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“I’m Not Broken”: Perspectives of Students with Disabilities on Identity-making and Social  
Inclusion on a College Campus

by

Melinda Leigh Maconi

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Arts  
Sociology Department  
College of Arts and Sciences  
University of South Florida

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Date of Approval:  
February 25, 2016

Keywords: disability, exclusion, hierarchy, identity, inclusion

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## Abstract

Narratives help individuals to make sense of their lives and their everyday worlds. Within these narratives, individuals make sense of identities. Historically, people with disabilities have been depicted as helpless victims of their own bodies. However, during the twentieth century, disability rights social movements constructed a counter-narrative, stating that society's reactions to different bodies was the real source of disability. While this was a positive status change for people with disabilities, it did not do enough to shed the status as victim. Yet many students with disabilities do not see themselves as victims. Therefore, I used narrative analysis to answer the question: "How do university students with disabilities make sense of their identities as adults with agency through narratives?" Furthermore, these narratives are not created in a vacuum. Many stories of identity-making surrounded narratives of being included or excluded from various social situations, leading to my second research question: To what extent have students with disabilities felt included/excluded in aspects of university life including clubs, organizations, sporting events, and other social aspects of the university in which other students participate? I am focusing on people with disabilities who seek accommodations, as they are acknowledging that they need help, which goes against the narrative of rugged individualism found in the United States of America. However, my research found that university students who seek accommodations do not construct themselves as victims. On the contrary, many students receiving accommodations construct narratives in which they are *more* hard working and *more* moral than other students.

## Chapter 1: What Do We Know About Disability?

### Introduction

There is a plethora of research on university students who use accommodations from disability services provided by the university. However, most of the research about student experiences with accommodations focuses only on the academic experience (Shah & Priestly, 2010). This is problematic as it repeats a problem that people with disabilities encounter for most of their lives; people with disabilities are assigned master statuses chosen by others instead of themselves. For the purposes of this proposal, I am defining master status as an attribute or identity that is perceived to override all other aspects of identity and transcend every aspect of the individual's life (Shakespeare 2014; Campbell 2009; Jung 2003). Campbell (2009) illustrates the fact that the power of disability in a society that views it as a tragic master status by stating, "From the moment a child is born, he/she emerges into a world where he/she receives messages that to be disabled is to be *less than*, a world where disability may be *tolerated* but in the *final instance*, is *inherently negative*" (Campbell 2009: 17).

When others who "know best" are given the power to assign someone a master status, as often happens to individuals with disabilities in their interactions with healthcare professionals, this also gives these others power over what resources are or aren't accessible to students with disabilities without taking the wishes of those with disabilities into account (Shakespeare 2014; Campbell 2009; Jung 2003; Zola, McKnight, Caplan & Shaiken, 1977). While the intention of

many of these institutions may be good, this approach implies that a person is defined by their disability and does not have needs outside of this master status, such as the desire for friends or privacy (Agarwal, Neelam, Calvo, Beverley, Kumar, & Vindo, 2014; Venville, Street, & Fossey, 2014; Shah & Priestly, 2010; Egilson & Traustadottir, 2009).

One of the biggest disconnections, however, between students with disabilities and the services designed to provide accommodations are the goals that students have when they seek accommodations and the extent to which the identities of “disabled” and “student” are master statuses. Even studies that explore non-academic needs of students with disabilities, focus almost exclusively on how accommodations set by the university fail students (Agarwal et. al. 2014; Al-Hmouz 2014; Venville, Street, & Fossey, 2014 Reinschmiedt, Buono, Sprong, Upton, & Dallas, 2013; Coriale, Grant, & Robertson, 2012; Lightner, Kipps-Vaughan, Schulte, & Trice, 2012; Jung 2003). Based on a case study in which a university took measures to make clubs and social organizations accessible for students with disabilities, Agarwal, Neelam, Calvo, Bererley, Kumar and Vindo (2014) assert that, “It is ironic that the programs and supports that we have on university campuses focus mostly on removing the academic and physical barriers but apparently do not reduce the social gap, stigma, and social isolation experienced by many students with disabilities, especially invisible disabilities.”

Therefore, for my thesis, I intend to examine the following questions:

- How do university students with disabilities make sense of their identities as adults with agency through personal narratives based on their experiences?

- To what extent have students with disabilities felt included/excluded in aspects of university life including clubs, organizations, sporting events, and other social aspects of the university in which other students participate?

I intend to focus on the entire experience of “university life” including academics but also experiences in making friends, involvement with university organizations, new housing experience, if applicable, and the experience of managing the freedoms of being an adult with the restrictions and surveillance of managing a disability (Venville, Street, & Fossey, 2014; Shah & Priestly, 2010; Egilson & Traustadottir, 2009). Understanding what students DO find helpful and why can be informative as to what can be done to improve aspects of the services with which students are dissatisfied. There is a need to explore the entire experience of being a university student with a disability, the good and the bad as well as the academic, and the non-academic issues faced.

### **Disability & Education: Then & Now**

Historically, people with disabilities have always been treated as second-class citizens in Western societies. However, this treatment became significantly worse with the Industrial Revolution (Oliver & Barnes, 2012: 54-56). With the emphasis on wage labor, which unlike agricultural communities, did not have the time or care to make an effort to include people with disabilities, people who could not work for wages were increasingly left out and segregated (Oliver & Barnes, 2012: 55; Shah & Priestly, 2010). Even small children were sent away from their homes either because their parents could not afford to take care of them (Oliver & Barnes

2012) or due to lack of accessibility for students with disabilities in local schools (Shah & Priestly, 2010). The experience of disability was largely seen as a tragedy at best or a source of shame at worse but never as something that schools, architects, or government officials had a responsibility to address (Shakespeare 2014; Oliver & Barnes, 2012; Shah & Priestly, 2010).

### **Disability & Social Movements**

Throughout the first half of the twentieth century, this pattern of segregation and pity was the norm (Oliver & Barnes, 2012; Shah & Priestly, 2010). However, as people with disabilities interacted with each other and realized that they were not alone, isolation gave way to empowerment (Patterson 2012). In 1927, Franklin D. Roosevelt founded the Warm Springs Institute, which was entirely wheelchair accessible, for those who had had polio or spinal cord injuries (Patterson 2012: 475). Through summer camps and resorts like this, people with disabilities were able to experience an accessible environment and create lasting friendships.

These friendships continued to form and strengthen for people with disabilities who attended college. Often times, these students were in a separate dormitory, if they were able to stay in dormitories at all (Patterson 2012). However, as Newell asserts, separation is a form of oppression (1999) and students quickly came to realize this and demanded change (Patterson 2012).

In addition to fighting for access to educational opportunities and equal protection under the law, the Independent Living Movement was a large part of the social movements for people with disabilities in the United States of America (Patterson 2012). Initially, many colleges did

not want to accept students with disabilities or allow them into the dormitories due to the perception that they would never be able to take care of themselves or be independent (Patterson 2012). However, as Oliver and Barnes point out, “independence is a relative concept” (2012: 23). The Center for Independent Living was founded at the University of California, Berkley campus in 1972, as one of the many successes of the social movements for students with disabilities at that campus (Patterson 2012: 484).

Many students became involved in the Civil Rights Movement during the 1960s and realized that they, too, were lacking civil rights and protection under the law. As one student activist at the University of California Berkley, who had a disability, stated, “I am part of a minority that is as segregated and devalued as any in America’s history,” (Patterson 2012: 479). In contrast to the ways in which many disability activists in the United Kingdom leave the body out of debates, focusing on the social and material lack of accessibility, many student activist in the social movements for civil rights for people with disabilities focused on the similarities between the embodiment of disability, and the embodiment of race and gender that previous movements for equality had been centered around (Shakespeare 2014; Oliver & Barnes 2012; Patterson 2012; Newell 1999: 48). Yet, President Richard Nixon vetoed the Rehabilitation Act once in November of 1972 and again in March of 1973 (Patterson 2012: 845). While President Nixon did sign the Vocational Rehabilitation Act of 1973, protests resurged around 1977 due to the lack of enforcement or implementation of the laws (Patterson 2012), particularly, Section 504, which applied to higher education (Rothstein 2014: 527).

In addition to being poorly enforced and unclear, Section 504 of the Rehabilitation Act of 1973 only applied to programs that received federal assistance and financial aid, leaving people with disabilities still legally vulnerable and discriminated against in the private sector (Rothstein 2014: 530). After multiple lawsuits, protests, and demonstrations, President George H.W. Bush signed the Americans with Disabilities Act of 1990 (Rothstein 2014: 533).

The Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 were not the only pieces of legislation passed regarding the rights of people with disabilities. In regards to education, the Education for All Handicapped Children Act of 1975 was passed in order to guarantee the presence of special education programs in public schools (Rothstein 2014: 527). However, Julie Allen critiques so-called “inclusive education,” arguing that the education system is designed with the assumption that it is for able-bodied, neuro-typical people. Accommodations are later added to “help” students with disabilities fit into a system that was not designed to be accessible to them, rather than creating classroom practices that make the class more accessible to certain groups of people (2010). Egilson and Traustadottir found that, “Despite legal and international agreements and declarations about equal rights of all pupils, access to curriculum and adaptations of the teaching environment to include children with special needs varies immensely, reflecting a gap between intention and implementation” (2009: 21).

### **How Do We Think About Disability?**

The experience of disability is difficult to define, due to both the subjective nature of what does or does not qualify as “disability” and the ways in which meanings have changed over time. Until a few decades ago, the Biomedical model of disability was the primary view of the

disabled experience, though, it was so taken for granted, it was not named until competing models emerged (Oliver & Barnes 2012; Shah & Priestly 2010; Jung 2003). The biomedical model problematizes the person with disabilities, taking their power and autonomy away in favor of medical professionals who “know best” (Zola et. al. 1977). Shah and Priestly (2010) have examined narratives that illustrate the final word that medical professionals had over the life course of a person with disabilities, regardless of the wishes of the person with the disability or their family. During this time period, people with disabilities were not expected to complete post-secondary education. People with disabilities were simply victims of circumstance who would never do anything productive. Shaw (2015) points out that this model was not only degrading but also kept the public from recognizing what people with disabilities can accomplish. In her examination of Deaf social movements in Soviet Russia, she states, “Viewing the disabled as passive victims...does not allow for the exploration of certain disabled groups’ agency in the construction of their own community identity or indeed in the furtherance of their own position of marginality within Soviet [or any] society” (Shaw 2015: 60). However, with medical advances and a rising focus on keeping disabled people with their families, a new model, the Social model of disability, arose, asserting that people were “disabled” due to the discriminatory, inaccessible environment and cultural attitudes (Shah & Priestly 2010; Jung 2003).

In the past few decades, multiple countries have passed laws mandating that universities and other institutions be more accessible to disabled people (van Jaarsveldt & Ntomboxolo Ndeya-Nderya 2015; Hmouz 2014; Barnard-Brak, Davis, Tate, & Sulak, 2009; Dutta, Schiro-Geist, & Kundu, 2009; Graham-Smith 2004; Jung 2003). However, despite these policy changes,

most studies and evidence indicate that the Biomedical model of disability is still the primary attitude held by not only healthcare institutions, but universities and even individuals with disabilities, themselves. A study done by van Jaarsvelt and Ntomboxolo Ndeya-Nderya (2015) found that instructors sometimes feel it is not their responsibility to change their lesson plans but rather, Disability Services and healthcare institutions' job to make the student fit the class. Furthermore, students themselves sometimes express doubts on their ability to succeed academically. Students with learning disabilities sometimes refer to themselves as “stupid” or “lazy” rather than addressing the lack of accommodations given to them by institutions (Herbert et. al. 2014; Orr & Goodman 2010). Furthermore, students are expected to provide medical documentation of a diagnosis at the beginning of the term to receive accommodations, regardless of the barriers that their disability may cause in meeting these demands. This can be problematic for students with mental illnesses such as depression or anxiety disorders that may prevent them from being able to easily approach institutions and describe their personal medical records (Venville, Street, & Fossey, 2014). The biggest difference is that now, it is the responsibility of students, rather than the institutions in place to “help” them, to advocate for accommodations (Jung 2003).

