

AN ABSTRACT OF THE DISSERTATION OF

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Title: Understanding University Students' Construction of their Hidden Disability Identity

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This study co-investigated with students with hidden disabilities the phenomenon of disability identity. This qualitative study utilized phenomenology and strategies proposed by Paulo Freire in an effort to understand identity development specific to individuals with hidden disabilities. There were seven students from a medium-sized, public university who participated in the study.

The participants shared their experiences with having a hidden disability in three one-hour individual conversations and three two-hour group conversations. The conversations were tape recorded and transcribed. The concepts and themes that appeared to emerge from the initial conversation guided subsequent conversations. Findings revealed that the use of traditional identity development literature was not useful to understanding students with hidden disabilities. Relying on social constructivist concepts findings revealed the following themes:

- 1) Identity Confusion – they tended to be neither able-bodied nor disabled;
- 2) Identity Refinement – they depended on perceptions of the other to varying

degrees; and 3) Identity Reconciliation – they were using accommodations to varying degrees.

A potential area for action and further study revolves around students with hidden disabilities, disability services practitioners, faculty and college student services administrators understanding the issues of normalcy and American individualism and their influence on both individuals with and without disabilities. Furthermore, fostering the development of a support system where students with hidden disabilities can interact with each other and discuss disability-related issues may help them cope with a fundamentally hostile collegiate environment. The institution may need to educate students, staff and faculty about the social construction of disability and the need to create a learning environment inclusive of diverse learners.

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Understanding University Students' Construction of their
Hidden Disability Identity

By
Tracy Bentley-Townlin

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I understand that my dissertation will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my dissertation to any reader upon request.

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Tracy Bentley-Townlin, Author

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Understanding University Students' Construction of their Hidden Disability Identity

CHAPTER 1: FRAMING THE STUDY

The number of students with learning disabilities pursuing post-secondary education has increased significantly in the last decade. Henderson (1999) utilizing data from the Cooperative Institutional Research Program, profiled the 1998 cohort of freshmen college students and found that nine percent of first-time, full-time freshmen students enrolled in higher education self-identified as having a disability (Henderson, 1999). "This mean[s] that one in every 11 freshmen enrolled full-time reported at least one disability" (Henderson, 1999, p. 3). Of the number of students who reported a disability, 41 percent identified as having a learning disability (Henderson, 1999). With the number of students with learning disability, and I include students with Attention Deficit Disorder (ADD) and Attention Deficit Hyperactive Disorder (ADHD), attending institutions of higher education, faculty and college student services administration (CSSA) personnel must become educated about this population.

Although the literature in CSSA has begun to address the issue of students with disabilities in higher education, it appears that much of the literature pertained to legal issues, physical accessibility, improving service delivery, faculty and peers without disabilities attitudes toward individuals with disabilities and emerging issues pertaining to career development (Beilke, 1999; Cosden & McNamara,

1997; Gibbs, 1995; Hill, 1996; Hitchings, Horvath, Luzzo, & Retish, 1998; Kroeger & Schuck, 1993; Low, 1996; McCarthy & Campbell, 1993).

The one issue that has been written about extensively pertained to students with learning disabilities transitioning to higher education. The literature indicated skill deficits in self-advocacy, self-determination, and self-regulatory strategies resulting in students with learning disabilities not understanding their own disability, how it affected their lives and willingness to disclose (Benz & Halpern, 1987; Brinckerhoff, Shaw, & McGuire, 1993; Durlak & Bursuck, 1994; Merchant & Gajar, 1997; Michaels, 1994; Saracoglu, Minden, & Wilchesky, 1989). Additionally, the literature often portrayed the problems with having a learning disability as individualistic and did not provide understanding as to how the environment has influenced the student with a disability.

Even though the literature in CSSA has begun to address the issue of students with disabilities in higher education, rarely does the literature contain information on identity development and disability (Belch, 2000; Kroeger & Schuck, 1993; Ryan & McCarthy, 1994). In Komives and Woodard's (1996) handbook on the CSSA profession, McEwen (1996) wrote a chapter that addressed new perspectives of identity development. In this chapter, she discussed identity development in students with disabilities and provided two recommendations for administrators. Both recommendations were based on the social construction of disability. "First, it is important to learn how an individual with a disability understands and conceptualizes that disability, rather than just relying on the

socially constructed definition of it” (McEwen, 1996, p. 205). This recommendation is problematic. McEwen’s recommendation requires that students are knowledgeable about, and willing to disclose the disability. As indicated in the transition literature, many students do not understand their disability and are often reluctant to disclose the disability. Being willing to learn about the disability, disclose the disability and able to self-advocate, are acquired skills that are in part, dependent on accepting the disability. Simply understanding how the student described their disability does not necessarily reflect the process by which one integrates disability into one’s identity. Further information is needed to understand why some students appeared to have no difficulties with claiming the disability while other students required a notice of suspension to prompt them to address the learning disability.

McEwen’s (1996) second recommendation to CSSA professionals was “it is again important to understand oneself...in terms of how one views disability” (McEwen, 1996, p. 205). This part of the recommendation does not reveal to CSSA professionals the values or beliefs that shape individual’s, with and without disabilities, belief about disability issues. As the number of students with a hidden disability, such as a learning disability, continues to increase, it behooves us, as college student services professionals, to understand the complexities surrounding identity development in students with hidden disabilities in order to meet their needs more effectively. To have this understanding, there is a need to understand

from the student's perspective, his or her understanding of the disability and how the disability influences their identity.

Thus, the focus of the study was to explore university students' understandings and description of their own identities related to disability identity development. I was interested in the meanings participants ascribed to identity development and their hidden disability. However, my purpose for engaging in the study was to inform my praxis.

Researcher Disclosure

Any gaze is always filtered through the lenses of language, gender, social class, race and ethnicity. There are no objective observations, only observation socially situated in the worlds of the observer and the observed. (Denzin, 1998, p. 24)

As I believe that all research is subjective and value-laden, some personal background about who I am as a person/researcher and how certain events have shaped my epistemological perspective is necessary. This disclosure is not comprehensive and only represents experiences that I perceive, at this time, to be the most influential. For clarity, I have divided my personal disclosure into two sections: personal experiences and theoretical influences. In the personal experiences, I will briefly discuss my foundation for living, my own struggles with a hidden disability and my professional experiences in working with students with disabilities. In the theoretical influence section, I will discuss the writings that have

influenced how I perceive “reality” and interpret this reality, and their implication for conducting research.

Foundation – Personal Experiences

I begin my story by presenting who I am at the core, my foundation and my way of knowing. My epistemology begins with my search for faith. Specifically, I was socialized with the Judeo-Christian belief system. My journey with regards to my faith has been tumultuous and one of questioning. It was not until Warren Suzuki, my major professor, recommended that I investigate the literature on “liberatory theology” that I found a body of work that illuminated my struggles. “Behind liberation theology are Christian communities, religious groups, and peoples who are becoming increasingly conscious that the oppression and neglect from which they suffer are incompatible with their faith in Jesus Christ...” (Gutierrez, 1988, p. xix) .

Liberatory theology was often attributed to Gustavo Gutierrez, a Roman Catholic theologian. Gutierrez, born in Lima, Peru, was sent to Europe to receive his theological training (Brown, 1990). Upon completion of his training, he returned to Latin America where he experienced dissonance between his training and experiences of working with people in his parish. This dissonance led to the formation of liberatory theology. Liberation theologians portrayed Jesus as a liberator, one whose words and actions challenged the dominant culture of that time. Gutierrez (1988) stated that “[t]he theology of liberation attempts to reflect

on the experience and meaning of the faith based on the commitment to abolish injustice and to build a new society; this theology must be verified by the practice of that commitment, by active, effective participation in the struggle which the exploited social classes have undertaken against their oppressors” (p. 174).

Gutierrez’s life work focused on the poor in Latin America. He advocated for the church to play a role in the liberation of the poor by stating that the Church was political and that attempting neutrality in politics masked a support for the status quo (McGovern, 1989). Because liberatory theology advocated for the poor, the oppressed, and the marginalized of society and, more specifically, the creation of a just society, Gutierrez and liberatory theology received much attention and criticism. Critics, including Rome and other theologians, accused Gutierrez and liberatory theology of reducing faith to politics and incorporating Marxist and Socialist ideologies into religion, and for being vague and ambiguous in his writing and espousing socialism as the avenue to alleviate the sufferings of the poor (McGovern, 1989; Novak, 1986). However, liberatory theologians believed that one could apply a Marxist analysis while rejecting the materialist philosophy or atheist message inherent in Marxism.

There are many facets to, and interpretations of, liberatory theology: from advocating that the Church should be political, to the debates of Marxism and Socialism, to questioning the soundness of biblical scholarship used in liberation theology (McGovern, 1989). Although there are debates for and against it, liberatory theology resonated with me “... [b]ecause liberation theology takes a

critical approach, it refuses to serve as a Christian justification of positions already taken” (Gutierrez, 1988, p. xxxiii) . This allowed for a reinterpretation of Biblical principles from a non-dominant perspective, from “the bottom.” Gutierrez’s passion was for the poor; my passion is my gender and my physical condition. Liberatory theology was a starting point; however, it did not address my questions as a woman or an individual in chronic pain. Thus, I turned to a feminist theology and a liberatory theology of disability.

“Feminist liberation theology, then, is about reflection on the praxis of acting to overcome injustice across class and race lines in the particular context of how women are oppressed... [i]t is about questioning and rereading the Bible from the perspective of the liberation of all women and men from ... oppression (Ruether, 1998, p. 214). There was a wide range of beliefs in feminist theology: from looking at the interpretations from the “bottom” or a woman’s perspective but still grounded in Jesus Christ (Ruether, 1983; Russell, 1987), to rejecting men and a God (Daly, 1985), to embracing homosexuality (Dynes & Donaldson, 1992; Hayward, 1984), to incorporating views from African American, Hispanic and Third World feminist theologians (Ruether, 1998). I struggled with the new information regarding feminist theology and found myself in the middle. My own perspective can be found in the words of Lucretia Mott, an abolitionist feminist:

All forms of human injustice and violence—subordination of women, the enslavement of blacks to whites, and war—flow from this basic sinful tendency to domination of some over others.
(Ruether, 1998, p. 7)

As you continue reading this disclosure, it becomes clear that the domination of some over others is my concern. This concern requires action to change the situation, as my silence would represent the status quo. While I believe that the Bible is the inspired word of God, I also believe the biblical interpretations are biased and incomplete, because the interpreters did not appropriately posit the Bible in the historical, social and political context of its time. As the interpretations have been biased against the poor, women and people of color, it has also been misunderstood in terms of people with disabilities.

Eiesland (1994) provided a liberatory theology of disability that critiqued the dominant discourse as promoting the virtuous suffering, or segregationist, charity. It "...perpetuates the belief that disability is inherently 'un (w) holy' and that the suffering of people with disabilities is the natural outcome of our impairments" (p. 93). Shapiro (1993) indicated that in the Old Testament, being blind, lame, deaf, crippled, or diseased was a sign of having done something to incur God's wrath, and in the New Testament, people with disabilities were cursed and/or possessed by evil. Eiesland (1994) attempted to reconstruct a theology that was inclusive of people with disabilities. "Jesus Christ as the disabled God provides a symbolic prototype and opens the door to the theological task of re-thinking Christian symbols, metaphors, rituals, and doctrines so as to make them accessible to people with disabilities and remove their able-bodied bias" (Eiesland, 1994, p. 104). Why was it important for me to explain to you, the reader, my faith? Because it is through this lens that I view others, the world, and myself. It is a

belief that this world is not the way it should be, based on a belief in a liberatory God.

Foundation - Medical Experience

Having laid a foundation of how I view the world, I next provide my own struggles with a hidden disability. At the age of nineteen, I was diagnosed with arthritis, systemic arthritis, throughout much of my body. I have been poked, prodded, tested and medicated hoping to reduce the constant pain and to control the seemingly random inflammation of joints. I continue to struggle with the results of this diagnosis on my life and identity. I have had to confront my own stereotypes of the term “disability.” I am not physically disabled in the stereotypical picture of someone in a wheelchair or someone who uses other auxiliary aids for mobility. Mine is chronic pain with the intermittent swelling of joints in the lower and upper extremities. While there is impairment, according to the disability studies literature, I may not be considered disabled. Linton (1998) indicated that if a person’s difference does not significantly affect daily life and the person does not consistently present himself/herself to the world at large as a disabled person, then they do not qualify as disabled. I have a hidden disability. I do not know how to consistently present my impairment to the world without telling everyone I meet. Perhaps I should not claim disability as an identity if I have not experienced significant discrimination due to the impairment. But if I do not claim the

impairment as part of my identity, then I am left with denying a part of me that has significantly shaped who I am.

The development of a disability identity is complex and further compounded by the question of “who qualifies” for individuals with hidden disabilities. Although I do not present myself to world on a daily basis as having difficulties with walking, standing and sitting, this diagnosis has affected my life and influenced how I view disabilities and the social construction of this term. Why does my medical experience influence my research interest? Because I am interested in understanding how individuals with hidden disabilities incorporate a disability into their own identity development. Specifically, I am interested in students who have been labeled with a learning disability, another hidden disability, and how it affects their identity.

Foundation – Professional Experience

My profession has provided a wealth of information regarding students with both visible and hidden disabilities. I have worked with, and learned from students with disabilities since 1985. My understanding of disability issues has been a learning experience in terms of attempting to understand the personal, social, and educational issues of different types of disabilities. My role as the Director of Services for Students with Disabilities Office has provided unique opportunities to see the benefits of a legal system designed to protect individuals with disabilities from the harm

and stigmatization which result from social and historical interpretations of disability. At the same time, I recognize that the legal system perpetuates the medical model, which can result in further stigmatization of individuals with disabilities.

