, *Claire* would “see it as a cop out from trying...not **thriving**.”

The goal of thriving is paramount to *Claire*'s understanding of the college experience and her decision-making. Her preparation emphasized mobility in a way that is least restrictive but also closely associated with maintaining her health. Unfortunately, as also experienced by *Dante*, her peers do not grasp the significance of her impairment, mistaking her mobility device as the extent of her differences. *Claire* has come to understand the way it will be, since “my disability really dictates my schedule.” She understands the broader implications of her Muscular Dystrophy while her peers, faculty,

and campus see just “someone on a Segway”. This created situations in which she was defending her decisions to opt out of going with other students to certain events, locations, or when her stamina had been exhausted. Despite being an underclassman, *Claire* has confidence when faced with situations in which she could easily feel as if she is not being given the respect by those around her to make choices best for her.

I take pride in—you recognize—that it is a significant aspect of **your** *life*, something that really affects *who you are* in the sense of how you see the world and how you view others. Yes, I think in general, I think people see it as something they take pride in, like their ethics or something. Me, specifically, I think I do take pride in my disability but I don’t know if that is common.

Whether identified as recognition, metacognition, or pride in her disability identity, *Claire*’s judgment and decision-making balances her goals to thrive and to be as healthy as she can be as long as she can be. If she must opt out of a late-night coffee trip or navigating treacherous access to a performance, she does so knowing she is operating with an eye toward the bigger picture.

Disability, being such an individual experience, impacts individuals in unique ways. Whereas *Claire* seeks methods by which to maintain or improve her mobility, *Dick* was looking forward to when he will be impaired enough that his situation could actually improve, when he could “be really happy when I can no longer walk” because maybe the pain would subside as well. After years of being denied “disability, I’m *glad* (government/Social Services) finally **gave me** (disability status)” because official recognition was accompanied by financial support, enabling *Dick* to acquire the equipment and mobility devices he needed to function more fully, “a combination of the cane and the crutches. I wish I had these a long time ago.”

He encountered the misconceptions of his peers who saw his gait and failed to understand the severity of his mobility concerns, minimizing consideration for his needs because it is *just a limp*. That expectation of performance prompted *Dick* to ignore his body's warnings--the near constant and excruciating pain radiating through his foot and leg—and led to over-extending himself. Moving forward he is forced to reconsider how he cares for himself. He is considering the question, *Do you push yourself to do the work* (“By the time I was done (with a group project) I had been on my feet for almost five hours”), or *do you take care of yourself and pay attention to your health* (“That was the end. The next day I could not walk...and I pretty much had to drop out for the rest of the semester”)? *Dick* was forced into a decision and prioritized a course of action meant to reduce the physical trauma upon his leg. To maintain what mobility he could, *Dick* opted to pull back from some of the social aspects in his life until he could better assess how to efficaciously navigate school and life in his newly impaired identity. Weighed against sacrificing long-term health and the threat of further deterioration, additional pursuits *Dick* had long considered important to his undergraduate experience and active lifestyle became less important; he wasn't going to run a 5k, rock climb, or hike a pack into the woods. He would need to adapt. He never indicated an interest in study abroad programs when talking about goals or his thoughts of college experience, though when turning his attention to how his experience was going to be different than it may have been previously, its appearance was prominent:

Study abroad, tour around Europe. “*Yeah*, I'll be here at the train station—you guys have a good time!”

I probably will not be able to do that (an international study trip) because I will not be able to keep up with the group.

Okay? **That** is the thought that goes through your mind.

With all things *Dick* now encounters, he focuses on developing a plan meant to accommodate his sensitivity to chronic fatigue, pain, and weakness in his lower extremities. “I’m a little bit of a homebody, you know like I said. It’s good for me to get out of the house and *do what I can do* but because of my disability...” There is comfort—ease—in staying home (paying bills, studying, watching a movie propped on the couch) but necessary tasks and errands prompt *Dick* to travel to campus frequently. He has, however, adjusted with thoughtfulness toward his wellness and safety. Long days on campus now mean bringing lunch or finding venues near his academic building instead of walking across the campus to dining facilities or the student union; searching for a vacant lounge or classroom in which to study rather than walking to the library; and riding with a friend who starts classes two hours before *Dick* needs to arrive in the morning because it keeps him from utilizing the park and ride lot a half-mile from his building (note: this point became moot; first, *Dick* recently had qualified for disability parking access, and second, he sold his car earlier in the term to cover medical and school expenses until he was granted disability funds). Moving forward, rather than dwell on the limitations, *Dick* expressed the process as “trying to find a balance. It...doesn’t just happen. I start with what works, what is **good**. And when you do that, when you start out *at that little thing*...it really doesn’t matter, and you don’t see *yourself*, as a cripple.”

The fear of a *crippling* impairment is realized by *Lauren*, whose big transition in identifying as a person with a disability was caused by recognition of her diminishing physical health and her awareness of increasing safety concerns. It “got to the point where I can no longer get up off the floor” without assistance when she falls. The

progressive nature of her impairment necessitates she continually pay attention to signs. The more it changes, the greater the frequency with which she requires use of her wheelchair.

I think a lot of people think, you know, you're not really **supposed to see that** (disability) as your number one identity, but since it affects so many other things, it's hard **not** to look at yourself that way.

There was a time when *Lauren* could get by without identifying—or being identified—as *with a disability*, and she intentionally chose to not be associated with her impairment.

I'd pretend like *I wasn't* disabled. (But as her disease progressed came an acknowledgement) “this is who I am now. Now I can think about *this* in terms of **this** part of my life. This **is** part of my life...It...helps me to kind of...(slight laugh, cutting off) **deal** with all these parts of my life.”

Lauren's adherence to a lifestyle in which she put her personal health first was paramount to her ability to engage in the other parts of her life. Unfortunately, her sentiment is if she fails to put her health first no one else will, “I really feel like my safety is not important” and goes so far as to suggest “they (the university)” have placed her at risk of injury through their practices. As she transitioned toward greater impairment, such experiences left her considering if going anywhere was worth the risk of personal injury, and in a sense, a feeling of being defenseless to the world around her. During her undergraduate years *Lauren* had difficulty establishing appropriate parking near her classrooms, trying to safely ride the buses in her wheelchair, and getting certain administrators, faculty, and staff to acknowledge her need for disability assistance, with the consequence it placed her in the position of “**having** to think about (her health).” She began withdrawing into a smaller and smaller world, spending the majority of time within her apartment where she controlled the environment. This tremendously impacted her

willingness to seek social involvement and more consequentially, her class attendance and academic pursuits. After a period in which she was reasonably at risk of disrupting her education, *Lauren* altered her mindset toward navigating campus life and her disability, learning to maneuver and make concessions, “staying away from crowds...parties...tailgaters.”

To preserve her sense of wellness and with deference to her precarious mobility, *Lauren* chose to move off campus. “My doctor told me it would be better for my health. You know, I have a complicated situation” and “need a lot of rest.” Though it may seem a negative, *Lauren* preferred to leave dorm life, and knew it was best for her long-term prognosis as the setting allowed her to more ably manage facets of her disease with greater privacy. Additionally, within her apartment *Lauren* could minimize some of the disabling aspects of campus and community.

I think it’s (identifying the disability) in the mix, but...I mean, you know I am not **using** my chair every day. It’s not (stops and glances upward, appearing to think)...*Some* days? (returns eye contact) I don’t really **feel** like it’s an issue because I’m just **sitting on the couch** with my fiancé, watching movies.

Lauren suggests she is seeking a sense of place, of peace, of safety—and the best situations allow her to exist with autonomy and freedom. Still, despite efforts, there can still be limits to the freedom from impairment, even when staying home to watch movies. “At that point it’s (the impairment) not an issue, **but** *when I get up to get popcorn?* Getting **off** the couch?...then it’s an issue because **that’s** hard for me.”

Limits on *Lauren*’s personal life and the activities she shares with her close circle prove more difficult to accept than those through the university, whether class or socially related. “School is school”—a means to an ends. On campus she knows how to minimize

(never eliminate) those risks, and makes the choice to use a power wheelchair for longer distances in which “I feel like I will normally be fatigued (e.g. most of her time on campus).” She prefers a particular coffee shop though not the particular coffee (“I can just go...because it’s so wide.”), and has learned to avoid areas that make her uneasy, are “crowded,” “narrow,” or instill a feeling of susceptibility.

Entrance into a graduate program after completing her degree provided *Lauren* an even smaller, closer group of friend, with whom she was more comfortable and seemingly more willing to be vulnerable. “I think they’re a little bit more...*open?*...to seeing you as a person.” Social gatherings consist of small, intimate groups rather than what she characterized as “college activities” where large crowds compromise her safety due to poor balance and her inability to recover and get up without assistance. More risky activities involved too many questions:

Is there parking?
Can I safely enter, get around, sit?
Does it cause too much stress even to consider?
Can I manage if I need the chair?

Her outside-of-campus life, where *Lauren* has focused more heavily since becoming involved with her fiancé, is cherished.

It’s (the disease) definitely a lot of work but it’s not always (she interrupts the current thought)...I mean, it’s there **all the time**. I can’t even change how I see myself in my relationship with my fiancé. It’s **everywhere**.

Yet whereas she was willing to forfeit many of the typical experiences of college life to preserve her mobility and waning energy, *Lauren* does what she can to not sacrifice within her romantic relationship. Even so, safety and health concerns remain a key aspect in considering her ability to lead a fulfilling life, and for *Lauren*, plan the wedding she

wants. The worries *Lauren* previously considered to be her individual issues are now understood to be a concern for her and her partner “because (my fiancé) gets flustered if there’s a lot of people there, and I don’t want to deal with that.” Even so, awareness of such concerns is generally recognized as a positive.

If (I) **didn’t** self-identify (identify to herself, or accept the nature of her impairment) like that, I mean, I couldn’t plan my wedding properly. I couldn’t plan *much* of the ceremony.

How am I going to *walk* down the aisle? **How?**—You know what I mean?

I guess you are who you are, so I guess it’s better to be realistic about you and *accept who you are*. I think...I think it’s more helpful for me to self-identify that way because I can...I can think about other aspects of my life through it.

Susan is at a university she felt “pushes involvement” as a core expectation of being at the school. Messages and newsletters with schedules of events and upcoming opportunities arrive in her email and campus mail regularly. On most occasions she chose not to follow up on these possibilities, perhaps because she was overly tentative and cautious with regard to the potential negative impact of her disability.