### **Identity-Making**

Even with the social movements to recognize people with disabilities as valuable members of society with agency, the historical narrative of disability as a victim status continues to be the dominant cultural narrative today. This can complicate the process of identity-making for people with disabilities, as few people want to define their identity around victimhood (Loseke, 2007; Merskin 2004). Identity-making is complicated by the fact that people do not

make their identities in a cultural vacuum. Loseke (2007) identifies different levels of identities, such as cultural identities, institutional identities organizational identities, and personal identities. Cultural narrative identity refers to the collective representation or categories of people depicted through widely told cultural stories, or as Berger, (1997) refers to them, formula stories. Disability is a particularly interesting, in that many people are diagnosed with their disability later in life, and therefore, have already been exposed to the cultural formula stories and identities before they could even begin to construct their own personal identities. However, Loseke (2007) argues that there are many different levels of narratives, each of which are “created for different purposes, do different types of work, and are evaluated by different criteria.” People tell stories to make sense of the world and these stories can be subversive to the cultural narrative. In addition to the cultural narratives, people with disabilities must also make sense of their lives and identities within institutional and organizational narrative identities. Institutional narratives dictate who qualifies for what services. Similarly, organizational narratives are created by organizations to evaluate who they help and how they help them. While people can create personal narratives and identities that are subversive to the cultural, institutional, and organizational narratives they are surrounded by, going against these narratives can lead people to be cut off or to lose services (Loseke 2007; Eakin 2007; Dunn 2004).

If telling subversive narratives can keep people from receiving services, why are they told? Many services are geared towards people with victim identities yet, to be a victim is to hold a devalued identity in American society (Loseke, 2007; Dunn 2004; Merskin 2004, Best, 1997). Blameless “perfect victims” gain sympathy and are deemed worthy of services. However, this can be harmful in that it excludes those who do not fall into the “perfect victim” narrative. It can

also be harmful to those who are able to fit the victim status enough to be eligible for services, as their agency is taken away and their stories can be co-opted by those the organizations and institutional narratives to further benefit the needs and power of the organizations (Rouso, 2013; Dunn 2004; Best, 1997).

The victim identity is not the only identity that people with disabilities fight against. Rouso (2013) writes about the ways in which the hero or “inspirational” identity sometimes placed on people with disabilities can be just as harmful and dehumanizing as the victim identity. Being labeled as “inspirational” or “heroic” simply for having a particular identity, in this case, having a disability, is dehumanizing as it casts the identity as “other.” While often well-intentioned, using expectations associated with the hero identity on a person for existing otherizes and objectifies the “hero”, in that they are on display, due to a condition they embody, as “motivation” for people without disabilities (Ruosso 2013). Furthermore, to be too “heroic,” individualizes the success of people with marginalized identities but then takes away the responsibility of organizations and policy-makers to provide the necessary accommodations and services for people with marginalized identities (Green, 2015; Dunn 2004). As Green (2015: 102) found in her interviews with parents of people with disabilities, “services are acquired by telling the right story in the right way.” Thus, the process of identity-making is further complicated by the desire to subvert the cultural “victim” narrative while simultaneously, acknowledging a need for services and rejecting the idea that they are “other.”

The Social Model of Disability is an essential part of the Disability Rights Movement as it removes shame from the disabled identity and places that shame on the society and built

environment. Danielle Every (2013) discusses the ways in which social movements use shame as a tactic to unify those who are part of the movement and devalue or humble those who oppose the movement. Shame occurs when a person feels that they are judged for who they are, such as disability status, rather than for their beliefs or actions (Manderson 1997). While shame is often used to isolate and disempower groups of people (Brown 2008), Every (2013) examines the way it can also be used to “subvert and reclaim shamed identities as proud identities” (p 668). The Social Model works to remove shame the shame and stigma that surround disability and to place it instead on the built environment and those who see disability as an inferior status.

### **Meanings & Stigma**

Symbolic Interactionist theorist, Erving Goffman, (1963) describes stigma as a characteristic of the relationships between people in which one person is considered devalued or inferior to others. While stigma is sometimes treated as a fixed, definable entity, Green (2007) measures perceptions of stigma between disabled and non-disabled students regarding the experience of disability. She found that although students in all categories expected that individuals with disability encounter people expressing awkwardness or sadness in their presence, disabled students were more likely to indicate that disabled people are devalued and kept from fully participating in society.

Not all people who feel stigma have the same experience. Erving Goffman (1963) makes a distinction between “discredited” and “discreditable” stigmas, meaning the difference between stigmatizing characteristics that are easily visible compared to those that can be hidden respectively. While on the surface, it may seem as though it would be “easier” to have a

discreditable stigma, it is typically considered a “responsibility” of the discreditable person to disclose their stigma and can lead to the person being labeled as being “deceptive” or a “liar” if their stigma is discovered later (Goffman 1963). This has not changed since Goffman’s work, as students are expected to inform Student Disability Services and their instructors at the beginning of the semester if they need accommodations and those who seek to obtain accommodations in the middle or end of the semester are often treated as if they are lying in order to get extra help or avoid failing the class (Venville et.al. 2014; Lightner et.al. 2012).

Stigma further complicates the process of inclusion and identity-making for people with disabilities. Disability is a complicated topic as there are people with discredited identities with disabilities, such as someone who uses a wheelchair or is missing a limb, and people with discreditable disabilities, such as auto-immune diseases that cause chronic pain or mental illnesses. Still, there are other disabilities that are discreditable that certain treatments make visible or discredited, such as a diabetic with a pump or a Deaf person with a cochlear implant. Someone with a discredited disability may be treated with pity or as different immediately when they meet people. On the other hand, people with discreditable disabilities must choose whether to “out” themselves and possibly expose themselves to pity or invasive questions, or whether to hide their disability and risk being accused of “lying” or “hiding things” if they are outed (Goffman 1963). Thus, there are multiple ways in which stigma complicates the process of identity-making for people with disabilities. For this reason, it is impossible to study the role of identity-making and disability without first understanding stigma.

## **To Seek, or Not To Seek: Stigma and Motives Behind Seeking or Not Seeking**

### **Accommodations**

Student Disability Services, and other equivalent entities at universities are in place to help students succeed in the university setting. Unfortunately, many students do not seek accommodations until AFTER they have had academic difficulties (Venville, Street, & Fossey, 2014; Lightner et. al. 2012). For example, reasons for not seeking services until this point varied but many students cited stigma as a reason for not seeking services immediately, indicating that they felt shame surrounding their learning disability or desired to start a new identity in a new place where no one knew about their learning disability. Others, however, did not even know that they could qualify for accommodations or how to go about it until instructors or others suggested it to them (Lightner et.al. 2012).

There are students who know that they qualify for services and choose not to take them. Many students found that their long-term career goals or social goals were incompatible with the short-term goals of services offering accommodations (Venville, Street, & Fossey, 2014). The stigma associated with their diagnosis and fears that this would either isolate them socially or follow them into their future careers was a concern that is not considered by many support services. Other studies have also indicated that students might not seek out services due to fears that disclosing their disability may lead to discrimination (Lund, Andrews, & Holt, 2014). Other students simply felt that the accommodations they had received in the past were not helpful and therefore, not worth pursuing (Venville, Street, & Fossey, 2014). Barnard-Brak, Davis, Tate, and Sulak (2009) found had students rate the extent to whether they agreed or disagreed with statements such as “Accommodations are for academically weaker students” or

“Accommodations are unfair to other students.” They found that Attitudes towards disability accommodations and services were a much stronger predictor than disability type on whether or not services would be used. However, it is not only student attitudes that matter in use of student disability services. Characteristics of the university campus were a strong predictor as well with students at small private universities being 7.108 times more likely to seek out accommodations than students at large public universities (Barnard-Brak et. al. 2009).

Still, not all students report negative experiences using accommodations (Reinschmiedt, Buono, Sprong, & Upton, 2013). Many students do have positive things to say about the accommodations offered to them and find them overall beneficial (Lightner et. al. 2012; Graham-Smith & Lafayette 2004). Yet, when asked about their experiences, multiple studies, both those portraying the accommodations offered to students with disabilities in a positive light and those that portray it in a negative light, indicate areas in which the goals and bureaucratic set up of disability services are incompatible or do not meet the needs and goals of students with disabilities (Venville, Street, & Fossey, 2014; Herbert et. al. 2014; Reinschmiedt et. al. 2013; Coriale et. al. 2012; Lightner et. al. 2012; Barnard-Brak et. al. 2009; Dutta, Schiro-Geist, & Kundu, 2009; Egilson & Traustadottir, 2009) It is important to look at the entire experience of social inclusion and exclusion from the perspective of students with disabilities, rather than just the consequences of accommodations on academic performance, in order to discover what is helpful, and what needs to be changed. This study will attempt to address this concern.

### **Do Accommodations Meet Students’ Needs?**

Just as there are multiple types of stigma (discredited and discreditable), there are

multiple types of disabilities (Goffman 1963). However, this can be broken down beyond simply what are often called “visible” and “invisible” disabilities. There are physical disabilities, which is what many people think of when the term “disability” comes up but there are also learning disabilities, cognitive impairments, sensory impairments, chronic illnesses, and mental illnesses (Newman, Wagner, Cameto & Knokey, 2009). However, with these different types of disabilities, there is some fluidity over what “disability” means and who does and does not qualify for accommodations from Student Disability Services (Lightner, Kipps-Vaughan, Schulte, & Trice 2012; Newman et.al. 2009; Jung 2003). In fact, only 24% of post-secondary students with disabilities report receiving accommodations in their post-secondary institutions (Newman et. al. 2009).

Most students in the study conducted by Reinschmidt, Buono, Sprong, Upton, and Dallas (2013), indicate that they are “satisfied” with the support they receive from their university’s Disability Support Services. However, in another study, Dutta, Schiro-Geist, and Kundu (2009) surveyed 445 students with disabilities as well as four coordinators for the Office of Disability Services at four universities in the United States and found that students were dissatisfied with the lack of communication between ODS (Office of Disability Services) staff and university faculty, and the length of time it took between seeking accommodations and receiving accommodations. These two findings are not necessarily at odds with each other but it means that there is a need for further research on how students feel about university accommodations.

Worries that the stigma of mental illness would follow them to the workplace and prevent them from being hired or promoted are not taken into account by the institution, which is

typically focused on helping students meet their short-term goals of passing the class (Venville et.al. 2014). Furthermore, concerns about the isolation that may come with the stigma of receiving accommodations was another reason students reported not seeking accommodations (Venville, Street, & Fossey, 2014; Lightner et.al. 2012; Orr & Goodman 2010). Lisa Coriale, a university student with cerebral palsy, reported that while she found the accommodations offered to her to be helpful overall, there were unintended negative consequences. Sometimes, instructors addressed the aides as if they were the students, rather than Coriale herself, leading to feelings of isolation and frustration at the low expectations others have for people with disabilities (Coriale, Grant & Robertson, 2012). Students often fear the stigma of seeking accommodations and services will be worse than navigating the course without the accommodations (Venville, Street, & Fossey, 2014; Lightner et.al. 2012; Egilson & Traustadottir, 2009). As students with mental illnesses stated in interviews, classmates are not just classmates but potential future co-workers. While some may feel that social obligations are not the university's job to accommodate, the narrative by Lisa Coriale, who had cerebral palsy asserted that, "feeling a sense of connectedness with other students is as important to learning as physical accommodations" (Coriale et. al. 2012 p 427; Orr & Goodman 2010; Graham-Smith & Lafayette 2004).

Students with mental illnesses often report that even when they seek accommodations for their mental illnesses, they do not find these accommodations helpful and report that most of the accommodations offered are tailored towards those with physical or learning disabilities. Furthermore, students who had both a mental illness and a physical disability found the accommodations given for their physical disability was more helpful in terms of helping them

navigate post-secondary education than any accommodations offered for their mental illness. For example, a student found that the notes and transcriptions of the class provided to her for her Deafness, also helped her keep up in the class when she missed classes due to her depression (Venville et.al. 2014). It is not only students with mental illnesses who feel failed by the very institutions designed to help them, though. While accommodations are available to students with learning disabilities, 56.7% of students with learning disabilities do not consider themselves to be “disabled” and therefore, do not know that they qualify for accommodations through the school’s disability services (Lightner et.al. 2012; Newman et.al. 2009) Those with chronic illnesses, which often fall under the category of “invisible disabilities” are also reluctant to identify as being “disabled” (Jung 2003). This is especially problematic as it is viewed as the student’s responsibility to identify themselves as disabled, rather than the university’s responsibility to make classes accessible (Venville et. al. 2014; Lightner et. al. 2012; Barnard-Brack et. al. 2009; Jung 2003).