The Americans with Disabilities Act (1990) and the Rehabilitation Act, section 504 (1973) designed to protect individuals with disabilities, are based on a medical model that requires delineation between impairment and disability. In order to receive accommodations, one must accept the label “disabled.” Yet, in conversations with students with learning disabilities, most comment that they are not “handicapped”; rather, they just learn differently. It was fascinating to watch how students made sense of their own being, reluctant to disclose a disability or utilize accommodations offered by the university for fear of reprisal from the faculty, or of being viewed as “less than” by peers.

Through the stories of the students with disabilities, I saw the struggle of attempting to maintain a positive self-identity while experiencing the discriminatory practices and prejudices of many faculty, administrators, staff, and students without disabilities. However, there were students who were successful and have developed some internal acceptance of their own disability and its relationship to their identity. From this group of students, I believe we can learn. Sharing their stories with other students

who are still struggling in terms of their own identity may help in reinterpreting the label of disability.

Theoretical Influences

The theories that inform my practice are critical theory, social constructivism, postmodernism, and disability theory. Critical theory is concerned with the “social, political, cultural, economic, ethnic, and gender structures that constrain and exploit humankind” (Guba & Lincoln, 1998). A critical theorist would also adhere to the idea that power relations are socially and historically constituted, that some groups are privileged over others, and all research is subjective, value-laden and may unwittingly reproduce system of oppression (Kincheloe & McLaren, 1998). For me, it was necessary to posit research issues with respect to social and historical contexts, oppressors and oppressed, and the systems that perpetuated the status quo. Burbules and Berk (1999) stated that critical theory “...regards specific belief claims not primarily as propositions to be assessed for their truth content, but as parts of systems of belief and action that have aggregate effects with the power structures of society. It asks first about these systems of beliefs and action, *who benefits*” (p. 47). As with my faith, it was necessary for me to identify who, historically, were in positions of power and thus authorized to interpret the world. Predominately it was white, able-bodied males. Who benefited, and more importantly, who was marginalized or pathologicalized, was of great concern to me as I began the research process. It was especially

important as I investigated disability issues, which have historically been conducted from an able-bodied, medical perspective.

Another component of critical theory was the attempt to transform current paradigms. “Critical pedagogy would never find it sufficient to reform the habits of thought of thinkers, however effectively, without challenging and transforming the institutions, ideologies, and relations that engender distorted, oppressed thinking in the first place”(Burbules & Berk, 1999, p. 52). It is in this aspect of critical theory that I find hope: to investigate the world from the bottom, to refute positivist and postpositivist paradigms, and to provide a venue for multiple experiences and voices. The new theory of disability, moving perspectives from a pathological, individual model to a social, minority model, reflects this challenge and will be discussed in further detail in the next section. I believe it is necessary to challenge old paradigms that limit human potential and harm all who are not part of the dominant discourse. In the process, I need to be aware of the role that language has in shaping my perspectives.

The role of language is important in critical theory. McLaren and Da Silva (1993) stated that, “[a]ll language, according to Freire, works to reproduce dominant forms of power relationships...” (p.53). Lyotard (1984) discussed the “language games” and how the society is the language. The works of Freire (1998) and Lyotard (1984) stressed the importance of language, and how one can never escape from historical and social boundaries because these boundaries were created by language. Paulo Freire (1998) in *Pedagogy of the Oppressed* discussed the use

of the “banking model” of education for perpetuating an oppressive system. This model viewed students as “empty repositories” to be filled with knowledge, the content of which was selected by the oppressors, and presented as reality, thus inhibiting critical “conscientizacao” of the students. Conscientizacao “refers to learning to perceive social, political and economic contradictions, and to take action against the oppressive elements of reality” (Freire, 1998, p. 17). I believe the use of language is significant when performing research. I need to be aware of the language I use and how specific words may produce a range of definitions as well as emotions.

I also found hope in how language can be used. Language “carries with it the resources for imminent critique, for dismantling the oppressive power structures of the social order, and also for articulating a more transformative and liberating vision of the future” (McLaren, 1993, p. 53). Freire (1998) believed that it is only through dialogue and critical reflection that we can transform an oppressive reality. While critical theory enlightened my practice, and provided hope with its discourse of emancipation and a new vision, it can only inform my practice, as I believe critical theory, focused on capitalism, subjugates other forms of oppression. As such, critical theory can be criticized for its superficial treatment of other oppressive structures, such as racism (Scheurich & Young, 1997), sexism (Alcoff & Potter, 1993; Yeatman, 1994), and ableism (Skrtic, 1995), and ignores the multiplicity of oppression (Ellsworth, 1992). Ellsworth (1992) argued, “...that key assumptions, goals, and pedagogical practices fundamental to the literature on

critical pedagogy are repressive myths that perpetuate relations of domination” (p. 90). Thus, I need to be aware of, and reflect on, my position in the dominant culture. For “...there are no objective observations, only observation socially situated in the worlds of the observer and the observed” (Denzin, 1998, p. 24). I, as a white woman educated in a patriarchal, racist and ableist society, must vigilantly reflect on my biases and my subjectivity in the research process, lest I perpetuate prejudices and stereotypes of people with disabilities, couched in the name of emancipatory research.

Another area of concern was the term “empowerment.” Critical research is concerned with the empowerment of individuals (Kincheloe & McLaren, 1998). Lather (1991) noted that “...empowerment is a process one undertakes for oneself; it is not something done ‘to’ or ‘for someone’” (p. 4). I cannot empower others; however, I can provide a setting that is safe, and conducive to learning. Freire (1998) stated that “...authentic education is not carried on by ‘A’ *for* ‘B’ or by ‘A’ *about* ‘B,’ but rather by ‘A’ *with* ‘B,’” (p. 74). We learn from each other. As an educator/researcher, I firmly believe that research should be a participatory process and that authentic research must engage in dialogue and reflexivity.

Social Constructivism

Constructivism is a psychological and philosophical perspective positing that individuals construct their own world based on individual experiences and schema. Schunk (2000) proposed three types of constructivism: exogenous,

endogenous and dialectical. The exogenous model posits that knowledge reflects external realities (Schunk, 2000). Endogenous constructivism is more cognitive and is built upon previous knowledge. “Mental structures are created out of earlier structures, not directly from environmental information; therefore, knowledge is not a mirror of the external world acquired through experiences, teaching, or social interactions. Knowledge develops through the cognitive activity of abstraction and follows a generally predictable sequence” (Schunk, 2000, p. 230). Dialectical knowledge posits that knowledge is constructed between individuals and their interactions with the external environment. “Constructions are not invariably bound to the external world nor are they wholly the result of the workings of the mind; rather, they reflect the outcomes of mental contradiction that result from interactions with the environment” (Schunk, 2000, p. 231).

The dialectical model of constructivism, or social constructivism, is the model that influences my understanding of learning. This model incorporates Freire’s (1998) notion that authentic education is interactive, it is “‘A’ *with* ‘B’.” Also, Vygotsky’s sociocultural or sociohistorical theory provides the framework that social environments facilitate development and learning.

Vygotsky (1978) developed his sociocultural theory in reaction to the dominant discourse of his time: empiricism in psychology. He was critical of “biological reductionism” and “mechanistic behaviorism”(Wertsch, 1985). His dissatisfaction resulted in a more holistic psychology and he emphasized the cultural and historical context of the individual. Influenced by Marxist thought and

Hegelian dialectical historicism, Vygotsky sought to develop a Marxist psychology. The premise of sociohistorical psychology was that “psychological phenomena are humanly constructed as individuals participate in social interactions and as they employ tools”(Ratner, 1991, p. 2-3) . For the purpose of this study, I will discuss two themes: that higher mental processes originate in social processes, and that in order to understand mental processes, we must understand the psychological tools that mediate them (Wertsch, 1985).

Vygotsky (1978) believed that the origins of higher mental functioning are found in social interactions.

Every function in the child’s cultural development appears twice: first, on the social level, and later, on the individual level; first between people (interpsychological), and then inside the child (intrapsychological). This applies equally to voluntary attention, to logical memory and to the formation of concepts. All the higher functions originate as actual relations between human individuals. (p. 57)

Although Vygotsky argued against biological reductionism, he does not dispute the role of biology in development. However, the biological role in human activities was limited. Biology provided the framework for perception, feeling, thinking, talking and personality but did not dictate specifically how an individual would act (Ratner, 1991). It was this voluntary activity that separated humans from the animals (Vygotsky, 1978). Thus, Vygotsky made a distinction between what he called elementary mental functions and higher mental functions. “The central characteristic of elementary functions is that they are totally and directly determined by stimulation from the environment”(Vygotsky, 1978, p. 39).

Elementary functions included sensing, hunger, sex, elementary perception, memory, and primordial involuntary reactions (Ratner, 1991). For higher functions, “the central feature is self-generated stimulation, that is, the creation and use of artificial stimuli which becomes the immediate cause of behavior”(Vygotsky, 1978, p. 39). Higher functions included voluntary control, conscious realization, and mediation by psychological tools (Van der Veer & Valsiner, 1991; Wertsch, 1985). As we develop, the elementary capacities were transformed into higher mental function through the influence of culture.

To understand the development of higher mental functions, it is necessary to understand the psychological tools that mediate them. Examples of psychological tools include language, counting systems, mnemonic techniques, algebraic symbol systems, art, and writing (Wertsch, 1985). All of these examples are products of our society. For Vygotsky, language was especially important. Language is the product of sociohistorical conditions, and as we learn language we become social, historical beings (Holzman, 1996). Holzman (1996) stated that “[w]e are historical [beings] in that we have the capacity for self-consciously asking how we know what we know, understand what we understand, and mean what we mean” (Holzman, 1996, p. 94). We become conscious beings, capable of reflection on self and society. Reflexivity is important in the learning process because it allows the learner to understand how systems were structured and it provides the opportunity to change those systems. Language is also social in that it is the medium for a shared understanding; we learn the norms and conventions of

society, and in the process, reflect on what it is that we know. Thus, individual learning, even "...in isolation, is inherently social, or sociocultural, in that it incorporates socially evolved and socially organized cultural tools" (Wertsch, 1996, p. 60).

For Vygotsky, education was social, and what was taught are those elements that were important to society. It is at this point that Freire and Vygotsky converge. If language is the tool for other higher mental functions, such as problem solving, then we have the means to dismantle the current reality. "In problem-posing education, people develop their power to perceive critically *the way they exist* in the world *with which* and *in which* they find themselves; they come to see the world not as a static reality, but as a reality in process, in transformation" (Freire, 1998, p. 64). Although Vygotsky identified the Zone of Proximal Development (ZPD) as a method for fostering learning, I believe it can be used as a method for transformation.

The Zone of Proximal Development "...is the distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance or in collaboration with more capable peers" (Vygotsky, 1978, p. 86). Learning is collaborative. Learners test their own knowledge or understanding against other more knowledgeable individuals. Potential learning happens in the ZPD as adult and child share cultural tools to mediate the interaction. Cognitive change occurs when the child internalizes the information. The child's ZPD will vary according to

his or her experiences, culture and interactions with the dominant society.

Educators have applied ZPD concepts in areas such as reciprocal teaching, peer collaboration, and apprenticeship (Rogoff, 1990). As stated earlier, I believe ZPD can be used to transform society. Education should provide experiences that challenge student's way of thinking, which requires them to rearrange their beliefs. Working with college students with and without disabilities, and challenging them to question current paradigms and practices as they relate to disability issues, is the first step in the transformation of an ableist society.

As a researcher, I hope to provide an opportunity to operate within ZPD; to learn as much from the participants as they will learn from me. As an educator, I have a responsibility to assist others in developing critical thinking skills which will allow them to develop cultural awareness, reflect on their own social positioning and then act to transform society. Through this process, I will continue to develop cultural awareness, reflect on my own social positioning and act to transform society. Research, learning, and transformation are intertwined processes that require dialogue and reflective consciousness. With this reflective consciousness, I recognize the criticism of Vygotsky's work. He has been criticized for being too abstract, ideological, incomplete and even contradictory in his writings (Daniels, 1996; Kozulin, 1990; Van der Veer & Valsiner, 1991; Wertsch, 1985). I believe that, had he not died at the early age of 38 due to tuberculosis, he would have been able to offer a more concise vision of

sociohistorical psychology. However, as it stands, his contribution to social constructivism has been valuable.

Postmodernism

At first glance, even considering the notion of postmodernism appeared contradictory to my faith. Postmodernism does not subscribe to a “grand narrative” of a liberatory God; it is polytheism. However, if I subscribe to the belief that this world was not how it was intended to be, and that we can never know the intent of the creator, as we are, and will forever be constrained by our own historical and cultural biases, then the negation of the grand narrative of humanity would not be a contradiction. From this perspective, there were some aspects of postmodernism that I found enlightening.

Postmodernism is defined as “a broad social and philosophical movement that questions assumptions about the rationality of human action, the use of positivist epistemology, and any human endeavor (e.g., science) that claims a privileged position with respect to the search for the truth” (Gall, 1999, p. 530) . Thus, most postmodernists believe that there is no single authority, method, or paradigm that is privileged over another, and that the scientific method is not superior to other forms of inquiry. Additionally, postmodern research is political because it challenges, or decenters, the established power relations found in society, and the issue of power is examined either as a substantive issue or as part of the research process (Constas, 1998). While I advocate challenging the dominant

discourse, taken to extreme, postmodernism can be criticized for being relative and nihilistic, rendering the researcher inactive because there is no “reality” or “meaning” to react to.

Although postmodernism can be identified by its political aims, it is the methodological practices and representational styles that I find intriguing. Specifically, the methodology favored by postmodernism is an idiosyncratic approach which is admittedly situated, quite personal, and examines the researcher’s biases and relationships to the project and participants (Constas, 1998). Postmodernists, and I, question the subject-object distinction. I do not believe it is possible to maintain the otherness of the participants. Research is a personal involvement into the lives of others, and as such, I am developing a relationship with the participants. I am interested in the multiple voices and multiple interpretations of the phenomena in question.