(Disability) is not *who you are*. It shapes **how you do things** very much. Everything you do...in your life, from the things—(she stops, waves a hand, and restarts)—What you choose to *eat* or *where* you choose to purchase (it), or **live**, or school you go to.

Aside from an awareness of the ease with which she can exhaust her energy, a condition she monitors closely to avoid dangerous levels of fatigue, involvement with various aspects of campus holds other perils due to her instability when walking independently or with crutches.

Yeah, I’m not supposed to be walking on campus. I’m supposed to be using my wheelchair...(long pause

highlighted by a tight-lipped smile) *for the doctors*. It's not a good idea to, you know...and... not a good thing. And *partially so I'm not wearing myself out*.

Susan's fears—that she will cause herself medical problems or be injured by the events around her—effectively cut her off from the vast majority of extra-curricular activities offered by her institution. During our first interview, we discussed a calendar of events picked up from the student union, and *Susan* found examples why she self-selects out of such endeavors and why she chooses others. First, her school hosted a campus fair in which 250-plus student organizations line the main academic corridor with tables and displays meant to showcase the many choices available for students: *Something For Everyone*, as they tout. Instead of seeing the prospect of discovering areas of involvement, *Susan* had a different take: “Huge crowds are definitely a turn-off.” Her regular route from one class to the next would have taken her through the main concourse on which the event was being hosted. On this day, *Susan* opted for a longer and less-direct path to class.

I would **never** have done it with my crutches. I don't know—*with a wheelchair?*—'cause so many people... There's **so many people**, confinement with it (does she mean the wheelchair or the crowd?) was very unnerving.

Her perspective is not only informed by an interest in the type of event, but also the design of the activity and its location, and further still, the recognized safety inherent in becoming a participant. And while none of the drawbacks are technically in compliance with ADA guidelines (the fair had stated policies for where tables and displays could be located in order to keep walkways clear) they might represent non-compliance with basic accessibility from the perspective of an individual with a physical impairment.

Susan's words used in discussing the particular situation—*turn-off*, *confinement*, *unnerving*—are telling of her decision to actively avoid the event, and not simply her choice to not take part.

Second, *Susan* pointed to the list of upcoming films being shown at the union's movie theater. “**Those.** Looking at it, it's much more pleasant ‘cause it's more organized, you know? Everything's in line, the staff there can kind of help you.” Unlike the fair, a movie theater offers a stationary environment with fewer variables. Viewers are not expected to be walking around other than when finding a seat or exiting to use facilities, purchase concessions, or leaving at the conclusion of the film. Evaluating the offering of titles, close to 20 in just the first two months of the semester, *Susan* said she would reasonably be interested in seeing about 75% of what was scheduled to play, though she believed it was far more likely she might attend two or three films all year. Movies play in the evening, and on the weekends often start later than she is willing to stay out on campus. After a full day on campus, which might begin ten hours before a 7:00 p.m. screening, the risk of depleting her energy level is too high. Being tired is not just being tired; *Susan*'s gait can become more unsteady, her ability to vocalize can be compromised, and her muscle strength can decrease to the point she does not feel safe driving or where it will force her to spend a day resting before resuming her school schedule. Was she to become significantly depleted, *Susan* is aware she is less cognizant of her surrounds, leaving her an easy target to assault or robbery. It frightens *Susan* to think wanting to see *Iron Man 3* could have such tremendously negative results. She remembered a list of opportunities never followed through on, and in each instance appeared to thwart participation due to disability.

But other things...ok, interesting but I can't. I'm tired, I've got all this other stuff (gesturing first to her bookbag and then her body) to do.

(Interviewer: Like what? What else have you thought about?)

(The health event) Looks super interesting. Everything will work...All the things that come up, I could think about, (it) would probably work and I'm thinking 'Will I be able to do that today?'

I would really like to try *exercise*... I'm afraid to overdo it. And I'm afraid that I'll have to take **more** school off. I'm **afraid** that I'll overdo it here and then I'm going to make up for some...you know...**no** (long pause, she gazes up to ceiling and looks around the room before returning to making eye contact). *I'm not going to be physically able to do all those things.*

With this, *Susan* appeared visibly distressed and returned to looking off to a corner of the room. Given an opportunity to temporarily halt the discussion or stop completely ("Maybe you'd like a break. Would you like to turn this (recorder) off?"), *Susan* smiled, ran a hand through her hair, and chose to continue. The look from that moment never left her face, and shortly thereafter the interview was halted based on its apparent impact on the participant. She seemed surprised, and maybe relieved.

Susan contacted me to arrange the follow-up conversation, and of all that may have been said, one thing typified the role disability plays in the choices she makes and how every decision is viewed through the eye of impairment:

There are definitely some places where I can go and blend in and it won't be a big deal. Aaaand...there are also some places where I am very...**nervous**. And I have to check these places out, and I'm not sure...*who will go with me?* For me, like, **eating on campus?** I'm not sure. If I have to carry the tray and everything...yeah, that makes me nervous.

Analytic Question 2: Does the Narrative Employed By Participants Add a Complexity to Their Assertions of an Overall Positive College/University Experience?

Participants in the study appeared to share a similar trait, whether speaking of their academics, social involvement, or day-to-day life. These individuals balance a desire to “blend in”—to be seen as a person, student, or any number of primary identities—with deep and challenging understandings of their physical bodies those without such impairments will have difficulty understanding. Given the magnitude to which disability defines their experiences, it may be surprising how participants characterized their stated overall positive college experiences.

I don't think that disability and acceptance is a big issue. I don't see, like bully of people with disabilities.

This campus just values acceptance a lot and tolerance for anything...the recent years there's a big push to make the campus more accessible, like all the buildings and everything.

Specifically on campus, I think there are more very positive experiences.
Even where I'm not able to do as much physically, I still feel like I'm...part of it.

Their declarations of positive experiences are self-identified, and when an individual perceives something to be good there exists no rationale to challenge that assertion.

However, based upon what was said in our conversations, participants revealed a deeper understanding of the situation than evidenced in their primary responses. Therefore, it is worth exploring how the extemporaneous narratives add complexity to initial assertions of overall positive experiences by participants at their universities. To be clear—to show a complexity of their encounters does not seek to define them as having been negative. If

anything, perhaps it highlights the degree to which *bad* has to be sensed as *bad enough* to reach the level of being truly damaging to the overall experience.

Physical Access

Access. To be accessible is to be attainable—available. Students with physical impairments have to be willing to trust the efforts of their universities to ensure accessibility of the campus and campus activities. A general sentiment of participants was that their decisions and involvement were not largely driven by accessibility concerns. But as participants were given time to speak freely, stories emerged which were not specifically in response to prompts or questions asked.

Andrew was adamant accessibility was not a concern of his in academics, campus life or social involvement. Yet, he offered what might be heard as contradictory information interspersed throughout other things he had to say, as if contrasting what he shared when recalling one of the best situations he had experienced at his university. For instance, in telling of his participation with different performance groups, he began by saying how he found it all “supportive of, like, a normal college experience”:

The only issue that I’ve had was like (shifting his focus to the window) getting **on to** the stage (for performances). They were able to get a lift and they would (hoist) me up on stage. Before that they had to, like lift me in the chair. I really don’t want to do that again. They just...set up a chair on the stage, carry me up the steps, then lift the chair and then transfer me back.

He continued by detailing arriving on the first day of classes to find

the building was not accessible, like there was no entrance, no elevator, or anything...I think the aide that was with me just went into the classroom (to inform the instructor). But the **next** time it was in a different location.

Andrew stated faculty had been easy to work with, understanding and willing to find ways to “work around” his accessibility needs. Further

for whatever reason, or if something doesn’t work (like an elevator or automatic door) it’s always fixed, so I guess it’s definitely a positive message whether it’s intended.

There are at least two ways of considering *Andrew*’s stories. First and maybe most obvious on the surface is an indication his university found ways to address his access concerns as they arise. He initially was carried on to the stage and placed in a different wheelchair (not the chair he uses the rest of the day), and later they acquired a hoist to lift him instead of him being carried by members of the group. When encountering a building he could not enter and attend class, his personal aide informed the instructor, *Andrew* left, and the class was moved for the next meeting. To *Andrew* his institution has been cooperative. Another interpretation is that *Andrew* encounters situations on a daily basis challenging his free mobility and access. He remains dependent on fixes, work-arounds, retro-fittings, and rescheduling to maintain class and extra-curricular involvement.

Claire told of similar dependence rather than access.

Yes, there are...*some buildings* that I can’t get into. But when I **have to get there**...people have worked it out in order for me to get there.

She, too, has been carried up steps because she was scheduled to participate in a performance only to find no one considered the accessibility of the venue ahead of the event. Or for that matter, how to get her off the stage after:

(A friend) asked me to play with her on it, well, at her recital. But the hall wasn’t great, like there were steps to get to the stage...like, there is no way to really get up to the stage so...(slight laugh)...Anyway, long story short, I ended up kind of being

trapped between two sets of stairs and no one was back there to help afterward.

So, yes, negative experience is pretty directly correlated to accessibility.

Claire went on to detail being unable to get to a phone, waiting for someone to return as the facility was emptying and watching the last audience members leave. She was relying on the same people who lifted her before the performance to realize she would need assistance at the end and help her. Eventually they did return but only after beginning their way home and turning back.

Though quick to offer her position that campus is accessible, *Claire* distinguished *access* from *convenient access*.

Like some buildings...*say* they're accessible, but it's like...yeah, you have to go along three other buildings to the back of this building...it's a maze. But it **is technically** accessible.

I come in through a different door.

The buildings are burdensome to enter at times, and equally challenging once inside.

(Classrooms) have accessible chairs but they are often very isolated...which makes them difficult to talk with people in. Make the first row open *on the ground* rather than **off the step**. It makes a difference.

I have a lecture class where it is **all steps** (i.e., stadium seating) and I sit in a chair in the very front. (short laugh, and she brushes her hair from her face) It is just a **completely separate** seat from everyone, and yes, it is *not good*.

While meeting the technical expectations, in so designing environments, physical space may establish an emotional feeling of separateness within the students reliant upon their accessibility. The issue, then, is not only one of access but building for inclusion.