Furthermore, the perception that people with disabilities are valued less by society was associated with decreased levels of well-being (Green 2007). This finding was echoed by other studies. The majority (67.3%) of people in a study of professionals in psychology with graduate degrees reported disability-related discrimination or barriers during their graduate programs and training (Lund, Andrews, & Holt, 2014). Survey research in universities in Jordan found that the vast majority of disabled students felt that the university did not really support them being there, despite legislation requiring equal access to higher education (Al-Hmouz 2014). Orr and Goodman (2010) had similar findings in their interviews with students with learning disabilities, as 13 out of the 14 students reported having felt, “embarrassment” and “shame” in school. Thus,

while stigma is a subjective experience, it has consequences for the quality of lives for those who have what are perceived as stigmatizing characteristics, such as disability.

### **It's Not All About Coursework: Why Social Inclusion Matters**

In his work on stigma, Erving Goffman (1963) referred to those with disabilities as a category of people who had stigma. Yet, students in multiple studies felt that services for students with disabilities regularly ignored the aspect of stigma in designing accommodations, leading students to sometimes feel more isolated due to the accommodations offered, or to avoid seeking accommodations altogether (Venville, et al. 2014; Lightner 2012; Orr & Goodman 2010; Egilson & Traustadottir, 2009). Knowing what aspects of accommodations students find stigmatizing and unhelpful can help SDS to improve the services provided and lead to both better academic outcomes, and a better quality of life holistically for students with disabilities (Agarwall et. al. 2014).

There is also the assumption that the accommodations provided by the university are to help students with disabilities meet their academic goals; yet, in a study done by Mowbray and Megivern (1999) on people with psychiatric disabilities who do not meet their post-secondary educational goals, only 13% responded that they were having academic difficulties that ultimately led to them not meeting their goals. Instead, issues such as finances, medical problems, and “external personal situations” were referred to as the main barriers to meeting academic goals. Other studies have found that whether one is living on-campus or at home, access to financial aid, university characteristics, and personal attitudes towards disability accommodations are stronger predictors of whether or not one will graduate than disability type

or access to academic accommodations (Herbert et. al. 2014; Barnard-Brak et. al. 2009).

Furthermore, a focus on the entire college experience, rather than just academics, would be beneficial, as the social experience of students with disabilities does have an effect on the graduation rates of that population within universities (Agarwal et. al. 2014). Agarwal and her colleagues use a case study to illustrate the ways in which quality of life, as well as academic performance improved at one university following the creation of a student organization for students with disabilities. In Jordan, 87% of students with disabilities surveyed at one university indicated that they did not have friends at the university and an overwhelming majority felt that the university should do more to help include students with disabilities in non-academic events and organizations (Al-Hmouz 2014). Orr and Goodman (2010) found that students with learning disabilities discussed the importance of making connections with others, overcoming self-esteem issues through these connections, and non-academic activities before academic success can be achieved. In fact, while one survey of 546 students who sought disability services and found that 54% of the students who tried to obtain services were not granted accommodations it also found that the graduation rates between those who received services and those who didn't were almost identical (66.5% & 65.1% respectively), though, still lower than the graduation rate for all college students (86.7%) (Herbert et. al. 2014). In another study of students who did receive accommodations, "caring people" working in disability services and counseling from the university were cited by more people as being helpful than accommodations such as extra time on test or private testing rooms (Graham-Smith & Lafayette 2004).

While many people may prefer to be included in ways that allow them to hide their disabilities, others feel that including people with disabilities into everyday social life will lead to disabilities becoming less stigmatized. According to Russian Deaf activist, Pavel Kirillovich Sutiagin, “We have not need to lock ourselves away behind the walls of our House of Culture. The more Deaf people associate the hearing, the better” (Shaw 2015: 57). Since the purpose of accommodations is to help students be “successful” in the university setting, it is important to explore meanings of “help” and “success” in the eyes of students with disabilities.

### **Instructors’ & Service Providers’ Attitudes**

Due to the stigma associated with receiving accommodations, as well as lack of knowledge or ability to seek accommodations, some instructors now use what are known as “inclusive teaching strategies” (Dallas, Sprong, & Upton, 2014). Inclusive teaching strategies take certain accommodations, such as having audio books available, having accessible notes online, and allowing assignments to be submitted online, and makes these available to all students so that those who may need accommodations are not “outed” if they do have accommodations, or punished for not seeking them. However, while 88% of the faculty surveyed in the study done by Dallas, Sprong, and Upton (2014) indicated that they were confident in their ability to provide accommodations and use inclusive teaching strategies, attitudes varied by discipline. Instructors teaching classes in the colleges of Mass Communications and Media Arts, Education, and Applied Sciences and Arts had more favorable views towards providing these accommodations than the College of Liberal Arts and Sciences.

Furthermore, university students studying teaching, counseling, and rehabilitation have

differing views of students with different types of disabilities (Thomas, Curtis, & Shippen, 2011). It was found that students in the field of education had fewer positive perceptions about working with students with mental disabilities than students studying counseling or rehabilitation. These negative attitudes could very well translate into the way students with mental disabilities are treated by instructors, regardless of their actual behavior or performance in the classroom (van Jaarsveldt & Ntomboxolo Ndeya-Nderya 2015; Thomas, Curtis, & Shippen, 2011; Jung 2003). This problem is exacerbated by the fact that from a policy perspective, it is not the instructor's responsibility to make their course accessible to students with disabilities but rather, the students' job to identify themselves as disabled and present their "unique needs." This shifts responsibility from the institution to make their campuses and courses more accessible, and onto the student who, depending on the disability, may be unable or unwilling to advocate for themselves (Venville, Street, & Fossey, 2014; Jung 2003).

It is not only the instructors who play a role in how helpful or unhelpful accommodations are but also, the attitudes of the aides, note-takers, and other people who are a part of the accommodations process (Coriale, Grant & Robertson, 2012). In her narrative, Lisa described two different aides she had during the course of her undergraduate degree, one of whom she found helpful, and another who caused her distress. While Lisa is the student taking the class, she found that one of her aides did not take satisfactory notes and left her out of group discussions. This problem is compounded with instructor attitudes, as some instructors had a tendency to address the aide when speaking, rather than Lisa herself (Coriale, Grant & Robertson 2012).

From a symbolic interactionists approach, it is clear that it is not only the student with disability who assigns meaning to situations that will shape their experience, but also the instructors and service providers they are interacting with, who give rise to meanings in interactions. Students' perceptions of meanings that instructors and service providers give to disability and accommodations shape the students' experience of receiving accommodations. Even with these steps forward in legal rights for people with disabilities, numerous studies have found that people with disabilities consistently feel excluded and devalued by society (Oliver & Barnes 2012). Worth (2013) illustrated the ways in which this can be especially devastating for young people who are trying to establish themselves as adults, an identity that asserts independence, with a disability, a marker that leads others to treat them as eternally dependent. Worth asserts that, "disabled people's emotional well-being is under threat when they are not recognized as equals in public space" (Worth, 2013: p 578).

### **Barriers to Inclusion in Daily Life**

Barriers to participation in the community, both physical and social, are harmful to people with disabilities of all ages. Many studies have addressed the fact that it would be beneficial for communities to make these changes to the communities, since with better healthcare, people are living longer, leading to a larger proportion of the community that identifies as elderly and/or disabled (Clarke, 2014; Clarke & Gallagher, 2013; Rosenberg, Huang, Simonovich, & Belza, 2012; Clarke & George, 2005). While this indicates that creating a more inclusive community environment would be beneficial to a large portion of the community, I will be focusing my study predominantly on the experiences of young people, as I will be studying students. Young adults, and people transitioning into college face the challenge

of adjusting to a new identity of independence despite the fact that people with disabilities are often treated as if they need to someone to take care of them (Worth 2013; Patterson 2012) “Visually impaired young people’s goals of achieving ‘unremarkable mobility’ is constrained by an ablest society that constantly marks them out, frustrating goals of independence and mobility which are important to young people transitioning into adulthood” (Worth, 2013: 574).

Details as simple as curb cuts and uneven sidewalk cracks could make a difference between how successful a participant was at reaching their destination (Rosenberg et. al. 2012; Meyers, Anderson, Miller, Shipp, & Hoening, 2002: p. 1437) Roughly 24-32% of Meyer, Anderson, Miller, Shipp and Hoening’s sample reported not reaching destinations they had set out to reach due to barriers in the outside environment (Meyers et. al. 2002: p 1442). However, it was not only the obvious things such as curb cuts and ramps that influenced whether or not wheel chair users were able to reach their destination or not. Narrow aisle ways, limited or impractical disability parking spaces, and the accessibility of bathrooms at a particular location were also pieces of the built environment that impacted the daily lives of wheel chair users. Climate and weather also played an important role in mobility (Meyers et. al. 2002). Rosenberg, Huang, Simmonvich, and Belza (2012) had similar findings but also brought up the ways in which accessibility to these places leads to a healthier, more active life in general. “When neighborhoods are designed in ways that provide a default opportunity for people of all ages and abilities to be active while engaging in daily living, physical activity can become an inherent part of daily life,” (Rosenberg et. al. 2012: p 277).

## **Conclusion**

The purpose of this research is not to vilify the institutions that offer accommodations to students with disabilities. Improved access to education for students with disabilities is a sign of progress in society and research indicates that while these institutions are imperfect, they have had positive effects. However, there are still some remnants of the view that the disabled body is problematic (Shah & Priestley 2010; Jung 2003). The role of accommodating medical needs is the primary goal whether this is the goal of the students with disabilities or not. Therefore, the goal of this research is to give a voice to the students these institutions are serving so that the goals and priorities of these students shape the policies and accommodations intended to meet their needs, rather than the needs others perceive.

## **Chapter 2: Research Methods**

As noted in the introduction, in order to accomplish the goal of contributing to what is known about the experience of being a university student with a disability, I explore the following research questions:

- How do university students with disabilities make sense of their identities as adults with agency in personal narratives of the university experience?
- To what extent have students with disabilities felt included/excluded in aspects of university life including clubs, organizations, sporting events, and other social aspects of the university in which other students participate?

In order to address these questions, I conducted seven in-depth, semi-structured interviews with students with disabilities who were receiving accommodations through the DSD office at a large, urban, public university. For the purpose of this project, I defined a “person with a disability” very broadly as a person who has a condition (physical or mental) that impacts their daily living and requires adjustments. Because my focus is on the experience of receiving accommodations, and the role of accommodations in identity making and inclusion/exclusion within the context of campus life, my sample includes only students with disabilities who are receiving services and accommodations through the SDS office. I defined “disability” broadly, rather than focusing on one particular type of disability for two reasons: 1. Previous research

suggests that type of disability is not a particularly important predictor of use or satisfaction with accommodations. 2. My goal is to bring the voices of students into the discussion of what kinds of accommodations are helpful. I did not want to exclude the voice of any student who receives accommodations who might be interested in discussing their perceptions of these accommodations with me.

### **Data Collection and Analysis**

In order to recruit participants, the SDS office sent recruitment e-mails to the list of students that they serve (the e-mail used is included as Appendix B). Students were asked to contact me if they were interested in participating in the study. They were also e-mailed an attachment with a document explaining informed consent and providing more information on the study (the informed consent document is included as Appendix C). Nine students responded to this e-mail and interviews were scheduled with seven of these students. An interview guide was used to ensure that each participant was given the chance to discuss issues related to my research questions (the interview guide is included as Appendix D). Participants were, however, given the chance to direct the course of the conversation and to discuss the issues that were most important to them. These semi-structured interviews allowed students with disabilities to construct their own stories about the services that they receive, their experiences with inclusion and exclusion, and the process by which they construct their identities as independent adults with disabilities. Throughout the interview, students were encouraged to explain their goals and their perceptions of the meanings behind receiving accommodations, stigma related to their disability, and the disability itself.

I approached this research with activism in mind. Unlike positivist approaches, which strive for neutrality, emancipatory research acknowledges that praxis can be a positive, driving force for research (Green 2015). However, many critics of emancipatory research criticize the fact that emancipatory researchers may silence the voices or stories that do not support their agenda. On the other hand, Green (2015) points out that the act of telling stories that are marginalized can be a type of activism. Thus, while it is my hope that the narratives told by my participants will be used to improve services for students with disabilities, many students did express relief and satisfaction with being able to unapologetically tell their stories.