The last area of postmodern research I found enlightening pertained to the representational style of writing. Historically, research writing has been written in a third person authorial style that attempted to persuade the reader that the researcher’s involvement was objective and free of bias. Postmodernism advocates for a more unbounded style of writing that may take the form of a narrative or poem or a short case study (Constas, 1998). As I stated previously, I believe that all research is personal. I think the research intent, political and social should be stated up-front for the reader. Postmodernists would advocate such a stance. I also believe that in writing ourselves out of the research, the audience is not presented

with all of the information needed to evaluate the research. Historically, researchers have abdicated their responsibility for self-reflection by a false belief that research is objective and free of bias. Although there is still a debate about postmodernism and what it stands for, at the least it provides an alternative to the positivist/postpositivist methodology and representational style.

Disability Theory

Utilizing both critical theory and postmodernism and applying them to the field of disability research, I needed to understand the historical, social and political underpinnings in the construction of the term, “disability.” Although the struggle for disability rights began in the 1960s (Johnstone, 1998), the field of disability studies is relatively new in academia (Linton, 1998). Because disability studies are relatively new, it would be remiss of me not to discuss the controversy surrounding disability models. In reading the literature, there were two primary bodies of work regarding disability issues: one from the United States (US) and one from the United Kingdom (UK). The new theory of disability from the US utilized the minority model, similar to the discrimination and marginalization experienced by ethnic minorities and women (Marks, 1999; Olkin, 1999). However, in the US there are still two other models that have historical influences, and will be discussed prior to the minority model.

Within the US, there are three models of viewing disability: moral, medical and more recently, minority (social) models. The moral model pertained to

viewing a disability as a result of “sin,” either of the individual or the parents (Olkin, 1999; Shapiro, 1993). This perspective perpetuated the myth that as one sense was impaired another sense was heightened. Physical tragedy or impairment equaled increased emotional or spiritual growth and strength (Olkin, 1999). Beginning in the mid-1800s, disability was viewed from the medical model. The medical model posited that the

Disability is seen as a medical problem that resides in the individual. It is a defect in, or failure of, a bodily system and as such is inherently abnormal and pathological. The goals of intervention are cure or amelioration of the physical condition to the greatest extent possible, and rehabilitation (i.e., the adjustment of the person with the disability to the condition and the environment) (Olkin, 1999, p. 26)

The medical model espouses the principles of normalization (Johnstone, 1998). It is the individual who is to be pitied for a disability or praised for overcoming it. The problem with the medical model is that it “... keep[s] the issue within the purview of the medical establishment to keep it a personal matter and ‘treat[s]’ the condition and the person with the condition rather than ‘treating’ the social processes and policies that constrict disabled people’s lives” (Linton, 1998, pg. 11).

Viewing disabilities as a political category was part of the next model: the minority model. The minority model can be traced back to Roger Barker (1948) who “...indicated that the minority status of physically disabled was due to the negative attitudes of the physically normal majority” (p. 29). Olkin (1999) interchanges “minority model” and “social model” which “posit[s] that disability is

a social construction, that the problem lies not within the persons with disabilities but in the environment that fails to accommodate persons with disabilities and in the negative attitudes of people without disabilities” (p. 26). Disability studies attempts to identify the distinction between impairment and disability. Impairment pertained to the biological attribute while disability pertained to how one identifies oneself. The analogy would be the biological attribute that identifies sex whereas the social identification would be gender (Linton, 1998). In reviewing the literature, there was little debate on utilizing the social model for advocating change within the United States. The social model significantly influenced my perspectives and research.

The UK provided the greatest amount of discourse on the social model of disability. It is important to recognize the difference in the social and cultural climates of the two countries in which these different models were developed. The UK is greatly influenced by socialist ideology whereas the US views disability from a civil rights perspective (Marks, 1999; Middleton, Rollins, & Harley, 1999). Oliver (1990), a prominent UK disability studies academician, delineates the social model, providing two views on the construction of disability.

The social constructivist view sees the problems as being located within the minds of able-bodied people, whether individually (prejudice) or collectively, through the manifestation of hostile social attitudes and the enactment of social policies based upon a tragic view of disability... The social creationist view, however, sees the problem as located within the institutionalized practices of society (p. 82-83).

The US incorporates both views in the minority model – problems are not located within the individual but within society, and both individual prejudices and institutional practices are seen as influential. The differences between a social constructivist and social creationist discourse is informative and was an example of the depth of scrutiny surrounding the social model, and the subsequent discussion on impairments and deviance (Reindal, 1995). Even more enlightening was the criticism of the social model as excluding stories that utilized impairments and personal experiences (Hughes, 1999; Shakespeare, 1997). Supporters of the social model of disability do not deny the experience of impairment, but were more concerned about the societal barriers that can be removed (Branfield, 1999).

The disability movement both in the UK and the US have been criticized for failing to incorporate multiple identities, such as gender, ethnicity, class, (Corker, 1999; Erevelles, 1996; Ingstad & Whyte, 1995; Neath, 1997; Olkin, 1999; Vernon, 1999) sexual orientation (Corbett, 1994), and cultural factors (Ingstad & Whyte, 1995). “Disability academics have either ignored or tagged on the experiences of disabled black and minority [sic] ethnic people, women, older people, and gay men and lesbians” (Vernon, 1999, p. 385). Although there appeared to be a debate among advocates of disability on the social model of disability, the end result was discrimination against individuals with disabilities (Reindal,

1995). Because of the social, historical, and political discriminations, individuals with disabilities can be considered as an oppressed group. As such, I am again brought back to critical theory and my subsequent concerns.

There are a number of concerns about researching disability issues, with the primary issue being research on individuals with disabilities by able-bodied researchers. The results are more often than not presented from a stereotypical, discriminatory perspective that a disability is a tragedy (Moore, Beazley, & Maelzer, 1998). Disability research is also criticized for failing to understand the politics underlying the specific research-- it fails to address *who benefits*. I hope that my research will benefit the students with hidden disabilities. It is not my desire or intent to pathologicalize individuals with hidden disabilities. To avoid stereotypes, I believe that I need to utilize a methodology that is participatory in nature, and one that requires reflection on my own biases and prejudices regarding individuals with hidden disabilities.

I have attempted to provide for you, the reader, the lenses that focus how I view research and why identity development in students with hidden disabilities is my research interest. In the next section, I will discuss identity literature, beginning with the dominant discourse of Erik Erikson's theory and James Marcia's conceptualization of Erikson's theory. Then, I will review the literature related to identity development for groups not part of the dominant discourse. I

will conclude with a review of the emerging literature on identity development in individuals with hidden disabilities, specifically learning disabilities.

CHAPTER 2: MY UNDERSTANDING OF THE RELATED LITERATURE

Erik Erickson Identity Development Theory

An optimal sense of identity, ... is experienced merely as a sense of psychosocial well being. Its most obvious concomitants are a feeling of being at home in one's body, a sense of 'knowing where one is going,' and an inner assuredness of anticipated recognition from those who count. (Erikson, 1968, p. 165)

Erik Erickson's name is most often linked with identity development literature (Friedman, 1999). Breaking with traditional Freudian psychology, Erikson proposed a psychosocial model of identity formation. "Erikson's work was the first to appreciate the *psychosocial* nature of identity with the important role played by the community in recognizing, supporting, and thus helping to shape the adolescent ego" (Kroger, 1996, p. 9). As I believe that engaging in dialogue with others, and our experiences with society affects learning, this social interaction would also affect identity development. Erikson's theory about the social element of identity development appears to be a natural starting point for investigating this phenomenon. His belief that identity is interdisciplinary, involving biological influences, personal experiences, and cultural milieu almost parallels Vygotsky's theory of development. Although Erikson's theory begins with a biological base, this does not negate his attempt to integrate sociocultural and historical factors into his theory. For Erikson (1968), identity formation is "...located in the core of the individual and yet also in the core of his [sic] communal culture" (p. 22). The

difference between the two is that Vygotsky believed we could never escape the social influences, whereas, for Erikson, identity is more individualistic. “It is up to the individual, then, to create and maintain a dynamic conception of oneself as a coherent whole, involving complex perspective coordination” (Penuel & Wertsch, 1995, p. 87).

Erikson founded his theory based on the “epigenetic principle.” The epigenetic principle “...states that anything that grows has a *ground plan*, and that out of this ground plan the *parts* arise, each part having its *time* of special ascendancy, until all parts have arisen to a functioning whole” (Erikson, 1959, p. 52). Erikson conceptualized identity as having a biological basis, where increased capacity, through maturation, allowed the individual to meet the opportunities and limitations of his or her culture. He conceptualized eight stages that one progressed through in finding an identity. The eight stages are: trust versus mistrust, autonomy versus shame and doubt, initiative versus guilt, industry versus inferiority, identity versus role confusion, intimacy versus isolation, generativity versus stagnation, and integrity versus despair.

Erikson believed that each stage built upon the last stage, and laid the foundation for the next stage. He also believed that each stage represented a crisis, a turning point, where internal psychological and biological changes interacted with the physical environment and with social and historical demands (Erikson, 1959). A successful resolution of the crisis leads to new skills while unsuccessful resolutions lead to a negative self-image and may result in identity confusion or

construction of a negative identity (Erikson, 1968). However, these are not either-or categories. All individuals must achieve some balance between the two. In order to change or to grow, it is necessary to experience both the negative and positive aspects of each stage (Marcia, 1994). For our purpose, stage five, identity versus role confusion, will be discussed.

In stage five, the central task of the adolescent is to establish a new identity amidst the physiological revolution happening within them, and his or her attempt at defining his or her social role (Erikson, 1959). Erikson stated that a sense of ego identity "...is the accrued confidence that one's ability to maintain inner sameness and continuity..." (Erikson, 1959, p. 89). Identity formation then is

... an assimilation of childhood identifications, and their absorption in a new configuration, which in turn, is dependent on the process by which a society (often in subsocieties) identifies the young individual, recognizing him as somebody who had to become the way he is, and who, being the way he is, is taken for granted. (Erikson, 1959, p. 113)

An identity has been established when an individual is able to commit (Erikson, 1964). For Erikson, this meant a commitment to fidelity, ideology and vocation. Thus, identity is formed when one achieves a "sense of inner identity" and is committed to a set of ideas (Erikson, 1968, p. 87). This set of ideas provides the continuity by which one identifies a career that is worthy of one's time and reflects one's values (Kroger, 1996).

Although Erikson was considered a pioneer in the field of identity development, his work has also been criticized. Erikson has been criticized for

failing to define the term, “identity,” and not indicating whether it is a structure or a process (Kroger, 1996). Yet Erikson himself commented that the term, identity, carried a number of connotations including a reference to a conscious sense of identity, an unconscious striving toward personal character, and solidarity with a group’s ideals (Erikson, 1959). Erikson has been criticized for failing to elaborate or articulate how social or cultural influences impact development (Kroger, 1996; Wright, 1982). His failure to address social and cultural issues prompted the criticism of his work by feminists and people of color. (Friedman, 1999). Erikson’s theory was criticized for its reliance on the norms associated with mainstream Western culture (white, European-American, middle-class males, traditional male sex roles) which emphasized individuation as the goal (Rotheram-Borus & Wyche, 1994). Josselson (1994) proposed that the research on identity had a male bias and was preoccupied with selfhood, and as such, not indicative of identity development for women. She offered an alternative theory that being connected is core to not only women’s identity, but men’s identity as well.

“Although identity is in part distinct, differentiated selfhood, it is also an integration of relational contexts that profoundly shape, bound, and limit but also create opportunities for the emergent identity” (Josselson, 1994, p. 89).

Even more disconcerting is that when Erikson (1963) does acknowledge the influences of culture, he suggested that identity achievement was superior in Western cultures: a statement fraught with his own biases. The concerns I have with Erikson’s theory were due to his unexamined biases. Utilizing Western norms

as the baseline, he diminished identity development in marginalized groups such as women, people of color, gay males, and lesbians. Thus, Erikson's theory was only one piece that contributed to my understanding of identity development. Prior to investigating other identity models, let me discuss how Marcia operationalized Erikson's theory. This is especially vital as it appears that Marcia's model on ego identity formation is similar to the formation of an ethnic identity (Phinney, 1990).

Marcia's Identity Development Model

James Marcia (1980, 1966) operationalized the process by which individuals formulate an identity. Building upon Erikson's premise that an achieved identity was the result of exploration that leads to a commitment in areas such as fidelity, ideology and vocation, Marcia's (1994) model categorized whether or not individuals had explored identity options and whether or not they had made a commitment to a specific way of being in the social world. The first status was identity diffusion: individuals have neither engaged in exploration nor made any commitments. Individuals in this status appear to have little motivation and lack a sense of direction (Marcia, 1980). The second status was foreclosure: individuals have not explored identity options but have made a commitment based on the values of parents, teachers or peers (Marcia, 1980). According to Marcia (1994) foreclosure was the status most frequently experienced by individuals, with the moratorium status coming in second. Individuals in the moratorium stage were beginning the exploration process. In the moratorium status, individuals were

experiencing an identity crisis represented by their struggles to identify values or goals that fit them; these individuals have not made a commitment. Individuals who have made a commitment after a period of exploration were considered to have achieved an identity. It should be noted that the four statuses are not hierarchical; it is not necessary to pass through one stage in order to progress to the next one. There is also no guarantee that one will always reach an achieved identity.

The criticism of Marcia is that he focused on individuals' choices and responses to their situation rather than looking at the sociocultural process (Penuel & Wertsch, 1995). Additionally, much of the research utilizing Marcia's model was focused on white males. As I believe that people with disabilities have historically and socially been marginalized, it behooves me to look at the identity development of groups who have also been historically and socially marginalized: women, minorities, gays, and lesbians.

The intent of the following review is to provide a landscape of the competing theories on identity development inclusive of social and historical oppression. For it is the disagreement with the dominant discourse on identity development that gives rise to the movement to define identity as reflective of the experiences of a collective group who are not part of this discourse. The multiplicity of theories defining this elusive "collective group" is indicative of the complexity in naming whether identity is a process or an achieved status, and its intersection with society.