Dante “can’t really call it a negative” that his impairment requires him to trust the care of others, that is, “to be at their mercy.” He is quick to praise the administration in campus housing, and does so repeatedly. Upon informing the university of his intention to enroll and disclosing his impairments, the housing office arranged to speak with him and discussed potential needs beyond the wheelchair accessible room. When he arrived on campus the following August, *Dante* found his ADA compliant room pre-arranged with the furniture moved as he stated would be necessary, and also equipped with various adaptations he asked to be in place. He had a plan for fire and emergency response, and was provided information about linking his phone to dial campus police through his Bluetooth hands-free device. Placing trust in others is an important step toward survival and his best chance at thriving. But that is not to say navigating certain settings are without stress or are not impactful.

Just thinking about all the *technical* elements or all the elements that we have to go into doing something which seems like it would be something someone could just do by **walking in**...it’s kind of overbearing sometimes, and it just makes things seem—I don’t know, hard?—when they are not, and say ‘I’m going to put this much effort into getting in this place.

He has conditioned himself to adhere to a pattern and systems causing the “**least amount** of disruption,” which by its nature, only suggests he has chosen a plan with *less* difficulty than it could be, rather than disruption-free. And though he speaks of the relative ease and comfort with the established patterns, *Dante* mentions a detached feeling with the outer areas of campus including the main dining facilities, student union, and a large section of campus housing. His choice to cordon off segments of his university is limiting in that he has cut from consideration many parts of campus so he can better prepare for

and thereby, better control, the more crucial aspects of his college experience. As for why and how he made the decision to shrink campus to its core:

I mean—a couple of the buildings (he then indicated three campus facilities)...they still don't have **push button doors** or things like that. But *overall* campus is really easy to navigate...or get around using a wheel chair.

One building in particular was noted by *Dante* as he spoke about the great support he was receiving from housing administrators when encountering physical accessibility of campus facilities, which exemplifies the very same point *Claire* previously made—that while campus is not technically inaccessible, it is not without difficulties, and quite possibly difficulties caused by failures to consider the actual individuals needing the access.

The push button on the outside of the building (laughing, and pulling himself more upright in his chair) was located in the most *bizarre place*...which happens **a lot**. The push button is **directly in front of the door**. See? You have to push it, the door opens, you have to get *out of the way*...but he got it moved quickly, very quickly for me.

Again, it is recognized by *Dante*, as it previously was viewed by *Andrew* and *Claire*, as a positive experience when people help modify or fix a problem he is having with access.

As *Dick* said, there is a feeling among several participants that navigating difficult issues on campus is “just the nature of the beast” when you have a physical impairment. They encounter situations, facilities, and inaccessibility, and have come to identify them less as negative experiences and more as the expectation. *Dick* utilizes the shuttle system for easier mobility but it can't fix every concern due to the campus layout.

I had to crutch all the way from the bookstore (the shuttle drop-off nearest his class) for a year...that is only, like, an **eighth of a mile** but on **crutches** that is **a haul**. I do not

care if you are **Chuck Norris—that is a haul.**

Getting across campus involved developing a best case plan, not necessarily a good plan, and the difficulty it causes him at times is seen as routine. *Dick*'s college has a free campus shuttle running into the late evening but because many buildings are in the interior with no bus access nearby, there is a certain amount of mobilizing required no matter how well he plans with the shuttle route. The perception that there are some experiences that are unavailable to him receives a “ho hum” response from *Dick*—an acknowledgement restrictions exist but as if it is anticipated.

There are a couple classes I'm not able to take because of my physical limitations...

He expresses this as a generally understood truth of physical disability, though it does not minimize frustration.

Last year I was in (a particular course requiring filming in community locations)...my legs would start to go. We had to schlep for two hours **beforehand**, so we got all set up...all that and by the time I was done I had been on my feet for *almost five hours*. The next day I could not walk anymore.

Dick had never explored, let alone considered, speaking with his campus' disability support office because most of what he encountered was seen to be unmodifiable.

Inquiring about additional services available to students with disabilities at his university, he knew of none though offered one particular criticism regarding the library.

You really have to know where the elevator **is** to be able to get there and even then, the thing (library) is like the size of a basketball stadium. (Chuckling but growing frustrated) I can't be...**running around**.”

Asked if he was aware of the library assistant services for persons with disabilities—for instance, book retrieval and an ability to reserve work space in particular areas—*Dick* just

laughed. It would have been nice to know before he prepared to graduate, but how was he to know? Perhaps, he thought, had he been more disabled when he entered college he would have known to look, or how to look, for the assistance.

Robert, on the other hand, has no choice but to explore accessibility issues before he enters a new environment. He is aware of the problem areas throughout campus, and in arriving for his first interview had questions for me as to why I chose a room on the second floor of the student union (one of the older buildings on campus) when more modern facilities could have been available. “This building is absolutely the worst on campus... Yeah, and when you told me that (the meeting location) I was like, ‘Ah, you did this intentionally.’” I informed *Robert* the reservations had been arranged by the offices at his university assisting in my visitation, and asked him to tell me what I was missing. “This building right here... I can only go so far. I can’t open the doors to get to the elevator.” Because I had taken the stairs I had not encountered what he was speaking about; access to the elevator from the ground floor required going through large wooden doors that are kept closed. Coming in to the meeting, the front desk receptionist helped open the doors for him.

Yeah, and once I get back **down**, I won’t be able to get **out** unless somebody comes *to open the door*. You know, things like **that**—I just kind of (becoming more serious)... where you can, cannot get... So basically the campus has the curb cut outs, it has buses with lifts, has buildings that have buttons on every door... (but when he raises issues such as the union elevator) “Oh, we’re going to, like (construct a new building), so there’s no need to do it now.” Which is the excuse or reason for this building. They’ve been doing that for **four years**—*since I’ve been here*.

A campus exhibits a negative message when its students continually are met with excuses as to why issues are present. *Robert* operates with the same assumptions as *Dick* and others. “That’s just the way it goes.” He is resigned to understanding barriers to accessibility will always be faced and there is nothing he can do but deal with it. Still, frustrations exist and are made even clearer as we continue to examine our current meeting location. Next to the door, just inside to the right, a heavy stone garbage can blocks *Robert* from moving anywhere except to his left, to the closest end of the table. The room arrangement prohibits him from choosing another position in the room without removing chairs and pushing the table to one side while he would move on the other. Settled where he is, *Robert* points out the other problem with the garbage can: its position keeps him from being able to open the door from the inside and get his chair in a position to exit. “You know, people were not thinking to do *that*.”

Susan does not utilize many resources on campus other than a particular building for classes. Her working environment is perhaps the smallest, and she states she is happiest with it. “I like the fact they do have a path to walk into different building, lots of places to sit outside (the food market)...” There may be another less-optimistic understanding in viewing her lack of campus engagement if examined more critically. What she likes about her small perimeter is how it does not challenge her to navigate more difficult walking routes (her area has “a path to walk into different buildings”), or the busier but much better equipped dining options elsewhere on campus. Questioned if staying in the singular location was preferred or necessary, *Susan* acquiesces, it “was very handy, I’d be able to say, ‘Ok I only have an hour so I can get here real quick.’ I

can—it’s really nice.” While her positive assertion is relative to her experiences, it also underlines *Susan*’s self-isolating from the rest of the campus grounds.

Many difficulties recognized by participants are accompanied with a laugh, maybe an incredulous laugh, but a laugh. *Lauren* was more direct in her condemnation of physical access issues on campus, and may have been most critical overall, though it, too, was embedded in the conversation of her positive experiences as it frequently was with other participants. Academics, where she devotes the most of her campus time, causes the greatest frustration. The majority of her courses are scheduled in newer lecture halls, arranged with stadium-style seating:

I’m always, like, say this (the room we were in) is the classroom, there are the seats. I’m always like, in the front—up here—so it’s hard to start conversations with people and classes because you’re up in the front, over to the side.

She is caught between steps. Students are sitting further up or down from the level they enter on and it contains no seating. But it is where she must position herself. The other classrooms are often equipped with chairs affixed to the floor, leaving little ability to modify the arrangement to satisfy her needs.

So you come in the door and *that’s* where I am (gesturing to a cut out area next to the door, currently occupied by a garbage receptacle). **Right in the trash can.**

I asked *Lauren* to clarify—was she suggesting in those rooms she was sitting where the garbage bin was previously stationed? Yes, she said, it was typical to have her settle into the small alcove because she was otherwise “in the way.” In either scenario, the impact of the physical environment is similar; while addressing accessibility they represent another

way of isolating *Lauren* from her peers, something she feels has always been part of her college learning experience.

Lauren began our follow up meeting pointing out something before I started her in a different direction. “It honestly brought back a lot of memories of my time here that I kind of...pushed back.” For instance, her college life has been highlighted by a series of confrontations with parking and transportation problems.

It’s just such a hassle to bring my car here, my van. The bus...the bus is only run until like, a certain time in the evening so that kind of was, you know (throws hands upward, gesturing frustration)? And then the (school), it’s such a hassle to bring your car here. They have parking here, but I have a **van with a wheelchair** so to find a van-accessible spot but there’s not somewhere in (changing thoughts)—It’s hard because you know I think the law, you have to have one van accessible spot for every eighteen spots?--or something like that. So...(unintelligible on recording) but you know, it was such a *hassle*.

If there’s not gonna be much parking, there’s probably not a point in going.

Each participant gave indications, despite being generally satisfied with their experiences, of specific instances complicating those assertions.

Viewed as a culmination of all the events rather than an isolated incident, campuses from which these participants were culled should get a sense of moving in the right direction, though to say they should be satisfied with what was found may be debatable.

Interactions and Interpersonal Relationships

The positive experiences (e.g., group assignments where one is able to be an equal contributor, proactive coordination by the school disability support, and housing administration addressing necessary room modifications) are usually because “it’s just—

good people. People being good” (*Dante*). Those situations are not dependent on someone specifically ensuring compliance with ADA requirements or addressing disability specifically, but result from people being helpful, being kind, or engaging on an individual level. However, the negative situations, while less numerous in these findings, often highlight the opposite scenario—people unwilling or unknowledgeable enough to provide appropriate support, or worse, individuals making a special effort to be disruptive.