Emancipatory research can be influenced by whether or not the researcher is an “insider” or an “outsider” to the population being studied. I do not currently use any accommodations through the university but I do have diabetes and bipolar disorder. As with any research where the researcher has some “insider” status, I did have the concern that my story might overshadow or influence the way that I interpreted the research (Green 2015: 105). I had two participants with whom I shared at least one diagnosis. While I thought that these interviews would yield more detailed data, the opposite actually happened. As for people with disabilities that I was less familiar with, I ended up asking for more clarification and details. On the other hand, when speaking with another diabetic, there were some instances of the participant saying “well, you know,” which I did not realize until I was transcribing the interview later.

Interviews ranged from lasting as long as an hour and a half to as short as eighteen minutes. Some of the patterns in interview length and scheduling seemed to be related to the diagnosis and interview space. My shortest interview was with a person who had somewhat

recently been diagnosed with generalized anxiety disorder. Despite having booked a conference room, there was a great deal of noise coming from the hall during the interview and the interview was interrupted at one point as a person entered the room. Of my two longest interviews, one was early in the morning and one was late in the evening, when there were few people in the hallway and no interruptions. It is also important to note that both of these participants were diagnosed with physical disabilities that they had had for eight or more years. One of these participants had identified as Deaf since birth and unlike many of the other participants, this person did not consider themselves to have a “disability.” All of these interviews were audio-recorded.

Once I had interviewed students with disabilities, I had to work on “getting to know the stories” (Green, 2015: 109). I transcribed each interview, in its entirety, individually on my own. Once the audio-recordings of the interviews were transcribed, I conducted a narrative analysis to look at how students constructed identities separate from victim identities in a culture that defines them as victims. I went through each transcription and looked for themes that I found to be repeated throughout multiple interviews. I found that while students had narratives about struggles and experiences of exclusion, they did not portray themselves as victims. Instead, many constructed themselves as being harder working than their fellow classmates who did not have accommodations and more moral than people who judge them. As these themes emerged, I compiled documents, each labeled with a theme I found, and copied and pasted quotes from the transcriptions that fit into these themes into the appropriate documents. I specifically focused on pieces of the transcription in which participants discussed their identity or moments that they felt defined them.

While I was in the role of researcher, there were some complications with the power dynamic. I noticed participants repeatedly saying things like, “I’m not trying to criticize SDS,” or “I know they do everything they can.” While I did not contest the idea that they were satisfied with SDS’s efforts to accommodate them, and believe many did, in fact, have an overall positive view of SDS, I had to occasionally remind participants again that I did not work for SDS, the information they are giving me is anonymous, and their participation in the interview and the information they give in the interview, will not be reported to SDS or influence the services they received. In order to keep the interview flowing like a conversation and to minimize power differences, I was also open to having participants ask me questions about myself. While there are no quotes from me in this thesis, I did answer questions from participants about what disabilities I had, what my background was, and what my intentions were for the project.

## **Participants**

In order to protect the identity of my participants, I won’t describe the characteristics of each student who participated. Rather, I provide a summary of characteristics of a whole group of participants. Six of the participants are women and one is a man. Most of the participants identify as white, though, two identified themselves as Hispanic and one identified as Middle Eastern. Some of the participants have been diagnosed with mental illnesses, such as ADHD, and bipolar disorder. Others have physical illnesses, such as diabetes and fibromyalgia. All of the women currently considered their disabilities to be “invisible,” meaning that they felt it was not apparent that they were diagnosed with disabilities by looking at them. One respondent was Deaf. While this participant felt that their condition was evident to others due to physical

markers, this student did not consider themselves to have an impairment or disability, similar to many other members of the Deaf community.

Despite the fact that no two interviewees had identical sets of diagnoses, similar themes arose during coding. These themes include: distancing the self from disability, comparisons of different types of disabilities, being harder working or more successful, being more moral than able-bodied people, martyr identities, stories of exclusion, feeling included with other people with disabilities, and a need for privacy. In the chapters that follow, I explore each of these themes individually (Chapters 3 through 5) and then collectively (Chapters 6 and 7).

### Chapter 3: Stigma & Hierarchies

#### **“I am a person WITH a disability”: How do students with disabilities identify with or distance themselves from the victim identity?**

In all of my interviews, I ask participants if they consider themselves to have a “disability” and whether or not they considered it to be a part of their identity. While it may seem like a straightforward, yes or no question, the answers I got were much more complicated than that. Despite the stigma attached to the disabled identity, only one person rejected the identity of having a disability. However, this person did not attempt to align themselves with able-bodied people but instead, regularly proclaimed, “I am Deaf,” and embraced the social model of disability.

*That’s the medical view. It’s “Let’s fix this.” I’m not broken. Cultural View is, “We don’t need to be fixed.” But they [people who are Deaf with the Cultural Views] also tend to stay in just the Deaf culture. They don’t go into hearing culture at all. But of course, those are the two extremes. I find myself right in the middle. Where yes, I’m Deaf, but I use the TOOL for hearing. It’s not a fix. It’s a TOOL. I mean, what do you call glasses? Are they gonna be a tool or are they a fix? You don’t want to be broken. They are TOOLS so that you can see better. I use hearing aids. They’re tools so that I can hear better. -Jacob (Deaf)*

Most people neither rejected the idea that they had a disability, nor did they define themselves by it. Every other participant stated that yes; they did consider themselves to have a

disability. However, most people had a more ambivalent response to whether or not it was a part of their identity.

*I think so. I think you kind of learn to, adjust to the vocabulary a little bit....I hate to use that word because, it can mean such a variety of things, um....., do not use, "I'm disabled," but to use, "I am a person with a disability" because it doesn't define me but it's part of my social make up. –Nicki (multiple sclerosis)*

While some of this ambivalence may come from the stigma attached to having a disability, many expressed the idea that they are essentially not “disabled enough” or that they do not meet the typical image of a person in a wheelchair. I will discuss this in more detail later in the paper but the presence of a hierarchy of disability came out in multiple interviews, usually with wheelchair use being the hegemonic default image of what it means to have a disability. In addition to constructing identities with agency, against the cultural narratives that people with disabilities do not have agency and need to be fixed, they must also construct an identity of disability, despite the fact that they do not use wheelchairs or “look” disabled in order to receive the services and accommodations that they need.

The need for services led many participants to ultimately claim the identity as a person with a disability. April had a particularly interesting shift in her sense of identity before and after the diagnosis of fibromyalgia. Initially, during the onset of feelings of chronic pain and fatigue, she resisted the idea of being a person who was “sick.” She talked about trying to exercise and push herself and how friends and family members disapproved of her “laziness.” However, once

she was diagnosed with fibromyalgia, she became familiar with other narratives about the disability and found comfort in it. She was the only participant who regularly referred to herself as “sick” or “disabled” rather than as a person who has disabilities.

*Someone suggested going to a medical support group, and I was like, "What's that?" You know? And they said, "Well, you go there with people with the same diagnosis and you try to work together to feel better and just talk about it," ... so I started going there and all of a sudden, it was like, "Yes! These are the same things that's going on." and some of the other people had the same issues when they were younger too, so all of a sudden everything made sense, and it fit.*  
–April (fibromyalgia)

In order to receive services, those seeking services must prove that they are in need of those services. Unfortunately, this need for services goes against American cultural codes of independence and risks putting students with disabilities in an identity as a victim (Dunn 2004). However, part of the identity of being a college student is establishing independence (Worth, 2013: p 578). This complicates the process of identity making for students, who want to be recognized as adults with agency, with disabilities, often meaning that there is a need for services.

Yet, as discussed earlier, not all disabilities are alike, either in terms of symptoms or in terms of the type of stigma they carry (Shakespeare 2014, Goffman 1963). Yet, since many services for people with disabilities try to incorporate such a variety to types of disabilities, some feel that their disabilities are overlooked. While much of the literature focused on identities with disabilities as opposed to identities of people who were able-bodied, there were many

comparisons between people with different types of disabilities in terms of who received what services, who experienced what difficulties, and whose experience was “worse.” While social movement leaders sometimes try to hide the fact that these comparisons happen, with worries that such comparisons and accusations may undermine the movement, one cannot understand the process of identity-making without looking at identity comparisons and hierarchies between people with disabilities.

### **“Why can’t I just have that?” Wheelchairs and Mental Illness in Hierarchies of Identities with Disabilities**

As stated earlier, one source of ambivalence surrounding the identity of having a disability is the image of the wheelchair on every parking space, seat, or image intended for people with disabilities or to represent them.

*So in the library, there are, in the computer center on the ground floor, there are terminals that have a little wheelchair on them, and they say like "For Students Registered with SDS." I had an embarrassing moment the other day because there were all these computer filled, and this poor girl was standing with like, with like a walker and like, 800 things balanced and she was waiting for someone to get up from a computer .... And I think also, the fact that there's like, a little wheelchair on it, I've seen people on them who-, it's not my place to judge if you have a disability or not but, people tend to like, give evil stares if they're not in a wheelchair, because I don't think they understand that, there's so many more factor than that. And I would like to see more of like a, I guess and explanation of like what it is for, because I think it's like, people misunderstand. -Nicki, (Multiple Sclerosis)*

In fact, the topic of wheelchairs and wheelchair users as the “typical” person with a disability came up in more than half of my interviews, even though none of them currently used wheelchairs and only two ever had in the past. Many used it as a comparison point when talking about their own disabilities. For many, it was simply a comparison between visible and invisible disabilities, and wheelchair use was the obvious example of a visible marker of disability. A few who valued their privacy and their ability to hide their disability framed the wheelchair as a source of stigma and they felt relieved that they did not have this visible marker. Others, however, felt that their lives would be easier if they were in a wheelchair.

*Sometimes, like I see other students here, in wheelchairs and stuff and I'm like, "Why can't I just have that?" (cries) "I know it's a different trade off and they're probably looking at me like "I wish I could go someplace, and someone wouldn't know that I had a disability," so not like, I'm not like, that jealous but, but I feel like sometimes, that I wish there was just something cut and dry that could be over with and done. And I could have, not such a complicated thing, you know, just a set thing with what I can and can't do, but it's not that. It's way more complicated. -April (fibromyalgia)*

It is important to note that April, who wished that she had a visible disability, was also the only participant to fully embrace the identity of “being disabled” as opposed to “having a disability.” Her disability, fibromyalgia, is not visible to others but it causes her chronic pain and fatigue. In fact, her interview was repeatedly rescheduled due to the unpredictable nature of her pain. This has prevented her from holding a full time job or going to school full time, leading her

to be accused of “laziness.” Furthermore, since her disability is not visible, she is constantly being questioned on the authenticity of her status as a person with a disability.

In fact, every person with an invisible illness stated that they felt that invisible illnesses were less understood and respected than disabilities that can be seen. Tessa’s disabilities, which were diabetes and Charcot-Marie-Tooth Disease (CMT), are for the most part invisible. Tessa occasionally uses a wheelchair. Her partner, on the other hand, has a visible disability that causes him less inconvenience in his daily life yet, according to Tessa, people overestimate the difficulties he faces while putting her on the spot to defend her disability and needs.

*P: I don't have any physical appearance [of disability]. I mean I've had surgeries before. I have scars and I walk a certain way because of the CMT and, you know, with my diabetes, I just, I know why there's certain things, but when it comes to actual physical, like wheelchair, they don't see that. So I guess they probably assume that I'm asking for something that I probably shouldn't or deserve but I've had that [being treated with suspicion] before. A professor once told me, she said, "There's nothing wrong with you." And I'm like, "Well, there's, internally, there's everything wrong with me." And she started laughing and she's like, "Ok, well just let me know what you need and I'll work with you," so, I think that's the problem.*

*R: That people can't see it?*

*P: They can't see it so they assume nothing's wrong with me but, my boyfriend, he has the, he was born with like a stump, so he doesn't have his actual hand. And he always, we always joke about cuz he's like, "People look at me all the time and assume I have a really bad disability, but it's just ONE HAND missing," and with me, no one thinks that I'm disabled but in reality, like, I*

*can't, like I can't go to the Busch Gardens. If I do, I have to walk slowly or use a wheel chair. When it comes to me like, getting to class here, I have to take extra time to walk, all the way to the other classes or take the bus cuz I walk very slow and I fall a lot. Like I fell two weeks ago here and the library. So it's something that people really really don't understand. -Tessa (Diabetes & Charcot-Marie-Tooth Disease).*

While people with invisible illnesses are constantly questioned and made to defend their need for services, they are not at the bottom of the hierarchy of disability. Of the three participants with mental illness, two reported that they actively hid their diagnosis from others. This is a very different approach than some of the participants with invisible but physical disabilities, some of whom wished their disabilities were *more* visible. The stigma surrounding mental illness is much stronger and a prejudice against it also reaches service providers. This has devastating consequences.