Identity Development of Other Oppressed Groups

Because disability identity was not part of the dominant discourse, I look at the identity development literature of oppressed groups. I utilized this body of knowledge to inform my understanding of disability identity development. While not always stated, it appeared that the theoretical foundation for the work in ethnic identity could be based on the Tajfel (1981) theory on social identity. Social identity is “the individual’s knowledge that he or she belongs to certain groups together with some emotional or value significance to him or her of the group membership”(Tajfel, 1981, p. 255). Group identity was important when discussing the identity development of ethnic/racial minorities, women, and sexual minorities, as most theories indicated an immersion into the group as part of the identity development process. Additionally, the development of identity models appeared to reflect the social movements of the country, beginning with black identity, feminist identity and followed by lesbian and gay identity models (Reynolds & Pope, 1991). This review will follow the order in which these identity models appeared, as later models utilize some of the nuances and themes from the earlier ones.

Phinney’s (1990) review of ethnic identity indicated that a positive self-concept may be related to “...the extent to which people have come to an understanding and acceptance of their ethnicity (p. 508). Many of the identity development models proposed for ethnic identity appeared to represent this idea of

coming to understand and accept one's ethnicity. Cross's (1971) model is the one most often cited and researched in the area of black identity. However, some researchers have noted that cultural and historical influences may influence identity development differently for other oppressed ethnic/racial groups, e.g. Asian Americans (Sue, 1981; Sue & Sue, 1971) and Latino/Chicano people (Keefe & Padilla, 1987; Ruiz, 1990). There have also been attempts to study how the dominant group obtains an identity, e.g. white identity (Helms, 1984). Because Cross's model appeared to be the foundation for the identity models of gender and sexual minorities, this model will be discussed.

Cross's (1971) model was developed during the civil rights movement and was called "the Negro-to-Black Conversion Experience- a psychology of Black liberation". Cross's model described the development of black identity as a transition, moving from a position of devaluation of one's self and culture to one of affirmation of black identity. "The Cross Model dealt primarily with the issue of racial oppression and African Americans' psychological responses to oppression" (Smith, 1991). Cross's model consisted of five stages. They were: (1) Pre-encounter – individual identifies with white people and culture while rejecting black people and culture; (2) Encounter – an experience that leads the individual to begin rejecting identification with whites and seeking identification with blacks. Guilt may be part of this stage due to engagement in stage one. (3) Immersion-emersion – individual identifies everything of value with blackness and abhors everything symbolized as white, followed by emersion, a movement away from the

dead-end either/or racist immersion experience; (4) Internalization – individual incorporates a positive black identity; (5) Internalization-commitment – individual maintains a positive black identity in spite of societal oppression, and is committed to action that will benefit the minority community.

Phinney (1990) compared the Cross model to Marcia's model and reviewed the similarities. The pre-encounter stage would reflect identity foreclosure, accepting the values of others without exploration, or an unexamined ethnic identity. The encounter stage would most closely represent identity crises, or the beginning of the moratorium stage. The immersion/emersion stage reflected the continuation of the moratorium stage. The last stage, internalization and internalization-commitment, reflected identity achievement. Thus, Marcia and Cross's models were similar. Both models progressed from a period of being unaware, with a preference for the dominant cultures to a period of exploration of one's own ethnicity, which may involve rejecting dominant culture value; to developing an understanding and appreciation of one's own ethnicity (Phinney, 1990). However, Cross's model was focused on the development of black identity. Perhaps the most inclusive identity model is the Minority Identification Development (MID) model.

Atkinson, Morten, and Sue (1979, 1993), proposed the MID model to be representative of the identity development of oppressed groups. McEwen (1996) contended that this was possible, because all people of color have been subjected to various forms of discrimination and racism. Thus, people of color share a common

experience regarding racial and ethnic identity development . The MID model is also a five stage model that reflects Cross's stages. Cross's and Marcia's corresponding stages are in parentheses. The first stage was conformity (pre-encounter, foreclosure) – the individual preferred the dominant group and depreciated self and one's own minority group. The second stage was dissonance (encounter, moratorium)– a period marked by conflicting feelings of appreciating and depreciating attitudes towards oneself, members of the same minority group and members of the dominant group. Stage three was one of resistance and immersion (immersion-emersion, moratorium). The individual felt guilty for denying and perhaps contributing to their own group's oppression; thus, they began to discard the views of the dominant majority group. The fourth stage was introspection (internalization, identity achievement). At this stage, individuals obtained their own sense of identity while reevaluating values of both the minority and dominant cultures. The final stage was synergism. Individuals experienced self-love, self-confidence, fulfillment, and pride in identifying with their own culture. Again, the same themes occurred. Individuals moved from a state of being unaware to one of self-actualization. This theme or process was also reflected in the models for gender and sexual minorities.

In reviewing the literature on gender issues in identity development, there are two models offered: Downing and Roush's (1985) feminist identity and Ossana, Helms and Leonard's (Ossana, Helms, & Leonard, 1992) womanist identity. The feminist identity model, crafted after Cross's model, also had five stages: passive

acceptance, revelation, embeddedness-emanation, synthesis, and active commitment. The movement in the model begins with passive acceptance, and indicates that the woman is “unaware of or denies the individual, institutional, and cultural prejudices and discrimination against her” (Downing & Roush, 1985, p. 698). The revelation stage was when the woman could no longer deny the oppressive element of society and became angry, often experiencing guilt, and utilized a dualistic mentality; men were negative, women were positive. The next stage, embeddedness-emanation represented an emotional connection with other women, leading to synthesis, a stage where women “are able to transcend traditional sex roles, make choices for themselves based on well-defined personal values, and evaluate men on an individual, rather than stereotypic, basis” (Downing & Roush, 1985, p. 702). The final stage resulted in an active, almost political requirement to change society. The womanist’s (Ossana et al., 1992) critique of feminist identity stated that ‘the feminist identity model assumes that ‘healthy’ identity development for a woman *requires* that she adopt a particular political orientation (feminism) and that she exhibit active commitment to societal change” (p. 403).

The womanist identity model, crafted by Helms (cited in Ossana), proposed four stages. They were preencounter, encounter, immersion/emersion, and internalization. This model followed the same path as the other models, but allowed for a different conceptualization of what was deemed “healthy”. The model maintained that “feminism is only one path that the woman may follow in

her search for a broader perspective on who she can be” (Ossana et al., 1992 p. 403). The progression through these stages was similar to the aforementioned models.

The models of ethnic/racial identity and gender identity are very similar. All deal with the oppressiveness of having a minority status within Western culture. Criticism of the models pertained to the fact that each model was developed in reaction to the environment and may be more reflective of a particular time than of a “universal” process. If this is true, then identity development is merely a reaction to environmental changes: limiting the role of the individual (Myers et al., 1991). The role of the individual was of particular concern, as it appeared that people of color and women will eventually find themselves in one of these stages solely by virtue of being a person of color and specific gender: overt categorization. As I am investigating the identity development of individuals with hidden disabilities, it was necessary to look at the identity development of another group that required a decision to disclose a minority status or sexual orientation.

There appeared to be a number of models proposed for sexual orientation, with some focused on the experiences of both gays and lesbians (Cass, 1979; Troiden, 1989), and others focused solely on the lesbian experience. McCarn (1996) provided an excellent overview of the multiple models proposed for lesbians, including her own model that was inclusive of “group membership identity,” which she believed was lacking in the other models. However, as Cass

(1979) is the most widely cited in the identity development of lesbian/gay identity and appears to be foundational for other models, this model will be examined.

Cass' model was composed of six stages. They were: identity confusion, identity comparison, identity tolerance, identity acceptance, identity pride, and identity synthesis. The process here was moving from questioning one's sexual orientation to feeling isolated as the differences between self and nonhomosexual others became apparent (Cass, 1984). Next, in identity tolerance, individuals sought out other selected homosexuals in order to lessen this isolation. However, individuals in this stage still maintained two identities: public – heterosexual, private - homosexual. In identity acceptance, there was increasing contact with the homosexual subculture, and selective disclosure was made, but the individual still maintained a "passing strategy to the dominant culture" (Cass, 1984). Identity pride was similar to other stages as it pertained to a dualistic perspective, where everything homosexual was seen as important while everything heterosexual was devalued. The last stage, identity synthesis, was characterized as an integrated identity, similar to the stage of internalization for ethnic/racial and gender models. In this stage, "[a] homosexual identity is no longer overwhelmingly *the* identity by which an individual can be characterized. Individuals come to see themselves as people having many sides to their character, only one part of which is related to homosexuality" (Cass, 1984, p. 152).

The significance of the sexual minority models to this study was due to identity disclosure and the realization that disclosure may be an option, while understanding that social context, embedded with stigmatism, may prevent disclosure. Additionally, these models appeared to be more circular "...because changing life situations always hold anew the possibility of rejection"(McCarn & Fassinger, 1996, p. 511). Thus, the costs and benefits of disclosure must be evaluated in each situation. This cost/benefit analysis may be of significance when investigating the identity development of hidden disabilities. I found the literature on sexual minorities identity development particularly informative, especially as it reviewed the social construction of heterosexuality and homosexuality and the changes of these constructs over time (Fuss, 1991). This information was especially valuable as the disability movement is attempting to change the current paradigm of disability, currently viewed from a medical, functional limitation, model to a socially constructed model. The difficulties with the developmental models of ethnicity, gender and sexuality were that they did not consider multiple oppression. Thus, two additional models, the Optimal Theory Applied to Identity Development (OTAID) (Myers et al., 1991) and the Multidimensional Identity Model (MIM) (Reynolds & Pope, 1991) are worth reviewing.

In developing the OTAID model, Myers and her colleagues stated that a "positive self-identity is not easily attained in this culture... [Their] premise was supported by the pervasive number of '-isms' (e.g. racism, sexism, heterosexism, ageism) and the adverse impact on those who were defined as inferior by the

dominant way of perceiving” (Myers et al., 1991, p. 54). Myers et al (1991) indicated that, in the process of coming to know who we are, we are moving from a narrow definition of self to a broad inclusive definition of self. She indicated that identity was a journey of “self-discovery and self-acceptance” (p. 59). Her model consisted of seven phases (Myers et al., 1991).

Phase 0 – *It is* - the individual lacks awareness of being, pertains to infancy.

Phase 1 – *The world is the way it is* – individuals do not have an objective view of self, and family values constitute personal identity.

Phase 2 – *I’m beginning to wonder who I am* – individuals begin exploring aspects of self that may be devalued by others. This phase may contain feelings of anger, guilt, or sadness as individuals wrestle with the image they have of themselves and the image of self that others consider inferior.

Phase 3 – *I focus my energy on people like me* – individuals identify with others like themselves who are also devalued. This phase is similar to the immersion stages of the other identity models.

Phase 4 – *I feel good about who I know I am* – individuals have incorporated self-worth allowing them to be more tolerant and accepting of others.

Phase 5 – *With my deeper understanding of myself, I am changing my assumptions about the world* – individuals have developed a secure sense of inner peace, which allows for a greater understanding of the nature of oppression. “All people can oppress or be oppressed, depending upon one’s assumption about one’s self and relationships to others (Myers et al., 1991, p. 60).

Phase 6 – *It is I* – “The self is redefined toward a sense of personhood that includes the ancestors, those yet unborn, nature, and community” (p. 60).

Myers model mirrors other models of identity development but incorporated a more spiritual tone. Although there have been some studies utilizing this model with some preliminary indication that the model was pluralistic, Myers et al (1991) stated that more empirical studies were needed.

The final identity model I reviewed was the Multidimensional Identity Model (MIM) (Reynolds & Pope, 1991). This model expanded on Root’s biracial identity model (Root, 1990, cited in Reynolds & Pope, 1991). The model was drawn as a box with four categories. A broken line indicated the demarcation between each category. The broken line reflected the dynamic and fluid nature of identity development. Reynolds and Pope (1991) indicated that “[t]hroughout one’s life, movement among these options occurs based on personal needs, reference group, or environment” (p. 179). The options were (1.) identify with one aspect of self (society assigned-passive acceptance), (2.) identify with one aspect of self (conscious identification), (3.) identify with multiple aspects of self in a segmented fashion, and (4.) identify with combined aspects of self (identity intersection). Reynolds and Pope (1991) accepted that all options were acceptable, and each position provided areas of pride and dilemmas to maintaining a sense of self. This model has not been used in research, thus whether or not the four areas are representative needs further investigation.

I have attempted to provide the landscape of identity development among other specifically marginalized or oppressed groups and offer models inclusive of all groups who have experienced oppression. The development of these models provided insight into the identity development among individuals with hidden disabilities. The models all reflect a movement from being unaware and uninformed to a more existentialist notion of self-actualization, one that surpasses categorization, knowledgeable in the realm of “self”.

The criticism of Erikson’s (1959) theory and Marcia’s (1966) model was that their models reflected Western norms, and were thus not reflective of the experiences of groups affected by the oppressiveness of Western culture. Cross’s (1971) model has been criticized for perhaps reflecting a Eurocentric worldview rather than an Afrocentric one (Myers et al., 1991). Additionally, his model did not incorporate the oppression of gender within experiences of women of color. Thus, I turned to the development of gender models. However, gender models have been criticized for reflecting white middle-class women values, and are not representative of women of color. The feminist model was the first to suggest that active political involvement was necessary in achieving a health identity, whereas the womanist model appeared to be more accepting of the different options available, e.g. women can still be healthy if they select a traditional women’s sex role. The gay and lesbian theories all involve the internal wrestling with oneself regarding sexual orientation. The issue of disclosure was an area of concern, and this issue was not found in racial/ethnic or gender identity models. Perhaps the last

two models, MIM (Reynolds & Pope, 1991) and OTAID (Myers et al., 1991), might be more applicable in investigating the multiple oppressions of individuals lives, with a hidden disability only being one facet of the story. The next section reviews the literature on disability identity.