Finding parking around campus may have been challenging for *Lauren*, but it was surpassed in causing frustration by the campus bus system, and the individuals adhering to the system. Early on, *Lauren* figured she would be able to mobilize most easily if she utilized the shuttles. She encountered situations where buses were too full or no one would make room for her wheelchair and help secure it properly (based upon stated procedures). According to *Lauren*, two morning shuttles would come and go from her stop, leaving her behind because drivers disregarded the protocols for wheelchair users. After repeatedly drawing attention to the problem, the university opted to assign a third bus to the route with a driver specifically trained on the accessibility policies rather than take steps to ensure the regularly scheduled drivers adhered to the same guidelines. “I guess I am *in the middle of it*. I mean, you know I don’t like to talk about this because it tends to make me angry, but I would love to share.” She felt compelled to continue speaking with the administrators about improving the process—not for herself—but since it was a systematic concern likely to impact future individuals with disability.

Eventually the first bus was assigned a driver aware of the university’s stated policy. The driver would clear people from the accessible seating if they did not need it,

and would assist *Lauren* before letting others to get in at the stop. One problem addressed begat another; students waiting while she was helped aboard and secured in place began taunting and verbally abusing *her*, complaining she was making them late, mocking her inability to “do it herself”, and threatening to unhook the straps securing her chair when the bus approached a turn.

I was miserable. I felt all the eyes are on me because I was the one who is responsible for having these kids get off the bus...I was miserable. I feel that they really didn't put a lot of value on my safety...

It kind of made me the bad guy but you know what I mean...I think they are angry with me back then.

This was a factor contributing to *Lauren's* previously mentioned difficulties leaving her apartment and attending classes. Another likely element was a series of interactions with particular university employees and faculty members. First, she detailed events at a particular coffee shop on campus that “happened once, possibly twice”:

And I went. And you know...they normally, they'll put your name on the cup. But on mine they put “wheelchair.” (Interviewer: You're kidding) *Right?* They wrote “wheelchair” **on my cup**.

Most discouraging to *Lauren* seems to be that it was not a malicious act but someone without any understanding of speaking or interacting with people with disabilities.

And I don't think that they did it to be rude or anything like that. I *think* that they probably did it because they didn't want to call my name out and then have me like, have to reach for the cup.

I feel like sometimes, people try to overcompensate because they don't want to offend somebody with disabilities. They try to, like, **overcompensate**, and they come out a little bit rude.

Honestly... Well, you know, I guess what I really get from it is... (waving off with a hand and starting again) You know, I like to think that when people look at me, they notice, you know, “Wow, she was a very polite girl”, or you know something like that.

Lauren understands the first thing people notice about her is generally her wheelchair.

But being seen in such terms is still a biting, difficult realization of the view of the world when seeing her.

That’s an *identifier*. It’s sad to me. I mean, it makes **me feel bad** because that’s not how I see myself. That’s not how **I see myself** at all, so when somebody else looks at me and that’s what they see, you know, it makes me feel a little bit bad (she forces a smile and checks her phone).

A situation with an instructor permeated multiple conversations *Lauren* and I had, such that I finally asked her if she would like an opportunity to elaborate more fully. What she explained was an instructor ignoring requests from a student to discontinue a practice of arranging classes in inaccessible locations (“she said, well, we’re going to meet at 5:30 and we’re going to meet at places downtown”), and then putting “a target on my back.” In the professor’s course students were required to perform observations inside of an ambulance during an assigned shift.

Obviously that’s not something that I could do. And so I was kind of hard-pressed to find something that I can replace it with...The teacher’s idea of something was answering phones at (a reception desk) and I didn’t feel that was the same experience. I wanted to have the *same experience* that my classmates were receiving and so **I tried** to come up with other things that I felt were comparable. She turned me down and she became angry with me...And she—I can tell she’s taking it out on me and that was difficult.

The instructor later announced in class that they were all going to have to do something different for their experiential learning projects because of *Lauren* and what she

characterized as Lauren's complaining. She made a tough decision at that point to file a formal grievance with the university.

(Obviously upset, she struggles) I don't want any special treatment as far as...I guess what I'm...I don't—
intellectually, I'm the same as everyone else. In that situation I couldn't physically get into the ambulance.

Other participants had their own challenging interactions with staff or peers, and shared similar feelings of an outsider perspective, of being a curiosity or as *Dante* stated it, “the freak effect.”

That *hesitation*...you should be able to say “wheelchair.”
That reserve for **using the word**, which separates people. It separates them from me.

I picked up this mentality a long time ago where I'm going to say, *I don't fit in*. (He adjusts in his chair and takes a drink using the long straw on his water bottle) I can fit in **mentally** and **emotionally** places, but still--you see me with that group of friends or me **anywhere**...I stick out. But that's ok.

He has classmates he considers friends but generally indicates a sense of himself separate from other students. In fact, he comes back around to say they are mostly class-friends.

It's very rare for someone to actually just...randomly start up a conversation with me and sit down for a bit and have that conversation. *Maybe they wouldn't do that to an able-bodied person either?*

As for his professors, “most are very accepting—or not, accepting...but accommodating.” He speaks openly with them of his needs and wanting to gain everything possible from his experiences. Given the vast distinction which could exist between accepting and accommodating and how he felt the need to catch—then alter—his statement, it raises more questions about how faculty interactions affect *Dante*. Are they accepting of him or simply providing his accommodations as required?

Generally, he would say “professors and faculty members have just gone above and beyond. (The housing officer) he was everywhere when I first got here.” *Dante* shared numerous positive experiences with student housing staff, and as evidenced previously, takes every opportunity to talk about what they have done for him and how they have sought his input as to his own needs. Despite this, he seemed surprised to have forgotten a vastly different incident from “a couple of years ago, maybe a year and a half? Something like that.” *Dante* would accompany his CNA from their car and return to the building. Each evening for approximately one month, the push button for the outside door would not engage, and he would have to wait for the evening custodial staff to see him and open the door. Later, escorting the CNA back outside in the morning, he would again be locked out until being noticed and let inside. His assumption was an electrical issue and reported the incident.

So in my head, at this time, I was getting suspicious. As like, these janitorial staff are *messing with me*. I was just like “Is this funny to you guys?” Then I really started pursuing it. I talked to my RA, I got **times**, gave them **exact times**, and said “review the cameras. I want you to review the cameras.” They went back. Yeah—the janitorial staff had been turning the thing off as a practical joke. They thought it was funny.

If you look at the footage, and you know, they turn it on, I leave. There’s a group of them on the couch. I come back in, one of them gets up—I guess they are laughing—and turns it back off when I was back in my room, and I didn’t see any of them. I wanted to see the footage but they wouldn’t let me watch it. Weird...

Though extreme in nature, such behavior belies the sense that able-bodied people understand the complicated experiences of some people with disabilities. More subtle experiences and exchanges are more common but no less distressing, such as *Claire*

being asked how she can afford her Segway and why she doesn't just use a wheelchair like other students with disabilities, or a participant being asked by a classmate she had never spoken with "So, can you have kids like that?" There is a sense at times that makes it allowable to entertain the curiosity of disability, as if doing so does not impact the individual. Each participant handles these situations in their own way, whether it is *Dante* inviting a conversation about his accident and paralysis, *Claire* proactively indicating she wants to maintain her core muscle strength and how the Segway helps, or *Lauren* taking her grievances to a higher university authority.

What participants repeatedly stated was that they wanted to be seen as themselves. They are students, intellectuals, musicians, artists, friends, and family members. But at times all of this is lost in the impressions other people have of them as nothing more than their disability. And sometimes through their disablement and these interactions they lose a sense of themselves, too. As we speak, and as *Robert* talks about himself in terms of being a helper and wanting to give of himself to other people in need of support because of addiction, subtle exchanges come together to show just how complex disability can be.

I was in student government and also a lot of meetings with different people and hanging out. I had a girlfriend then...

He was outgoing and likely to be right in the middle of the excitement before his accident. "I **was** the party. I don't know what you want to call it but I am not the person that I am now for sure." I ask—does he mean he has mellowed with age? Has he matured and left behind the boisterousness of his early twenties? "Even an undergrad will time change..." Prodded, he offered a brief explanation, "I was a person *in a group* instead of **the person** *with a disability*."

Robert is challenged by his new identity, perhaps because he has a clear recollection of himself without a disability. He dated and had been involved in a serious relationship. His verbal struggles personify the very nature of his own difficulty seeing himself as other than disabled in particular aspects of life.

For me it's kind of like, I *have* a disability. I know that I'm not going to be... (starting again) It really makes—it really hits on... but talking about absence, okay? Because before my accident I was, you know (laughing and smirking) I didn't have to worry about finding a girlfriend.

But now—you know, it's... I'm not first to try to find. They don't consider me a threat, which is *good*. I mean... Yeah, I'm not talking about **the** "threat."

I mean... they're someone they don't consider either, but there's the threat (of flirtation, and a possible relationship) and that's the hardest part about my disability. It's that I cannot form all the... **statuses**... relationships as easily as just like... before.

Since his injury, *Robert* has gone through tremendous efforts to adjust his prior expectations, and change himself into the man he wanted to be, even if the specific goals had to be altered at times. Despite his other assertions—his pride in regaining his independence and achieving the goals he puts his mind to—*Robert* feels less control, even resignation, in the prospect of forming romantic relationships as he is now.

For me, it's not so much (something) I think about anymore. Unfortunately (he offers a slight laugh, without looking up from the table). It took a while to get over that, but now it's just like, whatever. Yeah—somebody could be interested in me and I won't even know it. I mean that's how... it's *so unconsciously*... it's not something I think about.

Yet it seems very much the opposite is true. *Robert* does not see in himself a viable sexual identity, capable of being viewed as a romantic partner, though the internal want

to be seen in this way has not dissipated, despite his feeling that it is no longer be available to him. Rather than explore his belief, he embodies it. Rather than challenging himself and the individuals to whom he is attracted, *Robert* becomes the apologist for anyone who might reject him. “Before the accident, you know, what do you think of someone with a wheelchair...So I don’t blame.”

Therein lies the conflict, the challenge, and the complexity of individuals’ disability identities. While it is suggested discourses of disability give serious consideration toward academics and the medical well-being of the individual, each participant had a distinct view of him or herself and created expectations of college and future endeavors based on their personal experiences and the perceptions generated through those experiences. Even as similarities and some shared perspectives permeate individual narratives, they underline the uniqueness of each person’s story, and the individual nature of the disability experience.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

Utilizing my interpretations from conversations with the seven individuals with physical impairments who informed this study, this chapter revisits the problem of practice and reiterates the purpose of the study before continuing on with conclusions based upon the proposed findings, and then reconnects those findings to identity theory. Limitations of the study are shared, along with recommendations for future research, and closes with a discussion of implications for higher education—including the professionals and its students with and without disabilities.