*I was sexually assaulted, [specified # of years ago], by my doctor. One of my doctors. And, this institution, chewed me up and spit me out, and the community did too. I first went to the [CAMPUS SERVICE] here, and, they said, "Well, it happened in the community, so you need to go to the Community, you know, the Crisis Center, and get help there." And the Crisis Center said, "No, you are in the University," so nobody gave me services... because I have a [MENTAL ILLNESS] diagnosis, and, uh....., I made a report... I got chewed up and spit out, and uh, it just colors, it colors everything. It colors my experience here.*

While people with disabilities are generally stigmatized and mistreated, there are hierarchies and cultural codes within the disability community that lead people to question whether they can claim that identity at all. Some people with disabilities are further marginalized within an already marginal community. This hierarchy permeates society everywhere in terms of what is considered “accessible” for people with disabilities as far as laws go, and in terms of who is believed when they are seeking services, even when these services are not related to disability services.

These hierarchies further complicate the process of identity making for students with disabilities. Many of the participants expressed some awareness of where they were in this hierarchy and how their place in the hierarchy of disability led them to be perceived by others. In addition to trying to create an identity of agency that avoids adopting a victim identity, they must also construct an identity that they are “disabled enough” to deserve services, despite not being wheelchair bound. Yet, to acknowledge some disabilities, to get disability services, can have consequences for one’s ability to seek other services or to be taken seriously by those outside of disability services. Thus, students with disabilities must create identities where they are both disabled and as good, if not better, as a person than able-bodied people. Furthermore, these hierarchies influence feelings of inclusion and exclusion in the university setting.

## Chapter 4: Identity Construction & Disability

### Positive Identities: Talented Underdogs, Moral Saviors & Martyrs

As stated earlier, many participants distanced themselves from the identity of having a disability. Distancing techniques ranged from emphasizing that they were a person who *had* a disability, to minimizing their connection to disability, to constructing opposing identities, such as the identity of Deafness as not being a disability. However, for the purposes of this paper, I will focus on the ways in which people DO construct identities around their disability (or Deafness). Most of the participants did not strive to adopt an able-bodied identity and all but one of the participants incorporated and even embraced their disability (or Deafness) as part of their identity.

*They had the Miss Florida Wheelchair Contest here at [the university. You know, they take it to different universities and so, I, they had a workshop on advocacy, and I met all the contestants for the Miss Florida USA including, the Miss USA wheelchair uh, wheelchair USA was sitting right next to me and I had a chance to talk to her, and to talk about her platform and it was fascinating, and it helps me embrace the part of me that are "other."-Belinda (spinal problems, orthopedic problems, ADD, & Bipolar Disorder)*

Embracing “otherness” was an important part of many people’s identities, whether it was used to justify a need for services or to maintain a sense of being moral and hardworking in spite

of needing more rest and spending less hours working. To be sick, to need help, to not spend many hours working, is deviant and goes against cultural codes of what is good in the United States. In embracing “otherness” and distinguishing themselves as different, students with disabilities attempted to construct identities that were morally good, and deserving of services, and as people with agency, all at the same time. For many, their narratives began to look like hero identities, fighting against the barriers they face. However, as Dunn (2004) found, adopting a hero identity can lead to not receiving necessary services. Furthermore, to be too heroic can run the risk of being objectified as something “inspirational.” The story can no longer be their own story but instead, it is a cultural code appropriated by able-bodied people for motivation. Thus, a few participants adopted a new kind of hero identity: the martyr. In martyr narratives, the person is able to maintain agency and even some aspects of the hero identity but still acknowledges the experience of barriers and pain. However, there are aspects of victim identities within martyr narratives, giving up some agency.

### **The Talented Underdogs: “The results have been impressive.”**

For some, the obvious identity in contrast to the victim identity is the identity of the talented underdog hero who is successful against the odds. This can be complicated to construct, as the cultural story of disability locates the villain within the body. How can one be a hero when the villain, the disability, is part of their identity? For many, this meant not only reconstructing themselves as not being a victim but also reconstructing their disability as not being the villain.

*My brain works differently so, uh, even when I read fast, I'm a slow comprehender. I'm a slower processor and a slow comprehender. It doesn't mean I'm any less intelligent than anyone*

*else; it's just that I read differently. -Belinda (spinal problems, orthopedic problems, ADD, & Bipolar Disorder)*

For Belinda and others, the disability is not the villain. A disability is something that causes them to be *different*. Violet, who has ADHD and PTSD told me a story of a time at a former workplace, rather than school, where she surpassed her co-workers in terms of productivity by making the changes she needed to her work environment. Violet cannot focus with loud noises around her and works best in absolute silence. What is particularly interesting about this story is the changes made to her environment were HER idea, not accommodations given through an outside agency, thus, increasing the agency her character has in her story.

*"Do you mind if I go sit in the conference room?" and he said, "No," and I said, "Do you mind if I book the conference room for the rest of the time that I'm here? So there's one WAYYYY in the back in the corner. It's so quiet back there and I can just shut the door and you'll always know where I'm at? I can just honker down in there?"... I developed a tool for them, and it was done, and he said the results have been impressive. -Violet (ADHD & PTSD)*

If disability is not the villain, who, or what is? In order to adopt a hero identity, there must be a villain. While some people discussed it more explicitly than others, many participants expressed the fact that people's negative reactions to disability were more disabling than the diagnosis itself. Goffman's (1963) definition of stigma included the fact that it arises through the interaction, rather than from the stigmatizing entity itself. Over half of the participants said they

felt more comfortable interacting with other people with disabilities, but that they did not necessarily like discussing their disability with others who did not have disabilities due to the reactions.

*I think at the moment, the problem with, like I don't like telling people about my disability because the first thing they look at you is like with pity. And I don't like that because I can do almost anything that you can do. -Tessa (Diabetes & Charcot-Marie-Tooth Disease).*

Others, such as Jacob, who defines himself as “Deaf” and not “disabled” talked about how his diagnosis can even be beneficial to him sometimes, such as his ability to turn off his hearing aid when he needs a quiet space. Still, if these students are simply “different,” why then, do they need services, such as accommodations through SDS?

Every single participant stated that they overall had positive feelings and a positive experience working with SDS. There were times that I wondered if they had to say that. I had to correct some participants on the fact that I was not employed by SDS, and this research was not something being reported back to them. However, most participants seemed genuinely sincere that they felt that the accommodations were helpful and a good thing.

*I have almost a 4.0. And this is all pre-med. It's made the difference.... Yeah, it's made all the difference. I wouldn't be sitting in Tampa, Florida taking genetics and, I mean, I got an A+ in physics last summer. Um....., and even though this isn't a Top 25 institution, it's still a land-granting institution. It is still a good institution, and I got an A+ in physics here. So, could I have done it without it? No, I don't think so. So, I mean it's, it's, been life changing and had I had it,*

*you know, honestly, in 1982 when I started at the University of Minnesota and had I known then, I think I'd have been a physician at 29, and not at whatever age I will be now. –Violet (ADHD & PTSD)*

However, to them, Students with disabilities did not see SDS as their hero. While Being the hero, as oppose to being the victim, is a positively evaluated identity (Dunn 2004). SDS was framed as a sidekick. As Violet described, she could not have been as successful in her classes without the accommodations but ultimately, she used the pronoun “I” to describe her accomplishments. *“I got an A+ in Physics last summer.”* SDS was a sidekick who designed and created the tools that the hero used to defeat the villain of one-size-fits-all expectations that don’t allow for people with different needs. Jacob, who is Deaf, also described his hearing aid and medical equipment as “tools” rather than a savior or hero.

### **Moral Saviors: “I have more empathy.”**

The successful valiant hero is not only someone who is victorious against their villain. A well-constructed “villain” causes wide spread harm to a perfect victim who is targeted through no fault of their own (Merskin 2004). If the student with a disability is the hero, who is the victim? In her analysis of the media’s portrayal of Betty Ford as a breast cancer patient, Dubriwny (2009) shows the ways in which the “ideal patient” takes care of and *comforts* their family and friends with their positivity. There were many references to students with disabilities being positive, more moral, or implicitly better people. This helps them further construct their identities as heroes, since heroes are culturally good and moral people. However, able-bodied people in their lives were not the victims that emerged in the data. It is difficult, if not impossible

to escape cultural codes of disability as being a source of victimhood. Interestingly enough, roughly half of the participants discussed being a hero, but to other people with disabilities.

*I hope that the-, that being able to see the brilliance in myself, I can transfer that to my students so, the kids that fall asleep in class, the kids that are angry, the kids that, aren't motivated, I hope that I can look, look at that, but also look beyond that, and ask myself, "What could be playing a part in that?" not just saying, "Oh! Johnny's a bad student. He's not completing his work. He's never gonna amount to anything." I don't want to impose that, or even think that! -Belinda (spinal problems, orthopedic problems, ADD, & Bipolar Disorder)*

Belinda was not the only participant to discuss her disability status as giving her a unique understanding to help other “victims.” Many felt that their disabilities gave them a certain amount of insight that others without disabilities could not have. Jacob, who was Deaf stated, unprompted while describing himself and his identity as a Deaf person, “*I have more empathy [than most able-bodied people].*” April, who had fibromyalgia expressed a similar sentiment stating, “*Being sick, actually made me more empathetic and nicer.*” Like, Belinda, Tessa also felt that this understanding and empathy related to her experiences with disability would help her and influenced her calling in her career.

*I'm majoring in psychology. I want to work with children and teens therapy sessions or, um, my goal is to one day open up a farm, and have children go there and kind of have it like to be a therapeutic session for them, so, that's my goal...I love kids. When I used to go to high school, I use to, be with the kids who were in the disability courses because they had these type of disabilities, and a lot of them were talking to me and I remember that they didn't have a lot of*

*activities that they could do and a lot of them were in foster care, so when I was asking them those questions, I remember they use to tell me all these things that they wanted to do, and I just remember like, "Wow, like these kids deserve to have something," you know? At least something that they can enjoy. –Tessa (diabetes and Charcot-Marie-Tooth Disease)*

However, while hero identities can help students with disabilities give meanings that are positive to their disability, this “positive” has a negative side. The hero identity is one that people like to gravitate towards. However, there is a danger in it. As Dunn (2004) warns about, shedding the victim identity also runs the risk of shedding the claims-making ability for a need for services. In response to the need to construct an identity that is both heroic and in need of services, I saw a new identity emerging in some of those narratives: the martyr identity.

### **The Martyr: “If I try harder, I’ll make myself worse.”**

I am defining the martyr identity as separate from the traditional hero identity in that the martyr is both a hero and a victim. Traditionally speaking, a martyr is someone who is killed or undergoes great deal of suffering for a cause, usually, but not always, religious. Unlike the traditional hero identities martyr identities acknowledge and even highlight the fact that they are in pain and suffering greatly. Thus, there are some aspects of the victim identity, making them more worthy or in need of services. However, students with disabilities who adopt the martyr identity also work hard, arguably harder than most students, to be successful in work and school or community services. In other words, students with disabilities who construct martyr identities go through a great deal of suffering in order to live a life that is considered “productive” and “worth living” to show that people with disabilities can be successful and do matter.

April was the only participant to fully embrace the martyr identity. Unlike others, who saw misconceptions and one-size-fits-all policies as the villain, April casts the cultural codes that devalue people with disabilities as the villain. While she still goes to school and works part-time, she sees the American Dream that values people based on the number of hours they work as a villain. She states that works harder than most people do and is regularly in pain and yet, she is cast as “lazy” due to her limitations.

*I think, it's kind of a cultural thing to where, people in the US, they just want to keep trying harder. They keep, you know, this idea of "the American Dream," and if you try hard enough-, "Oh, there's people who come from," you know, "really terrible places in the world that are refugees and stuff and they've lived through really bad things, and they're able to make it, so YOU just try harder." And it's like, that's the whole frustrating thing. IF I try harder, I'll make myself worse. –April (fibromyalgia)*

Yet, her story also shows how embedded cultural codes and expectations are into our identities. Despite her apparent rejection of the American Dream, she goes on to discuss how hard she works and how having a job and taking classes improves her self-esteem and sense of self. She even goes so far as to cast herself as being responsible for her disability, wondering if her disability would be less progressive and painful if she hadn't worked so hard.