Literature Surrounding Disability Identity Development

The literature on disability identity development was almost nonexistent. In searching for articles on this topic, I found only three published articles (Gill, 1997; Gilson, Tusler, & Gill, 1997; Wilczenski, 1992). Wilczenski (1992) utilized a phenomenological study which examined the identity stages through which students with learning disabilities progressed, while clarifying the personal meaning of a learning disability. Wilczenski (1992) proposed three stages of identity: denial, exploration, and acceptance. Within in the exploration process, three themes regarding learning disability (LD) identity emerged: (1.) learning disabilities experienced as specifically versus globally handicapping. (2.) learning disabilities seen as modifiable versus permanent handicapping conditions, and (3.) learning disabilities viewed as a stigmatizing versus a non-stigmatizing identity. Wilczenski concluded that accepting a disability enabled one to make realistic attribution about one's own successes and failures. When students with learning disabilities can appreciate their own strengths and weaknesses, they were empowered to ask for appropriate services. The study also indicated that some students who were in denial, or maintained defenses about the disability, were at

risk of failing. Wilczenski concluded her study with a comment about the need to provide informed counseling services to the growing learning disabled populations.

My concern regarding this research does not necessary stem from the conclusion suggesting a need for counseling services for students with learning disabilities. Rather, my concern stems from statements such as “[w]hen students are able to appreciate their strengths, less personal identity will be founded on being learning disabled” and “[b]eyond acceptance, students must acknowledge their learning disability and diminish its importance in their lives, i.e., recognizing that the impact of a learning disability in one’s life can be lessened through effort or a change of college major” (Wilczenski, 1992, p. 58). It appeared she was suggesting that one should not incorporate a learning disability into a personal identity, thereby diminishing the importance of the disability in one’s life; and that through effort, one can limit the impact of that disability. All these phrases suggested that you should not welcome home a part of yourself that has helped shape who you are. While not indicated, and the study acknowledged disability as a social construct, there still seemed to be a hint of an ableist perspective. The other two articles promote the need to integrate the disability into one’s identity in order to be healthy.

The article by Gill (1997) proposed four types of integration. They were: coming to feel we belong (integrating into society), coming home (integrating with the disability community), coming together (internally integrating our sameness

and differentness) and coming out (integrating how we feel with how we present ourselves). Gill (1997) based her four categories on her experiences as a psychotherapist. “It is remarkable how many times the theme of integration emerges in the discourse of people with disabilities... a yearning for wholeness and belonging that surfaced repeatedly in the complaints of persons with varying disabilities and backgrounds” (Gill, 1997, p. 42). There were some similarities and differences between Gill’s work and the literature of identity development. The first similarity pertained to the need of a positive group identity. But for individuals with disabilities, group identity was not possible because of societal oppression.

Perhaps more than any other minority groups...disabled people’s identity striving have been impeded by the nagging details of our oppression. Inaccessible environments and transportation systems are barriers to community organizing. Poverty keeps resources beyond reach. Categorization by medicine and social service system perpetuates our separation from each. Social values that deem disability a fate worse than death discourages us from identifying as disabled individuals or seeking the company of stigmatized peers. (Gill, 1997, p. 41)

The identity development of other marginalized groups involved an immersion into that group. However, immersion has been historically difficult for people with disabilities due either to environmental constraints or to social values. In the “coming together” stage, Gill indicated that the self was split, wrestling with those elements of self that were not disabled as good, and those attributes that were disabled as bad. I believe this split was highlighted in Wilczenski’s research as indicated by the statement that when one appreciates one’s strength (obviously not

the disability), less personal identity will be founded on the disability (Wilczenski, 1992). Thus, there was an implied value judgment that to appreciate one's strengths, "...one should seek value in parts of his/her being that [have] not been impaired by the disability" (Gill, 1997, p. 43). Attempting to seek value through the non-disabled part of oneself requires one, through effort, to overcome the defective part (Gill, 1997). This effort may result in "...exhaustion by ceaselessly laboring to measure up to an ill-fitting standard, or one 'gives up' and surrenders to invalidity"(Gill, 1997, p. 43). Gill indicated that in order to be whole, people with disabilities must reject the values of the dominant culture that devalues disability.

One difference between disability identity and other identity literature, excluding sexual identity literature, is that most individuals with disabilities are the only one in their family, and perhaps their community, who have a disability. Again, the issue of immersion as a path toward a healthy identity is questionable. This issue may have significance when investigating identity development in individuals with hidden disabilities. Gill stated that developing disability pride and culture was a necessary step in developing a positive identity.

In the second article, Gilson et al. (1997) presented an ethnographic study on the topic of disability identity. Gilson et al. (1997) discussed the disabled community, the dominant discourse on disability and the need to change society's negative value of disability. Again, the issue of belonging to a group was discussed. "...[b]eing a part of a group or community is part of the struggle to

combat internalized oppression and the development of a sense of value in oneself” (Gilson et al., 1997, p. 11). In reviewing the literature on disability culture, it appeared that much of the work had been completed by and about, individuals with visible disabilities. One participant in Gilson’s study questioned the identity development of individuals with hidden disabilities. “Is part of our [people with hidden disabilities] culture a culture of isolation? Is it true that people with hidden disabilities don’t have a culture”(Gilson et al., 1997, p. 12)? Although no answers to this question was provided, the study did raise the issue of self-disclosure and questioned “...what adjustment should those with visible disabilities make to acknowledge and welcome individuals with hidden disabilities” (Gilson et al., 1997, p. 14). The question of disclosure, and affinity towards interaction with other disabled individuals will be an important part of my investigation. How do individuals with hidden disabilities achieve a healthy identity? My one concern regarding this study pertained to the participants. The participants all belonged to the Society for Disability Studies and perhaps, because of their involvement in this non-profit organization, had already begun to internalize a positive sense of disability identity. Gills’ (1997) and Gilson’s (1997) articles provided a contrast in thinking about disability identity development. However, due to the limited information available on disability identity development, I investigated the literature on self-concept and disability. As I was interested in hidden disabilities, I specifically reviewed the literature on self-concept and learning disabilities. Self-concept refers to the individual’s mental images of themselves.

The literature on self-concept and children or adults with learning disabilities (LD) was inconclusive. Older studies indicated that many LD children and adults have lowered self-concepts and lower self-efficacy (Buchanan & Wolf, 1986; Griffiths, 1970; Saracoglu et al., 1989). Newer studies indicated no difference in global self-concepts (Cosden & McNamara, 1997; Lewandowski & Arcangelo, 1994; McPhail & Stone, 1995). Still other researchers (Bryan & Pearl, 1979; Grolnick & Ryan, 1990; Meltzer, Roditi, Houser, & Perlman, 1998) found that students with learning disabilities may have lower academic self-concept but still maintained positive feelings of overall self-worth. However, in the Meltzer et al. (1998) study, the researchers noted a significant difference between LD students' self-rating of performance and teachers' judgment of their performance. Meltzer et al. (1998) suggested that the differences might stem from LD student's overrating their academic competencies and denying their difficulties as LD students based their academic abilities on their teacher's praise, which might be focused more on effort than achievement.

I found the self-concept literature informative, but limiting as self-concept appeared to be a fixed personality trait, maintained in all contexts. Based on my personal experiences with LD students, there is an oscillation between a positive self-concept and a negative one depending on the setting, with academic endeavors usually eliciting concern, anxiety and embarrassment while non-academic endeavors do not appear to be as much of a concern. Additionally, the literature on transition issues from secondary to postsecondary education revealed that LD

students lack self-determination and self-advocacy skills (Axelrod & Zvi, 1997; Brinckerhoff, 1993; Brinckerhoff, 1994; Cosden & McNamara, 1997; Feldmann & Messerli, 1995; Heyman, 1990; Hicks-Coolick & Kurtz, 1997; Levinson & Ohler, 1998; Wille-Gregory, 1995). Thus, I believe that most LD students have not wrestled with who they are, and the influence of a learning disability in developing their identity. Understanding how the disability has shaped one's identity is important in order to understand the range of emotions and actions by individuals with hidden disabilities. As the self-concept literature did not inform me of the process one undertakes to understand the impact of a hidden disability or more specifically a learning disability on identity development, I decided to pursue doctoral research on disability identity development for individuals with hidden disabilities.

At this time, it behooves me to address Goffman's (1963) work contained in his book, *Stigma: Notes on the Management of Spoiled Identity*. Initially, I was interested in Goffman's work because of the emphasis on social interaction and the impact on the individual. However, upon reading his book, I was left with the impression that individuals with disabilities could never rise above the stigma of disability. Goffman's work was often cited in Disability Studies literature, mainly in reaction against his conclusions. He concluded that "a major aspect of the experience of disability is the ongoing struggle to ward off potential interpersonal devaluation caused by one's social classification as less than normal, at best, and less than human, at worst" (Gill, 2001). In my work with students with disabilities,

I do not perceive that all the students simply cope with the stigma of having a disability. Rather, students who were successful appeared to have found a way to meld the disability into their identity, thus, I perceived that some of the students either confronted or ignored the stigma of the label “disabled”. Therefore, while Goffman’s work was informative, I did not place his body of work at the center of this study. Because Goffman’s work and the three articles discussed above, did not provide sufficient information, I investigated five unpublished doctoral research studies.

I found five doctoral dissertations that pertained to disability identity. The dissertations will be discussed according to the degree in which they informed my understanding of disability identity development. I begin with Cain (1997) who utilized Marcia’s model to investigate identity development of students with learning disabilities and followed with Grant (1996), who utilized Marcia’s model and other identity models to formulate his own disability identity model. Next is Dole (1999), who does not utilize any model but recognized the sociocultural influences on identity development. The last two, Ferri (1997) and Skolnikoff (1999), utilized a postmodern, multifaceted perspective of identity.

Cain (1997) researched the identity development of 84 senior university students. He utilized Marcia’s model and the self-administered assessment tool, the Extended Objective Measure of Ego Identity Status. Specifically, he was investigating eight identity areas that involved vocational, life style and interpersonal issues. His research revealed that most participants were in the

moratorium status, still exploring and uncommitted. Cain (1997) indicated that students with learning disabilities might differ in their identity development from other college students in the general population. But, he also stated that no conclusion could be made because there was no comparative sample from the general population. He indicated that, theoretically, seniors should be toward the end of their identity development, yet most students in the study were still exploring. However, he provided no rationale as to why this group might be still exploring. There were many cautions and potential limitations indicated (sample size, generalizability, use of multiple choice tests), and he proposed that future research should look at culture, level of abilities and disabilities, and socioeconomic status. Cain's research was informative in that it provided actual data on LD students while utilizing Marcia's model. However, this research does not provide information on the development of a disability identity. Rather, it investigated where LD students fit into an existing model-- a model that does not necessarily address issues of oppression.

Grant's (1996) study defined individuals with physical disabilities as a minority group, who, as such, experience "...identity development in a climate of societal prejudices, discrimination, and oppression" (p. 14). Grant investigated the adaptation and adjustment models applied to disability issues and found them lacking, as they addressed the issues of grief of a lost identity, and do not deal with the issue of oppression or the opportunity to experience a positive, healthy, disability identity. As such, she claimed that there were no models of disability

identity development in the literature. Her research was an attempt to create such a model. She then focused on the development of the instrument she created, the Disability Identity Attitude Scale (DAIS). The scale has four stages. (1.) Dissociation – denial of disability, self defense mechanisms to protect self-esteem; (2.) Diffusion/dysphoria – attitudes were characterized by low self-esteem, individuals are struggling with the dissonance between they way they viewed themselves and the way others viewed them; (3.) Immersion/solidarity – involved immersion into disability culture, mistrust of non-disabled, and reflected a positive self-esteem; and (4.) Introspective/acceptance – individuals exhibit attitudes of higher levels of self-esteem and confidence.

Grant's (1996) model resembled the models for other oppressed groups. Grant stated that the study should be replicated in order to confirm the findings, and that the model should be extended beyond the population of individuals with physical disabilities, and include non-college populations. I found Grant's study very informative, since this was the first attempt to "measure" the degree to which individuals accepted a disability, and the implication of that acceptance on identity development. Grant proceeded to indicate the usefulness of this information to counselors in assisting individuals to resolve identity crisis. However, Grant's sample group was individuals with visible disabilities. I am curious as to how students with invisible disability would have responded, and if the issue of immersion for students with hidden disabilities is a factor. An additional concern pertained to multiple oppression, as this model does not examine the potential

differences in disability identity development among women, people of color, gay men and lesbians.

Dole's (1999) study attempted to research identity development in college students with both giftedness and learning disabilities. She indicated that the process of identity formation for this group was complex, as they were wrestling with the paradoxical coexistence of giftedness in some areas and a learning disability in other areas. Dole does investigate the sociocultural aspects that surround identity development by drawing upon the literature of William James, a psychologist who emphasized relationships with others, and George Herbert Mead, a sociologist who believed that identity is defined through interactions with others. Dole utilized a narrative methodology in conducting her research. Her research revealed that identity formation occurs not in a linear fashion, but was a continuous process beginning with self-knowledge, moving to self-acceptance, then self-advocacy, and ending in self-determination. Sociocultural contexts did affect the meaning individuals attributed to having a learning disability. This meaning was influenced by the time of diagnosis, whether or not exposed to special education, and the meaning of learning disability as viewed by others. Dole then proceeds to make recommendations for the educational system, including assessment tools, early identification, individualized instruction, curriculum development, accommodations, and teacher preparation. What I found of value in this dissertation was the information on how the student's development of a disability identity began with self-knowledge and self-acceptance. Although she

acknowledged the influence of the educational system and the values of others on self, she does not approach the notion of a positive disability identity. It appeared that her participants identified more with the gifted (dominant accepted) aspect of their identity rather than the disability (dominant devalued) aspect. Additionally, she did not investigate the experiences of individuals with multiple oppression.

The last two dissertations Ferri (1997) and Skolnikoff (1999) applied a more holistic approach to identity development. Skolnikoff's (1999) dissertation delved into how people with a hidden disability experienced life. She indicated that her study was anthropological in design and was used to develop an understanding of disability and culture by investigating the lived experiences of "...how people develop skills to cope within a society that works differently from the way they function" (p. 3). Specifically, she utilized the following categories to review the data: liminality/stigma, revealing, performance/performativity and the role of the other.