Revisiting the Problem of Practice

The problem of practice addressed in this study was a lack of clear understanding as to decisions students with physical impairments make with regard to campus involvement. The purpose of this study was to explore conversations surrounding disability, as they are understood by the SWPI in higher education, in order to make meaning of their lived experiences, the messages they receive, and their interpretations of those messages. The intent was to develop deeper knowledge of how college students with physical impairments perceive the “discourses of disability” on campus by exploring what university students with physical impairments perceive to be the presuppositions *about students with physical impairments* held by people and practices throughout a traditional residential college campus.

While the explanation may be murkier than what had been ascertained in prior research, my examination partially supports suggestions that students with disabilities have an interest in, and acknowledge the additional benefit from, social involvement with

peers at college, (Kane, 2009; Hurst, 2006; Borthwick, 2002). Findings of this study suggest various influences contribute in meaningful ways as SWPI determine their social engagements and campus involvement. A significant impact is realized through what I previously identified as contributing factors of disablement, in Chapter Two. Issues of time constraints; safe, reliable, and convenient transportation; financial and resource burdens; and a problem of the increased stress associated with involvement shape the decision-making of students with physical impairments (Borthwick, 2002; Kane, 2009; Hodges & Keller, 1999; Hurst, 2006). In relation to the specific group of participants, it can be argued their social goals are secondary to over-riding serious academic and personal health and safety considerations.

Additionally, despite statements that, when taken in isolation, suggest participants have positive views of their prior experiences, a lack of emotional and physical inclusion cannot be discounted as a significant contributing factor. Participants detail isolated episodes of being taunted, forgotten, mistreated, and over-whelmed by the demands of their campus community—student, faculty, and staff alike—consistent with studies indicating students with disabilities find difficulty connecting with peers, forming or entering into meaningful relationships, and navigating the burdens of meaningful involvement, as higher education has defined it. In the situations participants speak of as positive experiences, they highlight an ability to identify as an individual first rather than the simplistic recognition of being *disabled*. Their personalities, interests, affinity groups, talents, and academic majors are the prominent characteristics and identities, and allow the individuals to seek out appropriate levels of engagement.

Conclusions

The overarching question asked through this research was: *What do college students with physical impairments say about the discourses of disability on campus?* Analysis of interviews with participants revealed information as to how their identities as people with physical impairments determine the types and level of engagement with various aspects of campus life and involvement: academics, campus services, social and cultural events, and interpersonal relationships. Prior research assisted in developing an avenue of inquiry, specifically identifying a need to investigate what SWPI:

- perceive to be the factors impacting their engagement decisions;
- think are key reasons for choosing when to participate in activities;
- sense it means to have an inclusive campus;
- feel their institutions do to create and encourage an inclusive campus for SWD;
- believe their non-disabled peers think of them.

Employing Gee's vision of identity as an analytic lens was useful in framing my investigation and interpretations. Utilizing discourse analysis proved a good fit for the investigation because it allows for the possibility of multiple truths, validating participants' perspectives and influences as they create unique meanings for those the individuals. In such a study, I was challenged as the researcher to analyze my discussions with participants and interpret meaning from what had been expressed, with the expectation (and burden) of finding truths within those conversations.

Establishing the investigation as such, it became increasingly evident students—and people—with physical impairments' experiences are best understood through the theory of Complex Embodiment. As explained by Siebers (2008), Complex Embodiment

“values disability as a form of human variation” (p. 25). In arguing disability as a form of diversity, it acknowledges the internal difficulties in how the individual mobilizes, thinks, or functions (impairment), as well as the impact society and environmental factors that impact their ability to integrate in systems as they exist. Analysis highlighted the degree to which aspects of being a person with an impairment drove decision making for students. Participants entered college with serious academic goals that frequently usurped objectives toward more social pursuits. Higher education created a pathway for independence from dependence—of family caregivers and social services. College was a means-to-an-end, not the final goal; because the stakes for this population were considerably high, and the number of opportunities for difficulty and failure were considerably high, they made decisions to fully commit to a successful academic undertaking even if at the expense of what is widely considered the total college experience.

Separating the medical aspects of the individual’s impairment from conversations of academics or social involvement proved difficult. So often, in determining campus and social engagement, participants first identified their want to do well in a class or academic program. Closely enmeshed, however, were all the considerations given to ensuring medical well-being and personal safety. With finite energy and time available, SWPI have come to understand the personal toll of committing to their education goals. They learned to manage the physical stress, wellness practices, and time constraints. Committing to doing well academically—and being well physically—was also acknowledging the lessened importance of social aspects of the college experience.

Additionally, while opportunities themselves were not necessarily inaccessible, many were still felt to be restrictive because of the students' physical impairments. Navigating crowds, being exposed to adverse effects of weather, and considerations of travel and personal safety were recognized as key aspects when determining when to “do involvement.” Discussants were well-informed about all the opportunities available, and frequently identified presentations, performances, and events they may like to see. However, they weighed the cost versus the benefit, and, at least judging by the small population with whom I spoke, rationalized away higher levels of involvement due to more serious regard for their overall wellness and safety, saving themselves for what was required of them to thrive within their educational pursuits.

Finally, while not particularly acknowledged by the study group as a factor in determining participation, the participants encountered situations of being identified as disabled due to environment, institutional, or interpersonal functions outside their control. Despite generally positive views of their college experiences, no one was immune from negative campus experiences as a result of their disability. They encountered struggles with connecting to peers, accessing services and facilities, in the worst of cases—being objects of ridicule. Taken together, the findings present several conclusions.

Even as Insiders, Participants in This Study Occupy Outsider Status

When we recognize a certain people as *normal* or *regular*, people unable to fit within the categorization find themselves identified as abnormal, different, irregular, and disabled. Returning to Taub, Blinde, and Greer (1999), the very nature of **not** ascribing to what a society has established as the idealized form—how one should look, behave, and communicate—creates a class of outsiders. People will come to recognize themselves as

such, and often will be further debilitated when opportunities for involvement arise. Opting away from these opportunities can be done in such ways that the *othering* is rather subtle, possibly even being perceived as an informed decision. For instance, *Susan* identifies opportunities she may like to explore but with each, whether the campus movie theater or fitness activities, she already has determined they are not available for her because she does not fit into what she recognizes as the normal way of engaging. Similarly, though giving no indication it was truly investigated or even something he had aspirations toward, *Dick* fully interprets study abroad programs to be unavailable for a student presenting as he does with a mobility impairment. Perceptions the students have developed of their place within such activities has already been formed and has led them away from additional exploration of said opportunities, echoing previous research stating students with disabilities feel inhibited from engaging despite awareness and interest (Hodges & Keller, 1999). Further, as suggested by Denny and Carson (1994), the problem may not be a true physical barrier so much as a perceived one; limited interactions and increased deferring of engagement can be the result of prior encounters coloring expectations for future opportunities for inclusion and experiences. Such veering away from involvement is not only caused by inaccessibility but also perceptions of being someone on the outside looking in.

Students with Disabilities Understand Disability/Impairment as an Over-arching Identity, But Campus May Not Be Thinking About It Enough

Again, students are more than their impairments. However, their lives and decisions are substantially shaped by their disabilities. In choosing social involvement and campus opportunities, participants were not disengaging because they were restricted

by ADA inaccessibility. Granted, facilities and conditions may be less-than-ideal to encourage their decision-making, but choice was a product of weighing the consequences—the trade-off—in pursuing other opportunities. Social events for university students frequently occur in the evenings or later at night, and as the study collaborators shared, great amounts of energy and planning are required to facilitate a successful academic experience. For someone unable to drive or mobilize independently (either by foot or vehicle), the day has already involved a series of buses or taxis to and from campus locations necessary for the school day. The prospect of coordinating additional transportation for later activities deemed as non-essential is detrimental to considering involvement.

For someone such as *Andrew* or *Dante*, on top of mobility concerns they have necessary constraints due to scheduling of auxiliary personal care assistants. While choice, interest, and accessibility are surely considerations, those questions fall to the wayside simply as a result of the opportunity existing outside what can be considered part of the active day. While study participants acknowledge the impactful nature of their disability identity in most aspects of their lives, the concern of most universities and entities within them (program boards, students, involvement coordinators, etc.) concludes when ADA compliance has been achieved. *Dante's* encounter with scheduling for a class project typifies such understandings of disability. In the carefully orchestrated activities of his day, subtle differences—such as an early morning group project—throw the schedule into disarray. The CNA is not going to change and arrive earlier, and the student still has certain activities which must occur for his health and personal wellness. Suddenly, instead of two hours for home health care and getting prepared for class there

is only one. Something in the morning routine must give, and it may be additional rest, nutrition, or preparation. Moving forward, whatever was skipped can impact how the rest of the day is carried out. Similarly with evening events, one must consider how attending a group meeting, movie, or party will coordinate with the needs related to the impairments. Again, none of the consideration is directly disability-access related, though it is without question disability related. The degree to which such impact is recognized and addressed by anyone other than the participant him/herself is likely minimal. Failure of the “students with disabilities” population to appear to be involved on campus is then under-represented and the understanding as to why may be misunderstood. SWD want to have a *normal* experience, but campuses may not comprehend that “normal” is not a stationary concept.

Students with Physical Impairments Have Remarkable Resilience, and Perhaps Strikingly Low Expectations, When It Comes to Inclusion, Thereby Setting a High Bar For Deeming a Situation as Truly Negative

The focus of the investigation was not to seek out students’ horror stories and vilify institutions. My intention was to understand student choice—how and why do students with physical impairments determine their social involvement on campus, and what about those decisions can assist higher education administrators in better serving this population of student. Only minimal inquiry was directed toward negative admissions, and was always done as a lead-in or follow-up to a question of more affirmative experiences. Confronted by specific questions as such, study participants generally countered with statements supporting their institutions and reflecting positively upon their experiences. Yet, through the narrative which developed as the trust and report

grew between investigator and subject, participants began to share incidents that seemed to show what I would consider highly-objectionable treatment or encounters due to the nature of their disabilities. Such situations struck them as neither uncommon, nor inflammatory. Participants spoke as if these situations were just part of the life experience for them. This is both enlightening and troubling.