*So I just got part-time jobs at Care.com and mostly like, companion care, where I just had to basically be there... that's the best I can do right now...I get enough money that I can come back to school and I, tried just doing one class a semester and it has been, kind of tough*

*...it's frustrating. I get so much pressure from other people. Even the people that saw me through all that time and saw how bad I get, it's like, they just don't understand or, they just don't care... "Why don't you do more?" "Why haven't you graduated yet?" You know, and I'm like, "Well, what exactly am I gonna do when I graduate anyway?" ... The pain and the inflammation, makes it really hard to remember things, um, even just like, words sometimes will, just slip out of my head and it's so simple or I can't remember. And I get tired really quickly so, you know, I can't go work in an office. Like, I can't, I don't know what I'm suppose to do. I can try working at home but, there's gonna be a lot of off and on, ...but, it just makes me feel better to be back in school, to be kind of productive and, it feels so much better just emotionally having a job and being useful again and knowing that there is a future, ..., I used to be really hyper, always busy, I never really really slept that much. I could go sometimes for two days without sleeping or getting things done...that's typical of fibro also, because, people who are kind of Type A and, and busy all the time, perfectionists, they sort of push themselves into it sometimes. There's a genetic component, but you have to kind of activate that, that gene with, you know, overwork, or illness, or something like that, some other illness. –April (fibromyalgia)*

This tendency to emphasize how hard one works is an important part of the martyr identity. The hard work increases the amount of physical pain and stress and, as April brought up, this effort may or may not lead to a career path. Yet, it is ingrained into our cultural identity that to be morally good, we must work hard, regardless of pain or practicality. April is in pain and is adamant that she needs services. Yet, with her illness being one that is not visible to most and is treated with prescription painkillers, she must defend her need and distance herself from someone who is “faking it” to get painkillers or to get out of working. To do this, she must

convince people that she is morally good and that in being a good person, she is deserving of services. Therefore, she must talk about the work and effort she does do in order to show that she wants to work more, since our cultural codes insist that good people want to work.

April was not the only one to combine the hero and victim identity to end up with a martyr identity. While April accepted more aspects of the victim identity than others, nearly all of the participants brought up aspects of continued hardship, pain, or difficulty stemming from their status as a person with a disability. Seeking services is often seen as a sign of victimhood, making service-seeking another hurdle some students must face, rather than a helpful tool.

*I would guess, that it's that people with disabilities have, may experience greater depression, greater anxiety, greater isolation. And, because there's a stigma and, some of us, you know, are, are affected by the stigma, this may not be a thing we want to talk about. And just like I'm having my two-year process of accepting that I have these disabilities, other people may be the same. So, it's easier to join a fraternity than to go and join Disability Services. - Belinda (spinal problems, orthopedic problems, ADD, & Bipolar Disorder)*

Furthermore, students with disabilities cannot always claim a heroic identity. They must constantly cross back and forth between emphasizing what they are able to do and reminding people that they do in fact have a disability. This is especially true, given that all but one of my participants had invisible illnesses, meaning that the legitimacy of their disabilities was constantly called into question. In order to defend the legitimacy of their need for services, they must also emphasize the struggles and barriers they face.

*I mean, the students that know I take the accommodated tests are like, "Oh, I should go get accommodated." I said "Really?" and they're like, "Well, I stress out with tests," and I'm like, "Do you black out?" –Violet (ADHD & PTSD)*

Thus, while students with disabilities do *not* see themselves as “victims” despite the cultural narrative, and adopt some aspects of hero identities, to box students with disabilities into these hero identities makes it more difficult to access services and would not represent their lived experience. In order to understand students with disabilities using narrative analysis, identities that incorporate both aspects of the victim narrative and aspects of the hero narrative must be recognized. Students with disabilities are constructing identities against a cultural narrative that casts them as victims. As they resist this narrative, they must also maintain the identity that they are struggling and need services. Furthermore, they must balance these demands with other cultural codes of morality and goodness, which demand that all “good” people are hard working and independent. Thus, many adopt the martyr narrative. They must construct identities *so* hard working, to the point that they are suffering, or at least struggling, and need services. While this can be dangerous, as it implies that those who cannot or do not “work hard” don’t deserve services, students with disabilities construct themselves in this way to placate their need for accommodations, and their need to be evaluated as a good, person with agency.

## Chapter 5: Social Inclusion & Exclusion

### “I had no friends”: Stories of Exclusion

Between issues of accessibility and social stigma surrounding disability, it was no surprise many participants had multiple stories surrounding the experience of being excluded. This was especially true with students who had disabilities in childhood.

*P: And then were moved to [city] and I was never allowed in the classrooms. Even back then, I mean, in second, first, second and third grade, mostly second and third grade, my desk was permanently placed in the hallway of the schools. I'm not allowed to be in the classroom.*

*R: It sounds like you were excluded from the classroom a lot. Was that-, did that ever carry over to peer groups or friendships-?*

*P: I had no friends...I think a lot of it was because, I was ostracized. I was kept outside of the classroom. I mean, how much more can you say, "You don't fit in," than, "You're not even allowed to sit in our classroom?" You know? And I'm 7 and 8 years old, so you're telling a seven and eight year old little child, that they don't belong and, you know, it didn't really, I had a couple of friends, but I really didn't have any friends. -Violet, (ADHD & PTSD)*

Violet was not the only student to describe being isolated and friendless in childhood. Jacob recalled, “I could count my friends on one hand, ok? I could give you their names still

even. As a matter of fact, I wanna say yeah, I don't even need a full hand." He went on to explain that he was badly bullied by his peers in school.

*I also had this situation in Texas where, second or first, first or second grade, I almost remember this, almost, I uh....., the phrase, "sticks and stones can break my bones but words will never hurt me?" Well some people decided to throw sticks and stones at me so I decided to be sneaky. I ran close to teachers, then right in front of them. They couldn't just say they weren't seeing anything because I ran right in front of them with the kids chasing me. And basically, the teachers went right after them. Of course, what I didn't know is one of those kids-, well; I did know that one of them was on my soccer team. What I didn't know is he got expelled for the day. Later that day at practice, that kid's parent, father, went up to my mother during practice saying, "You know, my kid got expelled from school today because he was having fun with your kid." Did you hear the part where I said "throwing sticks and stones?" -Jacob, (Deaf)*

Nearly, every participant interviewed could think of a time when they had been isolated or excluded. While many of these involved incidents of childhood teasing or bullying, some, such as Violet's narrative, discussed situations in which the school or another institution, facilitated or contributed to the experience of isolation. Belinda and April also experienced being isolated in a classroom setting though, they both had experiences of humiliation and isolation in the university setting.

*I probably was learning like the basic tenants of sociology, something like that, and um....., and I was having trouble producing on time, you know, uh, handing in my papers on time,*

*and um, I was being taught by a graduate student and, in the middle of the semester, he said, "Belinda, you don't belong [at this school]. Someone like you can't succeed here." -Belinda (spinal problems, orthopedic problems, ADD, & Bipolar Disorder)*

*He didn't even want to fill out the form that we have to fill out, with like, agreement stating what the accommodations are, and that they have to, by law, accommodate that. And um, you know, something about, like, going up in the attendance, about exactly how many days can I miss and what is the make up policy and stuff. And it's for a reason and I'm suppose to do that, you know, in order to keep up my accommodations and stuff, and he didn't want to do it, and he kept like refusing and I had to keep asking him over and over...For some reason, he got the impression that I had kind of "told on him" and, was trying to get him in trouble, rather than communicate better, and let him know what he needed to do, what I needed from him, you know, so he ended up getting kind of like, a retaliatory like, stance, where he, kept asking me like, singling me out in class and asking, "Are you fine?" "Do you need anything?" like in a rude way, and not wanting to give me like, extra time and stuff, like, for timed assignments. I'm suppose to have time and a half, and he would be like, telling, he'd put the timed assignment FIRST in the class, so I couldn't participate in the discussions and stuff until I finished my assignment. And he wouldn't say like, "Oh, you have more time." He'd be like, "Ok, everybody's got 40 minutes," Hurry! Hurry! Hurry! You know. Go! Go! Go! And he'd be, keep telling me, "You need to turn it in." "You need to turn it in right now!" -April (fibromyalgia)*

These instances led the students to feel isolated and stigmatized. Students were told they do not belong in the classroom, that they were “other.” Confidentiality had been broken yet,

some participants expressed the fear that seeking to fix this would lead to retaliation, as it did in April's case. Instructor attitudes and shame greatly influence one's sense of identity and performance in education and work (van Jaarsveldt, & Ntomboxolo Ndeya-Ndereya, 2015, Every 2013, Brown 2008).

### **“There's people like me”: Inclusion between students with disabilities**

Multiple participants discussed the ways in which they were able to find places of inclusion and ways of feeling positive about their identities by working with other people with disabilities. When asked about whether or not she was involved in any clubs, Tessa immediately launched into discussing about her volunteer work that she does with FUSE (For the Understanding of Students with Exceptionalities) and her motivation for being involved with them.

*I think it's more understanding, that people underestimate them [children with disabilities] ...it's more of an understanding with other kids that I see what they're going through. I understand the pain. I want to help out. I want to help you and just because we have a disability doesn't mean, that, our life is over. We can still do fun things; we just have to, of course, adjust a little. We can do, almost, pretty much anything anyone else can do with just a little bit of exceptions. So I really got motivated to do something about it. I also have an uncle with down syndrome so, it kind of motivated me to do something with the kids and with people like me in general, to help out and to show them that there are people, you know, that, are disabled and that you can still do activities and stuff with them..... But to have an understanding of, there's people like me, I needed to feel more of that, and my mother wasn't really into the type of person*

*to let me into groups and activities, cuz she was very very strict. Very, you know, Momly. So she always use to try to, not keep me away from that, but I just think she didn't think it was so important. But I realized that it was important to ME to have that so from then on, I always thought, if there was something I can do, to make someone else feel comfortable, I would do it. – Tessa (diabetes & Chacot-Marie-Tooth Disease)*

While Tessa was very articulate and brought up lots of reasons for her passion surrounding working with FUSE, it was interesting that while her mom and other able-bodied people in her life valued her health above everything else, Tessa stresses that inclusion and being social, were important to *her*, regardless of how her parents, medical professionals, or others who may feel that they know best felt about the situation. April, who at first experienced some depression with her fibromyalgia diagnosis, found some solace and comfort once she joined a support group with other people with the same diagnosis.

*Someone suggested going to a medical support group, and I was like, "What's that?" You know? And they said, "Well, you go there with people with the same diagnosis and you try to work together to feel better and just talk about it," and I was like, "Ok," so I just googled "Medical support group, fibromyalgia, [city]," you know and it came up with this [City] Fibro-Friends, and I was like, "Oh! Ok!" so I started going there and all of a sudden, it was like, "Yes! These are the same things that's going on." and some of the other people had the same issues when they were younger too, so all of a sudden everything made sense, and it fit. –April (fibromyalgia)*

Inclusion with other people with disabilities reminded many participants that they were not alone. In some cases, it reminded them of what they could do. For others, it allowed them to realize that it was okay to accept the limitations their impairments put on what they could do. Belinda expressed that she was satisfied with her current relationship with Disability Services but that the main thing that she would change though is to have more opportunities to feel included and interact with other people with disabilities, as opposed to being the one isolated person with a disability in a classroom.

*R: And um, so, if you could make any changes, in anyway, to SDS, or SOCAT, or here at UNIVERSITY, what would they be?*

*P: I, I think I would have more opportunities for; I would create more opportunities for socializing. Um... I don't know that that's available for, the undergraduates, but, uh....., for socializing with other people who have disabilities, yeah. And, and make it, make it focused on fun, not make it focused on learning statutes or learning how to get a job or not, you know, just make it a fun thing....I don't know what those fun things would be, but, you know. Like meeting all the candidates for the Miss Wheelchair Florida! That was a lot of fun! That was fun! And all of those women were just so smart, and focused, and positive and, hopeful. -Belinda (spinal problems, orthopedic problems, ADD, & Bipolar Disorder)*

Still, while inclusion with other people with disabilities was a positive influence for those who experienced it, there were fewer stories about students with disabilities who felt fully included in non-disability related clubs and groups. Furthermore, many students had stories that brought up the question, “What is inclusion?” For many students, the ability to have agency to

decide when and where they wanted to be “included” was more important than the inclusion itself.