Skolnikoff (1999) indicated that individuals with hidden disabilities often operate between two worlds, the world of physical and mental disabilities and the mainstream, non-LD world. She stated that how people respond to the experiences of marginality affected the choices made in revealing, performance, and the role of the other. Revealing, Skolnikoff acknowledged, was an ongoing process in which each situation is evaluated. Revealing issues were similar to the disclosure issues regarding one's sexual orientation discussed in gay/lesbian literature. It appeared

that past experiences, whether positive or negative continued to influence the individual's present day choices. This dissertation provided a wealth of insight into the way individuals with learning disabilities experienced life. Unfortunately, the participants in her study do not appear to have integrated the disability into their identity, which results in shame and embarrassment. Skolnikoff (1999) wrote: "[T]heir stories often illustrate the need to keep their disabilities hidden not just in the workplace, but also in social situations, such as playing board games or figuring out a restaurant bill. In many cases, these individuals walk a narrow line to protect themselves against further stigmatization" (p. 265).

In Ferri's (1997) dissertation, she (1997) stated that "[t]he purpose of this investigation is to create a forum for dialogue where participants collaborate in the generation of theory about how learning disabilities braid with more, and less visible, identity markers, such as race, class, gender, and culture" (p. 2). She contended that identity, or self, was socially constructed. Ferri (1997) utilized a participatory action research design methodology to obtain her data. This dissertation was the most informative regarding identity development due to its attempt to incorporate multiple identity markers. Through their stories, participants revealed the complexity of multiple oppressive systems on identity formation. Many of the participants spoke of feeling isolated and alone in their experiences, especially in terms of the disability. Ferri, noting the feelings of isolation, explored places where women felt a sense of belonging. In most cases, the women obtained a sense of belonging from other identity communities (race, sexual orientation).

The participants also recognized that building a sense of community among people with learning disabilities would be positive, but acknowledged that such communities have yet to be developed.

Ferri also explored the naming of self, how the participant negotiated the label of a learning disability. In most cases, the participant did not perceive the label to be reflective of their identity. Ferri stated that what "...participants seem to be doing in these posts is taking a term or label which is peopled with and even (de) valued by others and giving it their own interpretation and value—making it their own" (p. 128). Next, she explored the concept of claiming the self. The participants discussed the risks of keeping silent or of disclosing the disability, and that the two are not necessarily opposites. Because of the invisible nature of a learning disability, participants felt they might not be believed or understood. Ferri also indicated that participants "...found ways to value their strengths while downplaying weaknesses" (p. 161). It appears that these participants viewed themselves as split identities, wrestling with the idea that those elements of self that are not disabled are good and those attributes that are disabled are bad. Based on the themes of the data, Ferri indicated that the "self is personally, socially, and culturally constructed through narrative, but made understandable in a dialogic process of meaning making" (p. 182). My own perspectives (Vygotsky, social constructivism, and Erikson) would agree with this statement. Ferri concluded her dissertation with recommendations for disability service providers to reconsider how learning disabilities affect the individual, recognizing that the issues are not

just about academic domains, but involve social concerns as well. I found the dissertation by Ferri informative, as it highlighted the issues of isolation, the complexity of identity development, and social implications of having a hidden disability. However, Ferri's research does not necessarily address how individuals can become whole, the "coming home" to that part of self that is disabled.

CHAPTER 3: METHODOLOGY

Research Paradigm and Design

Traditionally, able-bodied persons have been the researchers and persons with disabilities have been the researched. This has allowed a disconnection between the authentic voices of persons with disabilities and the professional and academic empirical literature about such persons (Olkin, 1999 p. 503)

The purpose of this study was to inform my praxis. The focus of the study was to explore university students' understandings and description of their own identities related to disability identity development. I was interested in the meanings participants ascribed to identity development and their hidden disability. In this chapter, I describe my research assumptions, the strategies that framed the study, participant selection, data collection and analysis.

Denzin and Lincoln (1998) provided an overview of four major paradigms and delineated the ontological, epistemological, and methodological characteristic of each paradigm (positivism, postpositivism, critical theory, and constructivism). Postmodernism is treated as a "fifth" movement, representing a crisis of representation and legitimization. Denzin and Lincoln (1998) indicated that one's epistemology would influence one's methodology. I am neither a positivist, searching for an objective "truth"; nor a postpositivist, searching to refute the "truth" in a more natural setting. Of the remaining three paradigms, I do not

position myself in any of them, but am informed by them. Thus, critical theory, constructivism, and postmodernism influenced my epistemology as well as my methodology.

Methodology focuses on how one gains knowledge about the world (Denzin & Lincoln, 1998b). It also refers to the logical and theoretical perspective for a research project (Gall et al., 1999). Although both types of research, quantitative and qualitative, are informative, I preferred the qualitative method because it was more conducive to acquiring the type of information I was seeking. Maxwell (1996) stated that qualitative research was especially suited for “understanding the *meaning*, for participants in the study, of the events, situations, and actions they are involved with and of the accounts that they give of their lives and experiences” (p. 17). For the purpose of this study, I utilized Lincoln and Guba’s (1985) five axioms of interpretive inquiry to guide my methodology. They are:

1. There are multiple constructed realities that can be studied only holistically;
2. The inquirer and the ‘object’ of inquiry interact to influence one another; knower and known are inseparable;
3. The aim of the inquiry is to develop an idiographic body of knowledge in a form that describes the individual case;
4. All entities are in a state of mutual simultaneous shaping, so it is impossible to distinguish causes from effects;
5. Inquiry is value-bound, and is influenced by the inquirer’s values, choice of methodology, and choice of the substantive theory. (Lincoln and Guba, 1985, p. 37-38)

These axioms were congruent with my epistemological position informed by critical theory, constructivism, and postmodernism. Multiple realities are

shaped by social, political, cultural, economic, ethnic, and gender factors, and, while constructed by society, are considered as actual, historical realities (Denzin & Lincoln, 1998b). I also believe that these constructions are alterable, as we become more informed. As I believe that knowledge is constructed, my study was dialectical. The constructivist-interpretive paradigm allows for a design that is “emergent rather than preordinate...[and]... must therefore be ‘played by ear,’ it must unfold, cascade, role, emerge” (Lincoln, 1985, p. 208-209). Utilization of Lincoln and Guba’s axioms also recognizes that I do not come to this research as a clean slate. Thus, I needed to reflect on my own personal and professional experiences in interpreting the data. I also needed to be cognizant of my understanding and interpretation of the literature surrounding my research area. Because there is limited literature available on the construct of a hidden disability identity, the constructivist-interpretive paradigm allows for greater understanding of the participants without forcing them into a design based on my world construction.

Research Strategies

Two research strategies, phenomenology and critical theory, specifically, Freire’s strategies of liberation through dialogues, informed and framed my study. Phenomenology is informative in that it “attempts to explicate the meanings as we live them in our everyday existence, our lifeworld (VanManen, 1990, p. 9). Thus, phenomenology investigates individuals subjective experiences of reality. In

phenomenology, subjectivity is central to the research and “is the only sufficient guarantee that the world of social reality will not be replaced by a fictional non-existing world constructed by the scientific observer” (Holstein, 1998, p. 138). As subjectivity is central to the research, phenomenology acknowledges the subjectivity of the researcher. Van Manen (1990) stated that the problem of phenomenology is not that we do not know enough about the phenomenon, but that we know too much. He encouraged researchers to make explicit our understandings, beliefs, biases and assumptions in order to hold them “deliberately at bay and even to turn this knowledge against itself” (Van Manen, 1990, p. 47). Making explicit as much as I could at this time while an admirable goal, negated the fact that in this strategy the researcher is responsible for establishing the themes. Focusing on the meaning favors the role of the researcher while limiting the role of the participants in developing themes. Thus, phenomenology as the only strategy did not satisfy the critical theorist in me.

Informed by critical theory, I was concerned about how the participants would benefit from the research. Additionally, the approach I wanted was a more collaborative endeavor, engaging the participants in verification or reformulation of the themes. Thus, I turned to Freire’s strategies of liberation through dialogues. Freire’s liberation praxis requires co-investigation in order for the researcher to know the participants, “both their objective situation and their awareness of that situation—the various levels of perception of themselves and of the world in which and with which they exist” (Freire, 1998, p. 76). As it was my intent to derive the

meaning they attribute to identity and the influences of a hidden disability, the participants had to be actively involved in the formulation of these themes.

Both phenomenology and liberation praxis utilize the participant's oral descriptions or stories as the raw data. Phenomenology utilizes themes to analyze the data collected. Van Manen (1990) offered insights on conducting thematic analysis, wholistic or sententious approach, selective or highlighting approach or the detailed or line-by-line approach. I utilized identification of phrases that appeared to be thematic of the experience. I am also aware that by utilizing the participants in the construction of themes that the participants might adhere to the dominant discourse. Freire (1998) stated that "when people lack a critical understanding of their reality, apprehending it in fragments which they do not perceive as interacting constituent elements of the whole, they cannot truly know that reality (p. 85). Thus, the themes that might surface may be a reflection of housing the oppressors within themselves (Freire, 1998). As it was my intent to bring back to the participants the themes that emerge from the data, it was also my intent that reflecting on the themes together would introduce the participants to critically thinking about their world and hidden disability. Utilizing Freire's liberation praxis incorporated my concern about the social, political and cultural influences and attempted to promote critical consciousness in the participants. This tactic of co-constructing meaning also meant that meaning was dynamic since it changed as participants and I reflected on the text and our reactions to it and each other.

Participants

The participants in the study were seven students who were currently enrolled at Oregon State University. Six were still enrolled as the writing of this dissertation was coming to a close. There were four women whose ages ranged from 20 to 55 and two men ages 20 and 35. All of the participants were White. All the participants had disclosed a disability by presenting documentation of a learning disability to OSU and were currently receiving academic accommodations during the data collection-analysis of this study. For the purpose of this research, two definitions of a learning disability recognized by the field of learning disabilities were used. The federal definition states that:

‘Specific learning disability’ means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have learning problems, which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage. (Federal Register, December 29, 1977, p. 65083)

The federal definition is problematic as it pertained specifically to children, contained ill-defined conditions, and stated that a learning disability cannot occur concomitantly with other disabilities. The definition offered by the National Joint

Committee on Learning Disabilities (NJCLD) is more contemporary and appears to have support from other agencies (Hammill, 1990). That definition is as follows:

Learning disabilities is a general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities. These disorders are intrinsic to the individual and presumed to be due to central nervous system dysfunction. Even though a learning disability may occur concomitantly with other handicapping conditions (e.g., sensory impairment, mental retardation, social and emotional disturbance), or environmental influences (e.g., cultural differences, insufficient/inappropriate instruction, psychogenic factors), it is not the direct result of those conditions or influences. (NJCLD, 1994, p. 65-66)

Informed by both Stake (1995) and Van Manen (1990), I utilized a case study approach that allowed for purposeful sampling to select the participants. Purposeful sampling “is a strategy in which particular settings, persons, or events are selected deliberately in order to provide important information that can’t be gotten from other choices” (Maxwell, 1996, p. 70). The number of participants selected was restricted to ten. As a researcher, I decided to pursue a limited number of “cases” in the attempt to understand the depth of the issues surrounding disability identity. Recognizing that by using purposeful sampling to obtain information rich cases, I have limited the generalizability of the findings. But the rationale for purposeful sampling is to maximize available information, not to facilitate generalizations (Lincoln & Guba, 1985).

In selecting the participants, I looked for individuals who were open and receptive to discussing disability and identity. Four of the participants had

participated in a course on “Peer Guides” that I taught in spring of 2001. In this course, we briefly discussed disability identity; thus, some of the participants had already engaged in a discussion regarding identity and disability. Additionally, I contacted five other students with whom I had had previous conversations regarding disability and identity. All five indicated interest in the study, but two were not able to participate due to other commitments. Thus, there were seven participants. Although, it was my intent to have participants with varied backgrounds, ethnicity and sexual orientation in the study; no one from these other identity groups elected to participate. Participants completed an “Informed Consent” document that detailed the significance of the study, methods and procedures, personal benefits and risks of the research, and confidentiality. Participants were also informed that they could withdraw from the study at anytime and it was their decision as to whether or not information gathered prior to their withdrawal could be included in the dissertation or any other report.

Additionally, I was concerned with the potential impact that my role as the Director of Services for Students with Disabilities could have on the research participants. Participants were informed that participation in the research was voluntary, and that their decision to accept or decline the invitation would not affect services or future interactions. I also informed participants that should they have any concerns about accommodations or delivery of services and believed that their participation in the research was influential; they could contact Affirmative

Action as a course of action to resolve the issues, since the Director of Affirmative Action agreed to act as an ombudsman.

Data Collection

The method of data collection consisted of interviews, both individual and group. However, I prefer to use the word, “dialogues” or “conversations”, instead of interviews, as I did not plan on entering into the research with a specific list of questions beyond general questions to start the conversations for each meeting. Patton (1990) would categorize this type of interview as a general interview guide approach. In case study, “...the aim is to thoroughly understand the research question. If early questions are not working, if new issues become apparent, the design is changed (Stake, 1995, p. 9). This method is called “progressive focusing” (Stake, 1995). I believe that progressive focusing respected the participants’ involvement and allowed for negotiated outcomes. This means “...that both facts and interpretations that will ultimately find their way into the case report must be subjected to scrutiny by respondents...and the inquirer has an obligation to attend to those inputs and to honor them so far as possible” (Lincoln & Guba, 1985, p. 211).

The questions that frame my initial inquiry into this complex, multi-situated topic regarding identity were:

- (1) How do students with learning disabilities construct their identity, and what is the role of the disability on that construction?

- (2) What are their personal processes for making meaning of their disability?
- (3) How does the hidden aspect of their disability hinder or aid this process?
- (4) How does the disability influence relationships?
- (5) How does accepting the disability influence decisions on self-disclosure in their relationships with others?
- (6) How could college student affairs professionals assist students with this aspect of identity?