There is a Balancing Act of Being a Student with a Disability Versus Being a Disability

Participants are more than their disability. Though each may have stated it differently the sentiment was shared: one has a disability, he/she is not the disability. “With a disability” or “disabled” is a descriptor, always of something else: a person or individual *with a disability*. Still, the nature of the impairments is never far from their minds. It “is not who you are. It shapes how you do things very much” (*Susan*). In discussing themselves, the impairment or condition was acknowledged, but was a section of a greater whole, superseded by various other identities: Christian, musician, filmmaker, daughter, fiancé, helper, comedian, and a college student/graduate. To be successful fulfilling any of these various social roles, participants must navigate the disability embodiment. *Dante* and *Robert* allowed, despite anything else they may do or be, the first recognition of them is disabled. They become the physical embodiment of their impairment because it is the most powerfully descriptive characteristic of them, mainly because they stand out as a result of it. Their burden, and that of the rest of us as well, is to move beyond a person in a wheelchair being nothing other than the disability. A component in reaching this stage of identity is exposure in authentic situations, providing opportunities for meaningful engagement with people with disabilities where

the characteristic bringing them to the conversation is something other than the impairment.

Identity Revisited: Connecting the Findings to the Theory

This study relied heavily upon Gee’s view of discourse analysis as both a theory and methodological approach. As stated in Chapter Two, it presupposes language is “integrally connected to matters of equity and justice” because through it people have access to different identities and different practices “connect(ed) to different sorts of status and social goods” (Gee, 2000, p. 30). It was determined to utilize the analytic lens of identity, specifically Gee’s four views of identity: Natural (N-ID), Institutional (I-ID), Discursive (D-ID), and Affinity (A-ID)—and more specifically still, the N-ID—as an initial step to analyzing what students with physical impairments say about discourses of disability.

Natural Identities (N-ID) of disability exist because a condition, injury, or chronic illness exists. *They are because they are.* Individuals embody static and shifting N-ID statuses, depending on the specific nature of their impairments. While N-ID may not be a lens through which the majority of people view themselves, for the individuals in this study, the perspective of most other things is always colored by *disability*. “Since it (disability) affects so many other things, it’s hard not to look at yourself that way” (*Lauren*). Disability is not the only N-ID present; but its character can require an individual to embody it as a primary identity to explore or benefit from involvement opportunities and social aspects of college (A-ID), and can be at least partially dependent on being recognized by the university community (I-ID) in order to access those opportunities.

Participants in the study all acknowledge *disability* as important aspects of who they are, how they interact with their peers, and how their campus communities interact with them. At the same time, they are vastly more complex than only their impairments. They struggle to break free of preconceptions held by themselves and others about people with physical disabilities (D-ID)—a battle to be more than the D-ID held for people with disabilities—and to be viewed as a student, artist, musician, comedian, and a filmmaker. Simultaneously, they may grapple with our failure to adequately understand how all-encompassing the nature of impairment is as they seek to thrive in the systems created around them. The various aspects of having a disability impact decisions from choosing housing or dining options, to exploring involvement opportunities, attending social events, and creating relationships.

Individuals with physical disabilities face situations in which they must seek accommodation and access through bureaucratic means, be it Social Security, Medicaid, or Americans with Disabilities Act policies at their institutions (I-ID). Through such recognition they gain necessary resources, as exemplified by *Dick*, *Andrew*, and *Lauren*. The challenge, then, is having enough of a disability to receive support, but not be seen as *too* disabled to have inclusion. Study participants expressed desires to thrive in their university pursuits, and were to varying degrees reliant on being seen as a person with a disability to be supported appropriately. The I-ID can be necessary in allowing for exploration of Affinity Identities, and possibly to create opportunities for impacting and changing the operational Discursive Identities. Contributors to the research stated that a fundamental aspect of creating a better culture for people with disabilities is increasing other community members' exposure to these individuals through authentic experiences.

In Chapter Three I query: “Can a person with a physical impairment at times not identify as disabled but establish a D-ID “because other people treat, talk about, and interact” (Gee, 2000, p. 103) with the individual as if they are disabled?” Based on these findings, the answer to that question is undoubtedly, yes. But it comes with a caveat. Participants stated their want to be seen on par with their peers, neither *better-* or *less-than* because of an impairment. While one *can* establish a D-ID regardless of a choice he or she has made to identify, the aspirational goal is to alter the definition of what *with a disability* means in the lexicon of the people affixing it to the individual.

Study Limitations

Limitations of Process

Several factors were found to limit the study proceeding as intended. The result of these limitations was a participant group significantly smaller than anticipated. Confidentiality laws prohibit colleges from disclosing information about students with disabilities; in seeking participants I utilized gatekeepers in a disability service office to help disseminate information and invitations to the SWD group with whom I wished to speak. Additionally, I received assurances from the same individuals in disability support, or others on those campuses, that they could assist me in posting or otherwise advertising my invitation announcement to the larger student population. This made the recruitment process difficult, relegating me to the role of a passive observer as I waited in hopes the messages reached the intended audience, and until such time that I was contacted by willing participants. While grateful for the university personnel interested in assisting with the study, I found it necessary on some sites to repeatedly contact them before actions were taken as pre-arranged. For instance, invitations on one campus were emailed

three weeks after planned. Others did not follow through, or perhaps did not have the ability to follow through as they anticipated, in advertising the study opportunity to the larger university community. A significant limitation I identified in the prior research was the heavy reliance on SWD registered for disability support services. Regrettably, my own study now shares that limitation. I was fortunate to include one participant not associated with the disability office in any way. This individual learned of the study through his faculty, a colleague with whom I had discussed my study. This faculty mentioned the opportunity to a student during an advising meeting when the student began talking of the difficulties he was encountering with an assigned group project. From this meeting, I was able to include the voice of a student herein known as *Dick*.

While designed to involve between 5-7 participants from each collaborating institution, I was at one point concerned I could reach 5-7 total participants. I created a timeline for data collection that proved ambitious yet feasible, though ultimately undoable. The plan called for distribution of the invitations to potential participants in late September—late enough in the academic term that students had settled into routines but far enough in advance of finals’ preparation—but, in fact, did not commence this step until March and April of the following semester. Various causes were to blame: a slow IRB submission and approval, a break from the study while I transitioned into new employment, and staff turnover at two of the three participating sites key among them. I believe the proximity to mid-terms and end of year responsibilities restricted both recruitment efforts and student willingness. Additionally, two students wanted to participate but were not available when I was able to be on their campus and were moving too far out of the area once the school year ended. Three other potential

participants turned out to be ineligible because they had not yet completed a full academic year at their current institutions (per study parameters). Their confusion arose due to the lateness of the term, as they were unsure if they could be considered as having finished the year if all that remained was finals. I believe, based upon what I was told by my site contacts, that some graduating students were also unsure if they remained eligible if graduating.

Language, verbal, and nonverbal messaging were important elements of this investigation. The ways in which I established this study—from invitations designed to be inviting, to maintaining inclusive locations and environments within which to conduct the interviews—were vital considerations in my research preparation. Words such as *disability* and *impairment* carry powerful meanings, and people hold strong beliefs about having those meanings associated to them as individuals. For example, it was brought to my attention that a student contacted their disability support office to complain of my seeking students with physical impairments. The employee told me the student said, “I don’t have an impairment. I have a disability.” I found this exchange curious and important, and relayed my apologies through the office if I offended him/her, and I invited the student to speak so I could discuss my intention in making the decision. No reply was received from the student, but I must consider the choice I made to use one explanation of disability and impairment over another may have elicited similar reactions from other potential participants.

It is worth stating that despite missteps in the early stages of the study being put into action, the reduced study population was likely closer to an appropriate sample for this project than the 15-21 participants envisioned. Six participants volunteered for an

initial interview and a follow up discussion, and one student scheduled only the first session. From the seven participants, nearly sixteen hours of interviews were professionally transcribed to create 294 double-spaced pages. After review and consideration, I determined the depth and breadth of data (i.e. student interviews) compiled was more than sufficient for the purposes of this study. I am confident what is presented does not suffer, and in fact may more concise and focused, as a result of a smaller study sample.

Limitations in Design

First, readers of this study need to be aware of the individual nature of interpretations drawn from the students participating in the research. It is based upon what they chose to share of their experiences, and the subsequent analysis provided by me as the researcher. Second, even within the population of college students with disabilities I made a decision to study only one sub-population—those identifying with physical impairments. Third, the study was comprised of information derived from students generous with their time and open to letting a stranger gain access to incredibly personal aspects of their lives. An important issue of my study, that because of past experience and preconceptions this population may shy away from involvement opportunities, might have proven to be a constraint. As one cannot know why a person chooses to volunteer and another does not, it is possible individuals not responding to my invitation would express entirely different sentiments than those who did.

Fourth, despite the thoughtful and insightful conversations shared, I have to consider much could have been left unsaid due to participants' internal concern with a type of self-preservation. Therefore, while I believe the conclusions hold significant

value and provide meritorious insight, I urge you to refrain from over-generalizations. My statements and finding should not be uniformly applied across all of higher education, though I would encourage them to stand as a beneficial starting point in a conversation we need to have within higher education about inclusive campus involvement for students with disabilities.

Implications for Research and Practice

Recommendations for Future Research

Moving forward with future research, I still believe it important to conduct studies that include students who may self-identify as persons with disabilities but who may not need (or want) to register for accommodation services through a disability support office. As previously acknowledged, we know far too little about them, of their experiences, and if those experiences are significantly different from the type of students who do identify to a disability support office.

Further investigations should be designed to examine other subpopulations within the larger community of disability, such as students with sensory impairments and psychological/emotional disabilities. Too frequently *disability* is viewed as a homogenous group when the variation across types of impairments, and within a single type of impairment, is immense. Only the purposeful and pointed study that allows for such individuality captures the uniqueness of these populations. Experience has informed me the groups of students on any one campus identifying with these types of impairments can be relatively minute; yet it also has taught me that a small, but cooperative, group is sufficient to gain important insight. I would also suggest an examination at a single campus that incorporates student participants in conjunction with document analysis of

the policies, programming announcements, marketing materials, etc. to answer the salient question: Is the campus' stated and understood objectives and values toward SWD reflected in the discourses of disability recognized by SWD?