### **The Need for Privacy: How inclusive policies are not always so inclusive**

While I believe that inclusion is imperative for people with disabilities, many people with disabilities stress that inclusion is more than simply allowing people with disabilities to get to a place. Sometimes, the ability to leave and be alone is as important, if not more important for the quality of life for students with disabilities. As Worth (2013) discussed in her work with visually impaired young adults, are distressed by the fact that they are treated in an infantile manner, even as they are entering adulthood. Many people in general desire to have some degree of privacy. People, with and without disabilities, desire the right to chose how they present themselves and the desire to be alone. Yet, these are two aspects of the human condition that are often overlooked by institutions and people with disabilities.

Sometimes, well-meaning place-makers focus so much on making areas accessible and inclusive, they forget that people, including those with disabilities also deserve spaces to have privacy. Three of my participants actively kept their disability a secret from friends and family. While some people with disabilities fight for inclusion and acceptance, many also have the very real fear that having their disability status outed could leave them vulnerable for discrimination and bullying. The fact that five of the seven people who participated in the study discussed either the fear of experiencing discrimination or bullying or the actual experience of discrimination or bullying made it surprising how often participants reported being outed by those who were

suppose to keep their confidentiality. While individuals cannot always be controlled, one participant argued that even the built environment reveals her status to others.

*I know a lot of other girls on campus, like, main campus, and so, it's obviously on main campus too. Like, do you know where the office is located? So when you get out of there, I have already walked, like, bumped into people I know, and they know that I'm at UNIVERSITY Health, and so they ask me, "Oh, why are you here?" and I always come up with something, "Oh, I'm here to pick up something, like a form," or, "Oh, I'm just here to study a bit." So, I have been coming up with excuses, and I wish I didn't see people I knew, cuz I just don't want to talk about it to them. –Shasha (Generalized Anxiety Disorder)*

Furthermore, being alone and needing privacy can be a manifestation of one's disability and in some cases, forcing people to be included in the community and denying access to places to be alone is far more exclusive than inclusive. In Shasha's case, the inclusive, accessible nature of the Office of SDS made it more difficult to seek accommodations. Shasha was diagnosed with Generalized Anxiety Disorder and the idea of people she knew finding out about her diagnosis caused her to feel anxiety. Thus, the location of the very office that strives to include people with disabilities was very exclusive and alienating in her experience. Later in the interview, Shasha went on to discuss that she understood that the office needed to be easy to find and access but that having frosted windows and doors, instead of the glass ones currently used, would make her feel safer approaching SDS. Furthermore, Violet, who was quiet open about her disabilities with her classmates and people in her life, found that quiet places to be alone helped to minimize distractions and made it easier for her to concentrate, as a person who has ADHD. Being around

people while she was working on tests or projects was distracting to her and caused extra stress. She performed better when she was given a private place, free of distractions, and *away* from other students.

*So, what I've noticed is being in the private room [at another university], I wasn't distracted at all by people leaving...The first exam [at this university/ without a private room] was ok but the second one was really kind of wonky. And the third exam, my instructor himself went and put me in the tutoring center for physics, and he said, "I'm gonna block off the doors so nobody can come in here and bother you, but you're on your own because you can have the room to yourself," and. I got a 97%. And I think it really made the difference. –Violet (ADHD & PTSD)*

Thus, while I stress the importance of inclusion in the built environment, place makers must also be aware of diverse needs. By being mindful of these needs that allow people with disabilities to participate in, and retreat from, activities in the community, place-makers can make spaces welcoming to people with disabilities. In doing this, allow the space people with disabilities live in become a place they can call their community and their home. Even participants who were more open about their identity as someone with a disability experienced difficulty with the lack of ability to retreat from activities to be alone. Sarah, who experiences chronic pain from her fibromyalgia, discussed the ways in which the inability to cancel or leave early once she has registered for event kept her from registering at all.

*I can do but I WANT to get involved and I just need something where, it's not as like, regular attendance is mandatory, and you have to register before hand and like, you know, like, even when I try to do, yoga at the gym, they have yoga which is really therapeutic, and, you have to register, at least like, an hour or two ahead of time, and I feel like, I really want to go, but if I register and don't show up, you know, because I don't feel well, you only get three times before you're not allowed to go to that class anymore. And I'm like, "I don't want to mess it up!" That can happen really easily. That can happen in one month where I have three days where I have to cancel, you know? So, it's hard to find something. I haven't found anything yet, where, I feel like I have the skill level to do it, and I can commit to it. You know? I need something where I can just kind of drop in, and help, you know, and then go when I, when I need to, and I can't find anything like that so far. –April (fibromyalgia)*

In short, just as people without disabilities are able to easily make decisions to attend events and to get from place to place, they are also able to easily leave. They can leave offices, classes and events unquestioned and unencumbered. Having an accessible Students with Disabilities Office and providing access for students with disabilities to attend events is imperative. However, it is equally important that the Students with Disabilities Office offer privacy with accessibility. For events and classes to be truly accessible, students with disabilities must be able to leave, as well as arrive.

### **How Can We Meet Student Needs of Inclusion?**

In addition to resources on campus, many students reported receiving services from the wider community. However, while they did not necessarily expect the university to meet every

single one of their needs, some students reported being frustrated by the lack of guidance they received from SDS when it came to identifying community organizations that could help them.

*I know SDS will never have anything to wake me up, I mean, but I still asked, like, "Is there any way you can help me get up for class on time?" and they were like, "No," like, "Crap. "That's your own responsibility." Yeah, but I haven't learned that.*

*R: So do you think that um, SDS would be more effective if they had, more resources for, you know, living on your own in general and not just classes, such as, louder alarms or, things like that?*

*P: Yeah, or some sort of way to have resources to say, "Here's where you go." because I wasn't even pointed in the right direction. I went to the audiology center myself and I said, "Do you have an alarm clock?" and they said, "Sure, we have an alarm clock. It's called a sonic boom." I'm like, "Ok, sure, I'll try that." And it worked!. –Jacob (Deaf)*

Given the nature of universities, most of the services offer accommodations and assistance in terms of helping with succeeding in academics. Students with disabilities do not only want to be defined by those two status markers. Rather, they are whole, complex people with a variety of needs. While they understand those needs cannot be met by the university, given the variety of needs from different students, they would like more guidance to other community resources.

*Well, one of the things that I think is important and I haven't seen it yet here is, obviously, a lot of us have relocated from other places to come here, and SDS is great with navigating the university, but I would love to see them, have other services just for, general, like help, cuz I*

*know, for school like, I'm great, but um, one of the obstacles I faced was, getting a driver's license here. They're really strict about what they consider to be, something that could make you a danger on the road, and so, when I, applied for a driver's license, I applied for a disabled parking permit in the case that I have an issue, I can use it if I'm having trouble walking and, I was put under investigation by the Florida Board of Medicine, I had to give them paperwork, they refused to give me a license. It's crazy! And I had never experienced that before so I thought, "Oh my God! How do I even navigate this?" Cuz I've never heard of this before. And I went to SDS and asked them, like, "Do you have anybody that could like, help me figure this out?" and they're like, "No, we really only do like, university-based." So I'd love to see if they were able to, at least direct you in the right direction cuz I have not idea what I'm doing, and I still don't have a license here so... to be determined but. it's just frustrating. –Nicki (multiple sclerosis)*

No single institution will ever have the resources to meet all of a populations needs. However, should that institution not be able to meet the needs of its community or target population, it is imperative that they have the resources to know exactly where those services can be found. The disconnect between the services offered at the university and the services offered in the community is an essential part of our understanding of the experience of students with disabilities. Belinda, who has been both a service provider to people with disabilities as well as a student receiving accommodations herself discussed the ways in which a more inclusive, connected Disability Office would benefit both students who are already receiving accommodations, as well as students who have not yet applied but who might need or benefit from the accommodations.

*I know I would guess, and maybe from, you know, all my work as a, a community counselor for all those years, I would guess, that it's that people with disabilities have, may experience greater depression, greater anxiety, greater isolation. And, because there's a stigma and, some of us, you know, are, are affected by the stigma, this may not be a thing we want to talk about. And just like I'm having my two-year process of accepting that I have these disabilities, other people may be the same. So, it's easier to join a fraternity than to go and join Disability Services. - Belinda (spinal problems, orthopedic problems, ADD, & Bipolar Disorder)*

Again, it is important to stress that the purpose of this thesis is not to criticize or smear the Disability Services Office. In fact, all of the students who participated in the study stated at some point that they were satisfied with Disability Services and that they had positive interactions with the staff. Instead, many students asserted that they felt that the people at the Disability Services Office did everything they could to help clients but that these services either did not have the resources, or were too disconnected from off-campus resources to meet the needs of students with disabilities outside of the classroom.

## **Chapter 6: Discussion**

### **Identity-making in Inclusive and Exclusive Environments**

Students with disabilities are not constructing identities of agency in a vacuum. In addition to the cultural narrative of disability as a source of victimhood, they are seeking accommodations from SDS. Organizational narratives implicitly cast themselves as the hero, leaving students with disabilities, once again, vulnerable to the victim role. Yet, their disabilities require that they seek these services in order to reduce barriers to success. Additionally, people become familiar with cultural narratives throughout their lives. Only two of the participants were diagnosed with their disabilities before adulthood meaning that most already had pre-conceived notions about disabilities before they realized that they, too, would occupy this identity. While students with disabilities construct identities with agency, they are influenced by the cultural narratives, with which they are already familiar. Experiences of exclusion and isolation further emphasize their role as “other” and “different” in the university setting and in their lives in general.

Being treated as “other” through exclusion, students with disabilities, navigate their surroundings and experiences with a stigmatized identity. Yet, they construct narratives in a way to emphasize the hard work, morality, and other traits that are typically evaluated positively in American society. Since people with disabilities, just like all people, have complex identities that

are not based on one or two status markers, they need services that evaluate them as complex people who have status markers beyond that of “student” and “person with disabilities.”

There is the biomedical model’s construction of disability casts disability as a tragedy for the doctors to mitigate. On the other hand, there is the dominant competing narrative of people with disabilities being heroes who overcome barriers and are “inspirational” to others. While this narrative is often offered up with good intentions, it ignores the role of pain, discomfort, and other barriers that need to be discussed. It takes the responsibility off of service providers to make places more accessible and puts all of the responsibility on the heroic individual to make things work. Neither the hero nor the victim identity really fits the lived experience of people with disabilities nor does either of these identities suit their needs. Thus, many people with disabilities use aspects of both of these identities to create a new identity: the martyr identity.

How do students with disabilities construct this identity though? In this study, most participants did incorporate the fact that they had a disability into part of their identity. They acknowledged the pain, the inconvenience, and the stigma surrounding their daily experiences. By incorporating these aspects of the victim identity, they establish a need for services. However, some of the participants I interviewed then went on to discuss the ways in which even with the accommodations offered to them, they still worked much harder than their able-bodied peers to be successful. Others highlighted the ways in which they simply worked “differently” but that the minor adjustments put them in a position in which they were as successful, if not more successful, than their peers. Still, others highlighted ways in which their disability either led them to be a more moral, empathetic person. Some felt that their disability called them to a

career where they could be a hero to people that they would understand better than abled-bodied people would. All in all, all of my participants drew from aspects of the hero identity as well in order to construct themselves as having agency, against the image of the passive person with disabilities. However, often time, in constructing the martyr identity, students with disabilities diverted from the Social Model of disability and, to a certain extent returned the conversation back to the topic of embodiment. While this runs the risk of recasting the disability as the villain, it also gives provides some source of validity for claims that they are harder working, and other aspects of the hero identity that they choose to adopt.

### **Included and Excluded Identities**

While I used the term “students with disabilities” throughout the paper, due to the fact that there was one man with a visible disability marker of disability. This study was open to all students receiving accommodations. However, it was limited in that all but one of the participants were women and all of the women had what were currently invisible illnesses, though, some will eventually become visible or have been in the past. Whether these findings would apply to students with more obvious visible disabilities is unknown. Future studies could include more efforts to recruit students with more visible disabilities. Given that there appeared to be a hierarchy of disability, future studies could also look more into how students with disabilities construct the concept of disability and these hierarchies or how their construction of this hierarchy influences their identity-making.

Multiple studies have shown the ways in which inclusion benefits students both in and outside of the classroom (Agarwall et. al. 2014; Lund, Andrews, & Holt, 2014; Coriale et. al.