These research questions served as an initial frame for the conversations as participants were encouraged to elaborate, reframe, and ask their own questions. Participants were also offered the opportunity to submit their ideas, concerns and issues via e-mail with the understanding that the issues would be discussed in the group session. I offered this alternative form of communication to recognize that for some of the participants, auditory processing and processing speeds may affect their participation in the group conversations. Data collection occurred during fall term of the academic year 2001-2002.

Data collection consisted of three individual, one-hour conversations with each participant, and three two-hour group conversations; the order was: individual 1, group 1, group 2, individual 2, group 3 and finally individual 3. For the individual conversations, it was mutually agreed upon to meet at the library and obtain a small study room. The first individual conversation took place the second

week of the term. The purpose of the first conversation was two fold: first, to review the purpose of the research and to provide a brief personal disclosure of why I am interested in this area, and second, to obtain background information, discuss confidentiality, and request the participants to invent a pseudonym to be used in the presentation and publication of the research. The second individual conversation occurred during the sixth week of the term and was used to see if the participant had any concerns or issues, and in general, to find out how the participant was doing. The third individual conversation occurred during the tenth week of the term and provided the opportunity to discuss the group process, the benefits, and the risks the participants encountered and address any other concerns.

Group conversations occurred during the third, fifth, and seventh week of the term. The first group conversations allowed for the presentation of categories identified from the individual conversations. This afforded the participants the opportunity to recognize the differences and similarities in their stories. The second group conversation incorporated the categories refined from the first group conversation as well as thoughts and perceptions from the second individual conversation. The third group conversation allowed for the presentation of categories and the shift in thinking about certain categories since beginning the research.

The use of group and individual conversations was intentional. Historically, individuals with hidden disabilities have had limited opportunities to come together to discuss disability issues. Thus, the intent of the group

conversations was to provide the participants the opportunity to share their stories in hope that they would benefit from the interactions and the conversation. As I believe that research should not pathologicalize the participant and is political, I was concerned about critical consciousness and catalytic validity. Critical consciousness "...refers to learning to perceive social, political and economic contradictions and to take action against the oppressive elements of reality" (Freire, 1998, p. 17). "Catalytic validity represents the degree to which research re-orientes focuses and energizes participants toward knowing reality in order to transform it; participants gain self understanding and self-determination" (Lather, 1991, p. 68).

The provision of individual conversations was to allow the participants the opportunity to freely express their thoughts and emotions about the research and the categories. Scheduling almost two weeks between conversation allowed time to transcribe the taped conversations and to sift through the transcripts numerous times to develop the emerging categories. This also allowed time for me to formulate and present to the group my understanding and interpretations of the categories I identified from the previous conversations. Thus, working with the participants to clarify, refine and develop the categories allowed for multiple perspectives in negotiating the themes. A few participants who needed additional time to reflect on group conversations subsequently provided their insights via e-mail or during individual dialogues.

For both individual and group discussions, the conversations were tape-recorded. After each conversation, the data were transcribed verbatim either by a

professional transcriptionist or me. If a transcriptionist had transcribed the tape, I concurrently reviewed both the tape and the transcript, attempting to detail the conversational nuances beyond the text (e.g. speaker sighs, pauses). All transcriptions and tapes were kept confidential, and will be destroyed upon completion of this dissertation as promised in the informed consent document.

Another source of data was the participants' psychological report/assessments that documented the disability. While the information was informative on the functional impact of the disability, I was interested in the participants' understanding of the disability. One final method of data collection was my personal journal or research log. Though the research log, I attempted to capture my observations of the interactions, as much as possible. The journal also allowed me to reflect on the research process, thus articulating my own biases, concerns, and dilemmas for later discussion with my major professor. Having utilized a journal in a previous case study project, I found it valuable in identifying the emotional and ethical challenges in researching lived experiences.

Analysis

My analysis of the data was partially informed by thematic analysis as described by Van Manen (1990). Data were analyzed during the process of data collection to allow initially tentative findings to guide future conversations. Therefore, data collection and analysis were in a reciprocal relationship. I utilized the basic concepts from Van Manen with regards to categorization and

development of themes. However, my understanding of this method was also informed by Ely (1991), Silverman (2000), Marshall, (1999), and Maxwell (1996). My initial step involved listening to the tapes of the conversations, reading and rereading the transcriptions, a selective reading approach, which allowed me to develop tentative ideas about categories and relationships (Van Manen, 1990). This approach asked “[w]hat statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described (Van Manen, 1990, p. 93). Thus, I utilized a coding method by highlighting key words or phrases whereby establishing different categories. “Making categories means reading, thinking, trying out tentative categories, changing them when others do a better job, checking them until the very last piece of meaningful information is categorized and, even at that point, being open to revising the categories”(Ely, 1991, p. 145). Once the categories were saturated, I then began to identify the themes or patterns. Also, as the analysis was a continuous process, I utilized the group and individual interviews as a means to develop, test, and redefine the themes. Thus, in utilizing this method, the participants and I co-constructed knowledge or theory. Co-construction is important to me because of my epistemological position. Freire (1998) stated that “...the more active an attitude men and women take in regard to the exploration of their thematics, the more they deepen their critical awareness of reality and, in spelling out those thematics, take possession of that reality” (p. 87). Co-construction also assured that all participants were included in all insights that I had.

Traditional analysis of research calls for addressing issues of internal validity, external validity, reliability and objectivity. However, for qualitative research these conventional criteria were not appropriate. Lincoln and Guba (1985), in refuting charges that naturalistic or constructivist inquiry is “sloppy”, “soft” or “merely subjective observation,” offered alternative criteria for determining trustworthiness: prolonged engagement, persistent observation, triangulation, negative case searches, referential adequacy, member checks, thick descriptions, peer debriefing, feedback, and re-negotiations. I believe my research was trustworthy because the research design incorporated prolonged engagement, inclusive of persistent observation. I also utilized the participants’ perspectives on the generation of themes thus incorporating member checks, peer debriefing and re-negotiation. However, I believe trustworthiness involves more than a set of procedures. Ely (1991) offered an alternative to establishing trustworthiness.

Being trustworthy as a qualitative researcher means at the least that the processes of the research are carried out fairly, that the products represent as closely as possible the experiences of the people who are studied. The entire endeavor must be grounded in ethical principles about how data are collected and analyzed, how one’s own assumptions and conclusions are checked, how participants are involved, and how results are communicated. Trustworthiness is, thus, more than a set of procedures. To my mind, it is a personal belief system that shapes the procedures in process. (Ely, 1991, p. 93)

While research endeavors are never perfect, I believe that this research reflected the principles espoused by Ely. I attempted to assess and confront my own assumptions and conclusions by actively involving the participants.

Additionally, upon completion of the participants' story, I met with each participant individually to review the story in the attempt to ensure that I remained trustworthy in developing their case. I also believed that ethically I could not simply leave "the field", as this would violate the participants' trust in our relationship. Thus, from the onset of the research, I informed the participants that if they wished to continue the conversations after data collection was completed at the end of the fall term that I would be willing to continue meeting.

In presenting the information to the reader there was a need to develop an organized system in order to reference properly the individual and group dialogues, thus, the following format was used. If the quote occurred during an individual session then the first letter of the individual was used followed by the number that corresponded with either the first, second or third interview. The number after the colon represented the line number for easy reference. For example, a quote by Helen in the first interview would be represented as H1: 1000, or in the third conversation as H3: 3000. To represent the group conversations, "GP" was used. Again the number following the letters indicate whether the comments were spoken in the first, second or third group conversation.

Next, I will present each participant's story. Understanding that by attempting to provide a story that captures the emotions, beliefs and perceptions of the participants, I would have to confront my own biases. Each story presents information that the participants felt important to reveal regarding their experiences with a hidden disability, both personal and public, disability identity and the impact

of having a hidden disability in an educational setting.

CHAPTER 4: PARTICIPANTS' STORIES

My intent in this study was to co-investigate the phenomenon of disability identity. Below I have provided information on each of the participants as we investigated the issues of identity and disability. Obviously, this summary of information was only a small window into the participant's lives, as identity development is multifaceted and separating out one strand of one's identity does not provide the full story. My goal was to maintain the integrity of the participants' voices and their stories. As such, I have attempted to follow the progression of their wrestling with the concept of identity, while recognizing the influence the framework of the questions, and of my lenses in interpreting their responses. Their stories were further limited by the written word, which negated the dynamic interchange of our conversations, individual growth, and understanding.

Each participant's story was divided into two sections. In the first section, I presented the students using their voices, understanding that their story was filtered through my eyes on the issues of identity. As issues of identity were also revealed in the interaction with others, disclosure and perhaps using accommodations, I included these topics in the stories. The second section focused on issues that would better inform my own praxis. Specifically, the issues I am interested in were

1. How does the presence or absence of having a community affect identity development?
2. How could CSSA professionals assist students with integration

into the university community? 3. What social and institutional changes would foster this integration?

Jill

“It’s like everything else I had ever done; if I work hard enough, I’ll be fine” (J1: 1074).

Jill is twenty years old and is a junior majoring in general science. She is the eldest of two girls and is the only one in her family diagnosed with a disability. In speaking about her family, Jill stated that her family was very close, and that “my parents really protect me, they really take care of me” (J1: 1012). Jill indicated that her support systems are her family and her boyfriend. However, it should be noted that Jill’s boyfriend does not live in the same state, and therefore, she had limited opportunity to see him. Jill was working 20 hours a week in a group home where she is paid a small stipend, room and board. She indicated that she does not participate in other student activities at the university as her time is divided between work and school. At the time of data collection, Jill was concerned about her grades. She stated that she was very hard on herself. She also questioned why she was struggling in college. Jill started the research process with enthusiasm. However, as time wore on, she became more withdrawn. In the first group conversation she actively participated; in the second group conversation she rarely engaged in the discussion. Unfortunately Jill did not show up for the third

group conversation. In the second and third individual conversations, she expressed frustration about the process and believed that things were over analyzed.

Jill was diagnosed at the age of two with Cerebral Palsy (CP). She classified her CP as somewhat severe, although the CP appears to mildly impact her walking and does not present a visible disability. She has a second disability as well, but she classified her learning disability as not severe. Her learning disability was related to processing speed. The disability affects how quickly she can grasp new material, take notes and perform on timed exams. It should be noted that while Jill classified the CP as more severe than her learning disability, the learning disability appeared to be affecting her more in higher education.

Jill easily talked about having CP and stated that having CP had “never been an issue, it’s never, it’s always been just who I am. It’s not a problem, it’s not a disability, it’s just me” (J1: 1031). However, the experiences she selected to share, and the tone in which she conveyed her story leads me to believe that the disability has been more of an emotional issue than her words indicate. She was sarcastic about other family members who had difficulties accepting the disability when she was born. Jill stated that some of her relatives refused to go to the hospital “because they knew I was going to die anyway, so they wouldn’t come and see me” (J1: 1101). She also revealed that relatives told her parents that they “should just let me die, and if I didn’t die, then I needed to be put into a retarded person’s home, like immediately. They shouldn’t even take me home, because why take home something so bad” (J1: 1111). The perceptions and attitudes of family

members revealed a message of being less than, “bad” or abnormal. Jill cognitively wrestled with those messages and ultimately, discounted the messengers. She stated that the family members who made these comments could “go to hell” and that they had lost credibility within the family.

Jill’s struggle with reconciling the negative family messages continued as she negotiated negative societal messages. She stated that there had only been a couple of times that she felt the CP had been an issue. One example pertained to an experience within physical education in the fourth grade. As she was not able to complete the required one-mile run in a time similar to others, she was made to complete the mile on her own while the other students were dismissed. After her parents objected, Jill stated that the teacher “made me sit out, like, sit on the stage in the gym and not play ‘cause I was lazy” (J1: 1131). The issue of being perceived as lazy or not working hard enough was of concern to Jill and was echoed often in her story. The second example also pertained to not being athletic, but moved beyond the physical condition to influencing her interactions with others on the playground.

Recess, it would suck because I couldn’t play as much and I didn’t get picked for, like, games. I was too slow or sucked at it and they wanted to run so I didn’t get picked and [pause] there’s where I think I didn’t have as many friends either, because it’s like the social groups, you could tell that, she was not as good as everyone else. So, I think I had problems with that, but I didn’t look at it as being like, [pause] my disability was the problem, but people just knew something was wrong. I’m just not a good person to be friends with or something. (J1: 1039).

It was interesting to note that the interpretation of not being picked for lack of athleticism had moved to an internalization of not being a good person. For Jill, this internalization of “not being good enough” was another theme throughout her story. As Jill had difficulties with incorporating a more visible, medically recognizable disability into her identity, a hidden disability, such as her learning disability, presented even more angst for her. Due to not having any difficulties with learning throughout primary and secondary education, Jill was not diagnosed with a learning disability until the age of nineteen, when she was a freshman in college. Regarding the testing, Jill stated:

I didn't want to [get tested]. Because I didn't want to admit there was something wrong with me. Because there's never, [pause] it's never, [pause] CP isn't an issue. So, there's some other issues, and I know that the learning disability is directly related to the CP; I'm positive. And so I didn't want to go and say, [pause] I didn't know if I could admit disease, there's something wrong now. I mean surgery, having surgery because of my CP, it still wasn't because of CP, in my own brain it was just something that had to be done, it was never related to disability in my head, it's one of those things I do, it's just part of my life. But then the learning disability was like [pause], I worked my ass off my whole life, and tried really hard to be normal and keep stuff out of it, and then all of a sudden having to go and say “okay, I need help or I'm not going to make it through college.” Studying wouldn't do it. It would be just like, I'm going to struggle and I'm going to make it through it. It was like everything else I had ever done; if I work hard enough, I'll be fine. (J1: 1065)

It was challenging to observe Jill's wrestling with this facet of her identity. Jill's story was powerful in that she did not view herself as having a disability or necessarily being influenced by the disability, yet the stories that she selected to share all dealt with how she struggled with the perceptions and actions of others.

Words such as “disease”, “normal”, and “overcoming”, may reflect her beliefs about having a disability. These beliefs, shaped by societal messages and her personal encounters with others, influenced Jill’s identity development.