An additional area for future exploration may be the intersection of impairment and other social identities, such as race, gender or ethnicity. Though not highlighted within the current study, the participant group consisted of three women and four men, a majority of whom were Caucasian. While the particular make-up does not seem to lend itself to examining race or ethnicity, further analysis of gender and disability may be warranted. Future researchers would be well-served to keep these social identities in mind in developing further avenues of exploration.

Finally, I recommend conducting additional explorations of the discourses of disability recognized on campus by utilizing non-disabled students and/or faculty and staff. Again, it is advisable that future research involve a component wherein there is review of institutions' documents. What individuals can share, and what entities within the university produce, needs to be scrutinized equally. These variations and addendums to my investigation would provide vital acumen, adding to a developing landscape of research in the area of disability studies.

Practice in Higher Education

The following recommendations have been developed based upon the problems identified in Chapter One of this study, as well as the literature review and research findings. If we accept the disability experience as a shared experience--an intertwining of an individual's impairment and the environment which has been constructed around said individual--it is imperative to then consider recommendations toward a course of action

for both the person and society. While proposals are clearly based upon the study of students with physical impairments, it may be appropriate to consider these items for serving the needs of diverse student populations.

Some may question the decisions made in this study to steer the investigation, and subsequent recommendations for practice, away from the role or involvement of the universities' disability support services in addressing the suggestions presented. Simply, I counter the efforts necessary are institutional efforts more so than disability service issues. On most campuses, the office providing disability service has a role primary defined as ensuring mandated legal compliance. Based on their individual missions and philosophies, additional goals are often identified, such as advocating on behalf of persons with disabilities. In the best cases they serve as relative experts and leaders in beginning the conversation within the campus community, providing guidance and information (whether at the behest of colleagues or when trying to act proactively). But it is myopic and misinformed to view these facilities as wholly responsible for ensuring involvement of students with disabilities, when in fact those institutional agencies all students encounter, be it a campus activities or programming office, student union, or housing facility, share the duty and obligation. The responsibility lies with the institution and each individual unit to consider how they encourage, allow, or restrict the inclusion of students with disabilities just as each is accountable for considering the involvement of other students on the campus.

Reconsider Successful Involvement

In establishing the Problem of Practice, engagement and involvement were acknowledged as being important to students' academic performance, retention, and

matriculation, as well as the creation of “a high quality experience” (Kuh, 2009, p. 686). From the first days on campus, students are aware they are being encouraged to explore avenues of social involvement, and that their campuses expect such participation as important for being successful members of the community. Kuh’s research further indicated equal levels of involvement were not occurring for all students. Such suggestions that at-risk populations are not participating to the same degree as other students are premised on an understanding of involvement being the same for all students. Perhaps, in recognizing the great variation in students, it is appropriate to examine involvement as the student getting what he/she wants from their experience more than meeting an outside expectation. Participants in this study generally felt opportunities were available, and chose to engage based on their individual reasoning. Challenged to achieve substantive involvement, each may have failed based on the current ideal, as most chose to bypass many opportunities in favor of academics or personal reasons.

It would be beneficial to re-examine the message about involvement, highlighting students getting from it what they want, and minimize the supposition that lessened social involvement is an individual failure. Currently, we question what the university is doing to create opportunities, and what is wrong with the students who do not meet *our* expectations. A further avenue for research may be an exploration of the understanding students currently hold of the goals and benefit for engaging with their campus communities, and examining if they feel they are getting the opportunities they seek, and gaining what they want of the experiences in which they choose to engage. In such an undertaking, higher education administrators would de-emphasize external expectations

for the college experience and return the focus to students' self-determination of successful engagement.

Based on this study, the question needs to be reframed to emphasize that “the problem is the problem” (Dudley-Marling & Paugh, 2010, citing Freedman & Combs, 1996). According to my interpretation of the participants' interviews, students do not lack opportunities for involvement, nor is the choice to forego greater involvement indicative of something wrong with the student. Instead, we must focus on a more precise question in order to understand if a problem exists. Perhaps the concern should not be if students are equally involved, but if students with physical disabilities are participating to the degree they want to be involved. Is the student getting what they want from the college experience/involvement? Or more precisely, are things acting in opposition to that opportunity?

Emphasize the goals of involvement and the holistic college experience to students, faculty and staff.

Involvement is important in that it serves a greater purpose for student development. Too often the understood benefits appear to emphasize the individual, rather than the shared, gain. Faculty and staff must be cognizant of the value of participation of diverse populations such as students with physical impairments because of what their involvement does for all students. In reemphasizing this outcome, the participation events/opportunities become sites for student learning and community building. Those present must plan and arrange for meeting the needs of people who may not interact or engage as they do. Participants will gain experience and perspective with peers who they previously may not have engaged with except in the classroom.

According to study participants, authentic interactions with SWD would be the best way

to improve situations for SWD. Likewise, the same experiences may be the best opportunity for non-disabled students to combat their own ingrained preconceptions of people with impairments.

Create a plan for choice, voice, and opportunity

Students with physical disabilities need to be involved in the organizations and leadership of organizations on their campuses. While those opportunities are available to everyone, similar to diversity plans which purposefully encourage specific populations to be included, it would prove beneficial to engage SWPD in such a way as to invite their contribution to planning activities. While universities are generally meeting ADA requirements, having a student express a unique and personal perspective on how, why, and where they would be most likely to engage in involvement opportunities would surely add elements to the discussions no one had thought to consider. Further, campuses may find it beneficial to create specific language highlighting a mission to move beyond basic compliance and accommodation, and actually inviting under-represented populations (e.g., SWD) to participate in the administration of campus involvement.

Examine how involvement is scheduled and offered

Based upon the findings in this study, students made determinations of their participation for any number of reasons, though not chief among them was fundamental inaccessibility of the venue or activity. These findings present a reasonable avenue for further research about the impact of the standard presentation of opportunities for campus engagement on participation of students with physical impairments. Generally, the large majority of involvement activities occur at night and is dependent on face-to-face attendance. One investigative path may be exploring the feasibility and impact of offering

activities during different times of day. For instance, a club meeting Tuesday evenings at 8:00 p.m. is restrictive to the student because of the impairment needs. First, does the potential exist to some events (at least on regular intervals) during the day, thereby allowing students to attend while still in the main campus area rather than needing to make separate arrangements to return later? Though it may not be feasible to consider offering a speaker at 3:00 pm, it could be impactful to begin an event at 5:00 or 6:00 p.m., thereby keeping students near the core of campus and still allow time to get home in the later evening, ideally lessening some of the issues identified in Chapter Four (CNA scheduled appointments, hesitance to navigate campus alone later at night, costs of additional transportation, for example). Decisions of scheduling are based on the availability of space and when the largest population of attendees is likely to participate; however, if it is discovered that a particular class of people is being restricted from participating, it would behoove programmers to consider revisions such that opportunities were those of choice and not systematic exclusion.

Second, for some activities, it may be worthwhile to determine if similar goals and objectives could be achieved if a student were able to attend through remote access (e.g., Skype or FaceTime). This is possibly most relatable to a club or organization, but with some planning may extend to other opportunities as well. Virtual participation would benefit someone wishing to participate in a fitness session, such as yoga or aerobics. Staff is often already trained to provide instruction to participants with disabilities—it may be only a technical barrier prohibiting this same activity from being available to a student unable to attend in the early morning or later evening. Similarly, “attending” a lecture being given on campus might become a more attractive option for a

student who previously was feeling the event restrictive if he/she could log in and stream the live presentation without having to decide between the impact of their impairment and their interest in the event. Issues with intellectual property and presenters asserting any streaming compromises that ownership can be addressed through institutional policies and student codes of conduct, and access could be dependent on a user log on with university credentials.

Consider the broader implications

While developing this study, it became evident such a study has broader implications than being just a disability study. This in no way minimizes research meant to better serve the needs of students with disabilities; yet if we consider disability as a diversity issue, with nominal revision a similar investigation could be undertaken exchanging a number of underrepresented populations such as Hispanic, African-American, first-generation, non-native English speakers, low socio-economic, and LGBTQ. For the purposes of this project, I was concerned with a particular population based upon my own personal and work experiences. However, the goal was to determine how the student and campus community engage one another, and how to create greater opportunity for both the individual and larger populace. It stands to reason similar undertakings would equally serve an institution expressing a value for diversity, a mission of inclusion, and the value in learning through participation and engagement.

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Appendices

Appendix A: Interview Protocol

I. Setting

Private, pre-determined location arranged for one-on-one interview. The room has been established to provide flexibility, allowing it to allow for the diverse needs of study participants (e.g., space for larger wheelchairs, movable furniture).

II. Introductions

- a. Reiteration of informed consent – questions/answers (throughout)
- b. Verbal consent by participant
- c. Identification of pseudonym
- d. Activation of digital recorder
- e. Re-confirmation of verbal consent and re-iteration of pseudonym

III. Interview

Pillar Questions

1. How does being someone with a physical impairment impact you as a college student?
2. What impressions do you get from the various messages directed towards students and students with disabilities regarding the campus' view of disability?
3. Thinking about your experiences at (university), what would you say is done to enhance opportunities for students with disabilities? Are there aspects that work in opposition to that?

Additional Questions

- Through your participation in this study you are choosing to identify as a student with a physical impairment. What does it mean to you “to identify”?
- What does it mean that you are a person with a disability?
 - Is that different than a person with an impairment?
 - Disabled student?
- Considering the messages directed towards students with disabilities, what impression do they give you regarding views of students with disabilities?
- All of us have a variety of identities that are important to us. If I ask you to think about yourself in that way, what other identities do you embody? (explore race/ethnicity/gender in addition to what participants offer)
- If I then asked you to rank those identities in order of their importance to you as an individual, where would *with a disability* fall? What are you placing ahead/behind it?
- Where would you say the university would rank *student with disability* in its perspective of you?
 - Are there certain events, messages, or experiences that lead you to believe this?
- We’ll hopefully talk about you and your experiences in a variety of ways but how does recognizing yourself as someone with a disability impact you as a college student?
- What does disability mean when it’s talked about on your campus?