2012; Egilson & Traustadottir 2009; Graham-Smith & Lafayette 2004; Jung 203). Yet, looking at the data, it is clear that many students still face exclusion and isolation in the classroom based on their disability status. However, simply ending exclusion is not enough. Students must be actively included in campus life, both in terms of with other students in the classroom and with other students with disabilities.

The question remains, what is inclusion? Multiple participants stressed the fact that the ability to leave events when tired, in pain, or uncomfortable was as, if not more important than the ability to get to events with other students. Students' need for privacy, transportation, and autonomy to decide when and how they enter and exit is an important, yet often overlooked component of inclusion. Through these interviews, a variety of ideas were brought up, such as parking lots closer to buildings, to the option to ride golf carts on campus, to even simply more shade and places to sit down and rest. Other topics, such as the lack of quiet, or private spaces for one to take tests or go through the process of getting accommodations could also be practically and easily fixed. Frosted doors, cubicles, were easy-to-implement ideas that arose during some of the interviews, to allow people with disabilities to receive the services they need while maintaining the privacy they desire. The ability to have these needs yet is important to students' identities as adults with agency.

### **Identity-Making for Students with Disabilities**

Again, I cannot stress enough that identity-making is not a process that happens in a vacuum. Institutions attempt to be inclusive to people with disabilities but by seeing the people they are trying to include as one homogenous group defined by a diagnosis, exclusion, rather

than inclusion can be reinforced. There has been research on identity-making and research on policies that are inclusive or exclusive in the university setting but these two topics interact and cannot be completely separated from each other. Many students, though they were satisfied with the efforts the university made to include them in the classroom, could think of times when they felt isolated, excluded, and even humiliated due to their status as a student with a disability. Furthermore, hierarchies within the community of people with disabilities led some student to feel isolated from the very institutions in existence to include them. Many felt seemed to feel as though they were not disabled enough or that the services wouldn't be designed for them due to the fact that none of my participants were in a wheelchair.

While the SDS was designed to help students with a wide variety of disabilities, students, especially those who were diagnosed with their disabilities in adulthood, were somewhat ambivalent at first. Nearly all of the participants reported positive interactions with the institution itself. However, some expressed irritation over the fact that others who do not have disabilities or who do not receive services there may think they are “cheating” or coasting through classes easily with services others perceive them not to need.

To combat this, many students constructed their identities as people who worked *harder* than the students who thought that they were having an easy time. They constructed identities of being *more moral*, than those who accused them of cheating. This process of identity-making seemed very much to be in reaction to stigma and instances of social exclusion. Thus, making buildings wheelchair accessible or allowing students more time on tests is not enough to truly “include” students with disabilities, as it ignores their social needs and their need

for true acceptance at the university. One student who had the most positive things to say about SDS stated that she attended some of the workshops provided by the institution, and that she liked to attend them as a place to *socialize* with other students with disabilities. She stated that she would like more events where the explicit goal was socializing.

Social inclusion would be beneficial both for the university as well as the students with disabilities within the university. By including students with disabilities on a social level, students with disabilities will be better able to focus on schoolwork, self-care, and well-being without having to defend themselves as being people with agency who are not “cheating” or getting a “free pass.” This need for social inclusion applies not only to relations between students with disabilities and able-bodied students, but also between students with disabilities.

## **Chapter 7: Conclusion**

The process of identity-making is an important part of health and well-being for all people, including people with disabilities. Yet, students with disabilities are consistently marginalized and feel stigma due to instances of exclusion from able-bodied people and other people with disabilities alike. Despite this, people with disabilities do construct positive identities for themselves as hard-working, moral people with agency. It is important to look at the ways in which students with disabilities are, in fact, resilient people who are moral and hard working, but also the ways which social inclusion and exclusion influenced this process of identity-making, and the need to move towards more inclusive environments and policies.

Many students had their own policy suggestions to move towards this goal. This included either expanding or linking SDS to medical organizations and other organizations that could help students off-campus in their daily lives. Many students wanted advice regarding off-campus housing, driving, places to obtain medical supplies, and other services that were beyond the scope of what SDS offers. Furthermore, students saw the need for privacy and the ability and agency to leave events at will as being a crucial part of considering their social needs. Typically, policies geared towards inclusion, prioritize getting students to an event but ignores the fact that able-bodied people can easily and discretely leave in ways that people with disabilities sometimes cannot. In order to truly include students with disabilities so that they can create identities around feeling included as students, the university, and other institutions, need to

consider students with disabilities as whole people who may have questions about life outside of the university or classes. In linking students to outside resources and acknowledging them as people who are more complex than their disability or diagnosis, students can feel truly feel included. This is necessary for students to construct their own identities that do not center on deflecting the victim-identity or justifying their right to attend the university with accommodations.

### **Limitations and Suggestions for Future Research**

Of course, as with all research, there are some limitations. Given the small sample size and qualitative nature of the research, this study is not generalizable. I used the term “Students with disabilities” throughout the paper, but findings certainly cannot be generalized to all such students. This study was open to all students receiving accommodations. However, it was limited in that all but one of the participants were women and all of the women had what were currently invisible illnesses, though, some will eventually become visible or have been visible in the past. Whether these findings would apply to students with more obvious visible disabilities is unknown. Future studies could include more efforts to recruit students with more visible disabilities. Given that there appeared to be a hierarchy of disability, future studies could also look more into how students with disabilities construct the concept of disability and these hierarchies or how their construction of this hierarchy influences their identity-making.

Further more, while all of my participants compared their conditions to “people in wheelchairs,” none of my participants were wheelchair users. Thus, the information on hierarchies within the community of people with disabilities is very incomplete, in that while I

have the perspective from people who do not use wheelchairs about wheelchair users, I have no data on how wheelchair users may feel about other people with disabilities. This perspective would be valuable to future research projects. Furthermore, I only interviewed people who were receiving accommodations through SDS. This does not include students, who have disabilities but who do not use accommodations. Future research should include the perspective of students who do *not* receive accommodations.

Linking experiences of social inclusion and exclusion to identity-making is an important addition to the literature. While institutions and organizations have made efforts and positive changes for people with disabilities, in terms of accessibility, inclusion is more than accessibility. Students with disabilities continue to create their identities through their experiences within the university setting and unfortunately, many of these formative experiences involve feelings of exclusion. It is also important in order to understand the experiences of students with disabilities and to work towards policies that are truly inclusive for people with disabilities.

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## Appendix A: IRB Approval



RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-7091

7/13/2015

Melinda Maconi  
Sociology  
4202 E Fowler Ave CPR107  
Tampa, FL 33620

RE: **Expedited Approval for Initial Review**

IRB#: Pro00022166

Title: It's not all about coursework: Social Inclusion in university life from the perspective of students with disabilities on a college campus

**Study Approval Period: 7/12/2015 to 7/12/2016**

Dear Ms. Maconi:

On 7/12/2015, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

**Approved Item(s):**

**Protocol**

**Document(s):**

[Protocol Version 2 \(7-6-15\)](#)

**Consent/Assent Document(s)\*:**

[It's Not Just About Coursework Consent Form Version 1 \(6-23-15\).pdf](#)

\*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR

56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-

5638. Sincerely,



Kristen Salomon, Ph.D., Vice Chairperson  
USF Institutional Review Board

## **Appendix B: Recruitment Letter**

I am a Master's student conducting a research study for my thesis on the experience of life at the University for students who are receiving accommodations through SDS.

The project is called "It's not all about coursework: Social Inclusion in university life from the perspective of students with disabilities on a college campus." The University Institutional Review Board has assigned this project the number: Pro00022166.

I am seeking students who are currently receiving accommodations through SDS who are willing to be interviewed about what their life is like at the University both inside and outside of the classroom.

If you would be willing to be interviewed for this research study, please contact Melinda Maconi via email at [mmaconi@mail.university.edu](mailto:mmaconi@mail.university.edu).

Sincerely,

Melinda Maconi

## Appendix C: Informed Consent



### **Informed Consent to Participate in Research Involving Minimal Risk and Authorization to Collect, Use and Share Your Health Information**

**Pro # 00022166**

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You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:

#### **It's not all about coursework: Social Inclusion in university life from the perspective of students with disabilities on a college campus**

The person who is in charge of this research study is Melinda Maconi. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. She is being guided in this research by Dr. Sara Green.

The research will be conducted at the University of South Florida.

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#### **Purpose of the study**

The purpose of this study is to seek to understand how students with disabilities who are currently receiving accommodations through SDS as the University feel about those accommodations and how this affects their experience at the university overall.

### **Why are you being asked to take part?**

We are asking you to take part in this research study because you are a student at the University who is receiving accommodations through SDS. You are able to give insight to the ways in which accommodations affect your life at the university, both inside and outside of the classroom.

### **Study Procedures:**

If you take part in this study, you will be asked to meet with the researcher, at a time of your choosing, in person to be interviewed for approximately one to two hours to discuss how the accommodations you are receiving influence your life at the university. Interviews will be audio-recorded and transcribed word for word but your name and information will not be associated with the transcriptions. Recordings will be deleted once the interview is transcribed.

### **Total Number of Participants**

About 25 individuals will take part in this study at UNIVERSITY.

### **Alternatives / Voluntary Participation / Withdrawal**

You do not have to participate in this research study. You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study. Whether or not you participate will not be disclosed to SDS or any other institution.

### **Benefits**

We are unsure if you will receive any benefits by taking part in this research study.

### **Risks or Discomfort**

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study. If you feel uncomfortable at any time, there will be no penalty for declining to answer a question, or withdrawing from the study altogether.

### **Privacy and Confidentiality**

We will keep your study records private and confidential. Certain people may need to see your study records. Anyone who looks at your records must keep them confidential. These

individuals include:

- The research team, including the Principal Investigator, study coordinator, research nurses, and all other research staff.
- Certain government and university people who need to know more about the study, and individuals who provide oversight to ensure that we are doing the study in the right way.

Any agency of the federal, state, or local government that regulates this research. This includes the Food and Drug Administration (FDA), Florida Department of Health, and the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP)

- The UNIVERSITY Institutional Review Board (IRB) and related staff who have oversight responsibilities for this study, including staff in UNIVERSITY Research Integrity and Compliance.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

### **You can get the answers to your questions, concerns, or complaints**

If you have any questions, concerns or complaints about this study, or experience an unanticipated problem, call Melinda Maconi at (904) 866-9198.

If you have questions about your rights as a participant in this study, or have complaints, concerns or issues you want to discuss with someone outside the research, call the UNIVERSITY IRB at (813) 974-5638.

## **Consent to Take Part in this Research Study And Authorization to Collect, Use and Share Your Health Information for Research**

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

\_\_\_\_\_  
Signature of Person Taking Part in Study

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Person Taking Part in Study

### **Statement of Person Obtaining Informed Consent**

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in their primary language. This research subject has provided legally effective informed consent.

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Signature of Person obtaining Informed Consent

Date

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Printed Name of Person Obtaining Informed Consent

## **Appendix D: Interview Guide**

Note: This is a semi-structured interview guide. While these are the topics the researcher aims to cover, interviewees will be given wide latitude to deviate and to talk about the topics most important to them, which may or may not be on the guide.

### **Experiences**

What brought you to seek accommodations through SDS?

What is the process of seeking accommodations like? Can you walk me through the step-by-step process?

Can you tell me a bit about how things have changed for you since seeking accommodations?

Do you ever find that instructors treat you any differently than before?

Do other students in your classes know that you receive accommodations?

Has there ever been a time when someone has treated you differently due to the accommodations you receive?

Has there ever been a time when an instructor has outright refused to acknowledge your

accommodations?

## **Identity**

Do you consider yourself to be “disabled” or to have a disability?

To what extent is your disability a part of your identity?

To what extent does it affect your daily life?

To what extent does it affect your life inside the classroom?

To what extent does it affect your life outside of the classroom?

How do you feel about the accommodations you are receiving?

Can you tell me about a time that you have used them? What was that like?

Are there any times you don't use the accommodations available to you? (If so, why?)

Do you feel the accommodations you have been given are effective in meeting your social needs?

Can you tell me about any difficulties you've had with SDS or using accommodations?

## **Ideals**

What do you think is the job or goal of SDS accommodations SHOULD be? And what should it do? (too abstract)

Do you agree with that goal?

Are those your goals?

Do you have any other goals for your time at UNIVERSITY outside of that?

Does SDS help you achieve any of those goals?

(If not) Do you think they should?

If you could make changes to the ways that SDS and accommodations operate or the ways in which accommodations are carried out, what changes would you make?