- What perspectives, values, or beliefs do you recognize being held regarding students with impairments?
- How have you recognized the different considerations toward disability operating for your benefit or detriment?
- Have you registered with a disability services office at [university]?
 - Was it a difficult decision to make—seeking out and disclosing a need for assistance?
 - (yes) What made it difficult do you think?
 - (no) Why was it an easy decision for you?
- Talk about what it's like for you going to disability services for accommodations.
- Have you utilized other services available on the campus for students with disabilities (e.g., library aids, auxiliary/parking services)?
 - What is the process to gain those services?
 - How did you know what to do to get access to the support?
 - As you reviewed/learned of the processes, were there other messages you could infer from the language used to talk about disability? For instance, was the support: a requirement they (the campus) felt obligated to meet; a way to provide you fuller opportunity; a personal benefit for which you should feel grateful (*not meant to be an exclusive list*)?

- Considering experiences you may have had on campus with offices/dept./ programs for all students, such as advising, tutoring, health services, dining facilities, etc.
 - Can you recall a particularly positive experience and share what made it overwhelmingly positive?
 - How about a negative incident? Why was it so poor?
- Can identifying as a student with disability ever be a positive thing? Negative? Neutral? Explain to me a situation(s) where this is exemplified.
- Regarding your social involvement and engagement with other students.
 - When you think about *college life* what's the image or stereotypical experience that comes to mind?
 - How does that align to your own lived experience?
 - New students often take some time to find their place within campus. What challenges did/do you face when seeking to be 'one of the crowd'?
 - Do you have ideas of what caused your difficulties?
 - How did you approach/manage those challenges?
 - What helped you connect?
- Tell me about the types of things you like to do for entertainment/leisure when you're on campus or not in class.
- Imagine there is something happening on campus that you're interested in attending/taking part in. First, what might that be? Can you take me

through your decision making—how do you decide if you’re going to actually “do” involvement?

- Do you think your process is typical of students generally?

What about students with physical disability?

- Do you remember a particularly positive involvement experience? What made it memorable?
- Can you recall a particularly negative involvement experience? What made it so bad?
- Thinking about the new friendships you’ve established since coming to college, how/where did you meet the people you consider your close friends? Who initiated the friendships?
- Based on your own experiences, how might you suggest a campus go about creating an inclusive campus environment? What does it mean that it’s inclusive?

Appendix B: Invitation to Participate in Study

[Date]

[Customary Salutation]

You are receiving this email message because you have registered with [university disability services office] as being a student with a physical impairment. Having self-identified as a student with a physical impairment, you are invited to participate in a research study being conducted by Mr. Christopher Stone, a doctoral student at The George Washington University. Mr. Stone has worked in the field of disability services for several years and is currently working on a dissertation entitled, “What College Students with Physical Impairments Say about Discourses of Disability on Campus.”

Below you will find a message from him including further details.

[Signature of University Official(s)]

+++++

Greetings. My name is Christopher Stone and I am working on a Doctor of Education degree at The George Washington University. I am writing to invite you to participate in a research study that is focused on learning about your experiences as a college student with a physical impairment. I am the student-investigator for this study and the principal investigator is my dissertation supervisor, Jason Johnson. Although the [name of university disability services office] has assisted with the circulation of this invitation, it is in not a formal partner in this research project.

Having worked in the field of disability student support services for many years, I am grateful for the opportunity to reach out to you with this invitation. The purpose of this study is to develop a deep understanding of how college students with physical impairments perceive the “discourses of disability” on campus. By “discourses of

disability” I mean that there are ways in which beliefs about what it means to have a “disability” or “impairment” are embedded in the ideas and practices that are part and parcel of the campus community. Further, such discourses have an impact on your experience as a college student. By learning from you and others, the aim of this project is to advance understandings of how colleges and universities can better serve students with physical impairments.

If you participate in this study you would meet with me for two interviews, both of which would be approximately one hour in duration. In the first interview I would ask you a series of questions that will open up a conversation about your experiences on campus and in the second interview we would simply continue that conversation and bring it to a close. Both interviews would be digitally recorded (audio) so that I could analyze them closely later. You could opt out of the study at any time.

I hope that you will strongly consider participation in this research study. Although you would not be compensated for participating, I trust that you would find our conversation enriching and that you would appreciate being a part of a project that would inform researchers and professionals concerned with advancing quality of education for all students. Thank you in advance for considering this invitation. If you are interested in participating in the study or have questions about participation, please contact me directly at 910-512-2944 or stonec@gwu.edu. Alternately, you are welcome to contact the Principal Investigator, Dr. Jason Johnson, at (202) 994-5369 or jason_j@gwu.edu.

Regards,

Christopher Stone
Doctoral Candidate
The George Washington University

Appendix C: Text for Recruitment Flyers

Attention Students with Physical Impairments:

A student researcher from The George Washington University in Washington, DC, will be here later this semester to interview students with physical impairments about their experiences on campus. The study consists of two open-ended interviews lasting approximately one hour. The purpose of this study is to inform researchers and university professionals who are concerned with advancing the quality of higher education for all students.

If you would like to learn more, please contact:

Christopher Stone (GW Doctoral Student)
910-512-2944 or stonec@gwu.edu

Please note: Although the [office of disability services name] is not a formal partner in this research, they are aware that this study is being conducted on campus.

Appendix D: Informed Consent

Title of Study: “What College Students with Physical Impairments Say about Discourses of Disability on Campus”

Principal Investigator: Dr. Jason Johnson, Faculty (The George Washington University)

Student Investigator: Mr. Christopher Stone (Doctoral Student, The George Washington University)

Thank you for your interest in this study. This form outlines the purposes of the study and provides a description of your involvement and rights as a participant. This is a research study. Please take your time in confirming your decision to participate. Please feel free to ask questions at any time.

INTRODUCTION

The purpose of this study is to explore what university students with physical impairments perceive to be the presuppositions *about students with physical impairments* held by people and practices throughout a traditional residential college campus. For eligibility purposes this study presumes that you are a full-time student at [university], that you have been for at least one full academic year, and that you identify as a person with a physical impairment. Further and moreover, this study presumes that you, as a college student with a physical impairment, have made some observations about what some of the beliefs are about you – beliefs that are in circulation throughout the campus community.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, you can expect the following study procedures to be followed:

1. During the study you will be asked to meet with the student researcher (Chris Stone) for two interviews. The first interview will last approximately one hour, will be held in a private meeting room on campus, and will include a series of questions that prompt you to think about the experiences you’ve had on campus as a student with a physical impairment. The goal of this interview is to generate focused conversation rather than a strict question-and-answer exchange. The second interview will occur approximately 1-3 days after the first interview and will be more informal in nature; you will have the opportunity to choose an alternative meeting location and the conversation will be focused on following-up on questions and observations that both you and the student researcher have upon reflecting on the first interview. The second interview is open-ended in terms of time, but it is expected that it would likely not last longer than an hour.
2. With your permission the interviews will be digitally recorded. Electronic copies of the transcripts will be de-identified and stored on a password-protected external hard drive in the student researcher’s home office. You may skip any question that you do not wish to answer or move away from a topic that makes you feel uncomfortable at any time during either of the interviews.
3. The results of the study may be published or otherwise reported to scientific bodies, but your identity will in no way be revealed. Also, the name of your school will not be published or otherwise shared. Findings will be presented in

predominantly narrative form and may include direct quotations from participants. To ensure confidentiality, participants will choose their own pseudonym and that pseudonym will be used when referring to them in public presentations, written or otherwise.

RISKS

While participating in this study you might experience the following risks: discomfort discussing matters related to the topics of serving as a college student with a physical impairment.

BENEFITS

If you decide to participate in this study there is likely no direct benefit to you other than having participated in what is hopefully an enriching conversation about your experiences as a university student. Moreover, the information gained in this study is aimed at scholars and practitioners concerned with matters affecting college students generally and college students with physical impairments in particular so that they (scholars and practitioners) may develop better understandings and practices of this important population of which you are a part.

COSTS AND COMPENSATION

You will neither incur any costs (other than those associated with whatever costs you might regularly incur through travel to campus, etc.) nor receive any compensation from your participation in this study.

PARTICIPANT RIGHTS

Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. Your academic status at the university and your employment status, if applicable, will not, in any way, be affected should you choose not to participate or withdraw your participation at any time. If you decide to not participate in the study or leave the study early it will not result in any penalty or loss of benefits to which you are otherwise entitled.

CONFIDENTIALITY

At the beginning of your interview you will be asked to identify a pseudonym for yourself. Only the student researcher and his dissertation chair will have immediate access to a key that connects your actual name and other demographic information (e.g., age, ethnicity, gender, school name/location, grade level) with this pseudonym, which will be used to refer to you throughout the interview transcription, data analysis, and write-up stages of this study. These records may contain private information that emerges in the course of either interview.

To ensure confidentiality, the following measures will be taken: This student investigator and his dissertation chair are the only people who will have immediate access to the data for this study. If that data is not with the principal investigator or student researcher it will be secured in a locked digital or physical storage space. Materials from this study, including audio recordings, interview transcripts and researcher field notes, will be

destroyed no later than seven years after the completion of the dissertation. If the results of this study are published beyond the dissertation, your identity will continue to remain strictly confidential/pseudonymous.

The Office of Human Research at The George Washington University also retains the right to review data collected for this study in order to ensure that proper protections of human subjects are being implemented.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study. For further information about the study contact:

Christopher Stone (student researcher), Higher Education Administration Ed.D. Candidate, Graduate School of Education and Human Development, The George Washington University; 2134 G St NW, Washington, DC 20052; 910-512-2944, stonec@gwu.edu

Jason Johnson, Ph.D. (principal investigator), Assistant Professor of Higher Education, Graduate School of Education and Human Development, The George Washington University, 2129 G St #204, Washington, DC, 20016; 202-994-5369, jason_j@gwu.edu

If you have any questions about the rights of research subjects or research-related injury, please contact the Office of Human Research, The George Washington University and Medical Center.

Voice: 202-994-2715, Email: ohrirb@gwu.edu

Website: www.gwumc.edu/research/human

PROMPT FOR PARTICIPANT VERBAL CONSENT

By providing your oral consent prior to being interviewed, you will confirm that the study has been explained to you, that you have been given the time to read this document, that your questions have been satisfactorily answered, and that you voluntarily agree to participate in this study.

INVESTIGATOR STATEMENT

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

(Student Researcher)

(Date of Informed Consent)