In Jill’s story, the need to separate the disability from her identity became understandable given her history and the encounters in her life. What was intriguing about Jill’s story was the two types of disabilities: the CP and the learning disability. It appeared that she was more at ease in discussing the CP than the learning disability. When first asked about the impact of the disabilities, she stated that the CP had “to an extent changed my life, it’s who I am and I wouldn’t change who I am” (J1: 1054). But later in the conversation in response to whether or not she identified with having a disability, she replied that she did not. “No, I don’t identify, like, I don’t have a disability. I mean, like, I have CP, but what’s the definition of disability? What’s my definition?” (J1: 1252). In this conversation, Jill focused on the CP and did not mention the learning disability. In the second individual conversation, Jill provided more information on the struggle between the functional impact of the physical disability, the cognitive recognition of having a physical disability and the emotional toll of denying the functional impact.

Like, instead of saying it’s because I have a disability, I say, “No, it’s because I’m not good enough”. So I don’t think I relate it to having a disability. I admit I have a disability, I go around telling people, but any shortcomings are not related to my disability, in my head. I mean, I know logically they most likely are, but like in my head, most of the time I just say, “no, it’s just because I am not good enough”. Which just kind of [pause], I do a number on my self-esteem. (J2: 2075)

It was interesting to note the differences in her responses. In the first conversation, she stated that she did not identify with having a disability; in the second conversation, she admitted to having a disability, and informs others about her disability. However, she denied any correlation between her disabilities and the educational difficulties she was experiencing. Later in the second interview, Jill provided more information on how she would identify with having a disability and that the identification was dependent on the situation. When asked to explain the types of situations, she replied with an example about going to Shriner's Hospital for surgery, and that when people look at her feet she could identify why she walks or runs differently. For Jill, having something tangible to support that she had a disability appeared to be important. Perhaps being able to point to her feet as indicative of having a physical disability was why Jill was having such a difficult time with accepting a learning disability.

I want someone to prove to me what's wrong. Like I remember when I took that test from that guy. I did the best I could, but who says he's right? You know. [pause] I want someone to scientifically scoop my brain out and someone to say, "look these two don't connect and look, these two are going backward" [laugh]. I'm so hard on myself that it's hard for me to accept that, [pause] that someone writes on a piece of paper, [pause] that, I don't know what it said, blah, blah, blah. Here's what I recommend, and all of a sudden, TA DA! I'm getting testing and notes, all because of one guy. (J2: 2227)

Jill's doubt about having a learning disability was complicated due to the fact that she was not diagnosed early in her education, and thus questions the validity of the testing. Additionally, if she continued to doubt the validity of the

testing, then there were only two options left to explain why she was struggling with grades. Either she was not working hard enough, or she cannot compete academically at the university level. In the third individual interview, Jill again expressed a separation from cognitively recognizing the disabilities, but that the recognition does not impact her own personal, emotional wrestling with a disability identity.

I mean, I could be an advocate for SSD and talk to all the freshmen and incoming transfer students that you want, and be like, 'Yeah, I have a disability and I'm okay with that'. You know what I mean? But for me personally, [pause] what goes on in my mind and my heart is completely separate from that. [pause] So I mean I feel like I could do a good job of representing the program or something, but as for myself having to think about my own personal stuff, it's just nobody's business but my own, and I could, just, like, kind of push that aside. (J3: 3191)

I found it interesting that, on one hand, she believed that she could be a role model for incoming students with disability, yet at the same time indicated that she was not comfortable with her disability and identity. Even more interesting was the recognition that, while she oscillated between accepting and denying the impacts of the disabilities, she acknowledged how the disability had been beneficial. She felt confident that her experiences with CP had made her a more compassionate person.

It's just easier for me to be more compassionate than most people I think because of the stuff that I've been through. And my encounters with people. Completely normal people, completely disabled people, completely psychologically messed up people, I mean I've just been around everybody (J1: 1093).

Jill's story reflected the struggle to keep the disability separate from her identity. On one hand, she does not identify as having a disability, nor has the

disability been an issue. On the other hand, it defines who she is, and had allowed her to be more empathetic with others. What was interesting to note was the change in her response related to the CP, and that she did identify with having a disability, but only in certain situations. But having a learning disability in higher education could be considered as a specific situation. Higher education values time. Time, coupled with a processing speed deficit, produced the same effect as when she needed more time to complete the one-mile run in the fourth grade. Perhaps the experience of being perceived as lazy had contributed to her strong work ethic.

Jill's strong work ethic coupled with her perception of lack of performance, appeared to take a toll on her confidence that she could be successful. Her performance in college was a 2.7 GPA, which was not on par with the 3.5 GPA in high school, and was a source of stress and anxiety, as academic success is part of her identity.

Because my academics have been, what has defined me and what has been, like, such a huge part of my identity. I was involved in everything and I did everything in high school, middle school, and grade school. I didn't have a lot of friends, but I was involved and I had a lot of fun [pause]. Because I was involved and I had really good grades, and my parents were, "you've got good grades," and my sister got bad grades." And so I identified myself with the grades that I got, and the fact that I was in upper level classes and the top 25% of my class, and now I'm, umm, [pause] I'm holding my breath to get through this shit, which doesn't make sense to me. (J2: 2170)

In trying to meet her own expectations, she had withdrawn from all extracurricular activities other than her job. "I'm not involved in jack, and I don't

have a good social life and my GPA is still crap, and I still work my ass off for my grades, and I still don't get anywhere. So it's like I'm working my ass off for nothing sometimes" (J1: 1204). Jill was so focused on obtaining grades as part of her identity that she was isolating herself in the process. Thus, she limited her opportunities to build support systems or find other activities in which she could be successful. Jill implied that her anxiety had increased since coming to college, and that she was now on medication. Jill also experienced additional anxiety when she was required to disclose her disability in order to receive services. Although she appeared more at ease with disclosing that she had CP, having to disclose a learning disability, which she had difficulties in accepting, resulted in inconsistent responses. In discussing how disclosure of the disability impacted her, Jill indicated that "for the most part, it doesn't matter who knows because I'm okay with myself and what I'm doing, anybody else can think what they want, and kiss my ass, for the most part (GP1: 1341). However, her next sentence belied that bravado. "It hurts my feelings sometimes, but I get over it" (GP1: 1343).

Jill's oscillation between being okay with who she is, to bravado of not caring about how others perceive her, to admitting that their perceptions hurt her feelings, was indicative of the struggle with melding the disability into her identity. The complexity of emotions that occurred each time she disclosed. Disclosure was not only difficult because of her own emotions, it also meant that she had to deal with the attitudes and stereotypes of other individuals. Jill provided an example of a note taker who was condescending toward her and believed that she was in need

of her help beyond the notes. In fact, when the professor expressed he wanted to speak with Jill, the note taker asked Jill if she wanted her to come with her to meet the professor. Jill was angry that the note taker believed that she needed this type of support and wished the note taker had never known she had a disability.

As disclosure was a difficult process for Jill, so, too, was using services. It appeared that Jill wrestled with using services, as she wondered if the problem with school was really due to a disability, or due to her perception that she was not working hard enough. "...the attitude that if I take services, I might not be working hard enough or I might not deserve it as much as everyone else does as far as deserving my diploma (J1: 1158). She was also upset with herself when she does use services. "I am just pissed at myself because I need to not have note takers and I need to not take tests [with additional time]" (J1: 1203). In the second individual conversation, she again alluded to the use of services as a possible indicator that she was not working hard enough. "I think I just need to work harder, take a tape, a tape recorder, write faster, I don't need a note taker in this class, I just need to stay focused" (J2: 2114). Ultimately, the use of services was equated with doing less, or some how diminished the accomplishment of the degree. "I don't want to feel like my degree is less. That's it, and that's my issue. I don't want to graduate and be thinking that I didn't work as hard as everybody else is (J1: 1262).

In terms of identity, Jill does not identify with having a disability, especially difficult to accept was the learning disability. She also experienced difficulties with using services. However, in terms of disclosure, Jill expressed that she had no

problems with telling other individuals that she had a disability. The problem arose when she was forced to disclose in order to receive an accommodation. Jill's difficulties with accepting the hidden disability and using accommodations indicated that she was still struggling with melding the disability into her identity. One aspect of identity development, specifically as it related to other minority identity development was the concept of community, and the need for immersion into a community as part of the process of finding value in self. In the first individual interview, I asked Jill, if she felt any isolation because of a hidden disability. She replied "yes". I then asked if she had any strategies that would help students not feel so isolated. She responded,

I think it's really psychological. There's not something you could do like 'make a friend with a disability student connection week'. I mean, and it's not even like [pause], it's not public awareness. We're different. It's hard to see my disability as [pause], like everyone has a disability, but it's hard, it would be easier if a disability was something that everyone had. I think that's the only way to stop the segregation. Disability does have a difference and disability does change you from normal. (J1: 1273).

I found her comments regarding that disability does indicate difference perplexing, especially as much of her story centers on being normal, not different. But yet, she still did not respond to whether or not, because of isolation, she would participate in a university recognized student group or community. In the first group conversation, I asked about the possibility of meeting others with disabilities and seeing if there would be any benefit from doing so: finding common ground. Jill's response appeared to me to be skeptical. "If you'd identify yourself with it.

Hey, I'm an individual with a disability, and I need someone else with a disability to relate with (laugh). Tests are hard, and I can relate with anyone that the test sucked, or I can relate with anyone that the class sucks..."(GP1: 1107).

In the second group conversation, I introduced the concept of having a safe place to go, a place where having a disability was accepted and disability issues were freely discussed, a disability community, or for lack of a better term: a disability cultural center. Jill's response was a flat "I wouldn't go" (GP: 2943). Later, she stated "You can talk to someone at the psychological services, but I wouldn't want to talk to a group meeting about the 14 hours I spent on my test" (GP2: 2948). I attempted to clarify to the group that I was not discussing group therapy, but rather, envisioning a place to meet with other people with disabilities, and that perhaps this experience might be beneficial in reducing the isolation that the participants appeared to be experiencing. Unfortunately, Jill did not join in the remainder of that conversation. Jill did not show up for the third group conversation. In the third individual conversation, I asked if the opportunity to discuss issues with other students with disabilities was as helpful as it appeared to be for the other students. Jill's response was "I think actually thinking about the disability stuff actually lowered my confidence level" (J3: 3134). She went on to say how listening to others talk about the challenges with disabilities was not helpful. "...for the most part I just was like, why sit in here, and talk about how life sucks, how difficult it is to have a disability, I don't know, they just didn't come out with anything positive" (J3: 3136).

Jill appeared to believe that there would be no value in having some place on campus that was designated as a disability community. With respect to what the CSSA professions could do to facilitate the transition into and out of the university, Jill replied that she did not know. But she did impart that the Services for Students with Disabilities office was, for the most part, doing a great job as far as accommodating people. With respect to what institutional and societal changes would need to occur to foster integration, Jill could not think of a response.

Luke

At times...I would think of my disability as a blessing in disguise, and at other times, I would think of it as the worst thing ever (L3: 3245)

Luke is twenty years old and a sophomore majoring in Engineering. He has two older sisters and one younger sister and is the only one diagnosed with a disability in his family. He stated that his family was very close and supportive. He also mentioned the support of his extended family, cousins, uncles, aunts, and grandparents. Luke was actively involved in the cycling club at the university and had participated in mountain bike racing in the past. He found value in being an athlete and hoped to participate in intercollegiate competition soon. At the time of the data collection, Luke was concerned about his performance in school, and it appeared to be affecting his self-esteem.

Luke was diagnosed with learning disabilities in kindergarten and with ADHD in third grade. He classified his learning disabilities as very severe and his

ADHD as moderately severe. Luke's learning disability was a receptive and expressive language disability. The disability affected reading, writing, and verbal expression. Luke believed that his ADHD was affecting his performance more so than the learning disabilities as he was having difficulties with being motivated to study and complete his homework assignments in a timely manner. Organizational difficulties and completing daily tasks are often a concern for students diagnosed with ADHD. It appeared that Luke was placed on medication in grade school to control for the difficulties with attention. However, he discontinued the medication after a year due to negative side effects. Recently he tried medication again due to his performance at the university, but he had such a negative reaction, resulting in a seizure, that he discontinued the medication.

Although Luke did not indicate his struggles with expressing himself verbally, this facet of his learning disability did have implications for the research process, creating a challenge unique to this story. At the end of the first conversation, Luke stated that the process was difficult because his mind was whirling with information that he could not express (L1: 1253). There was often silence as Luke struggled to find the word that would express his ideas. This difficulty was evident throughout the individual conversations as well as the group conversations. Luke's quotes were edited to allow for space consideration, and for an easier reading of his story. Small pauses have been denoted as [pause] while long periods of silence have been indicated as [silence].

Luke was from a small agricultural community, and his early educational experience was one of support. Luke remembered being pulled out of regular education classes to attend special classes concentrating on specific skills such as writing, reading, and speech. Luke was not aware that he was placed on an individual education plan (IEP) until high school. He did utilize the Learning Resource Center (LRC) if he needed more time on the exam, or someone to read the exam to him. Luke's parents were actively involved in providing informal accommodations such as reading his textbooks to him, helping him study for an exam, as well as helping him with his homework.

When asked about experiences with his peers and using the LRC Luke stated,

Yeah, that's [pause] I remember, umm, some of the students they would kind of poke fun of that, [pause] of that, umm, class and like people in there. Umm, most of the time I didn't really take much offense to it. I thought, [pause] umm, that, just thought it was silly to think, umm, just, [pause], kinda, some of them would think that they weren't so smart, or something like that, umm, but, there were smart kids in there. (L3: 3053)

Although Luke believed that there were smart kids in the class, he implied that he never felt like he belonged in the LRC. He considered himself an outsider (L3: 3043). The difficulties stemmed from being perceived as smart, but needing assistance due to the disability, as if intelligence was negated by the presence of the disability. "I was viewed as one of the smarter kids in the class. I don't know, sometimes that was a little confusing, because, umm, you know, you're viewed as being really smart, but you had great difficulty with reading and writing, so that

was a really confusing time (GP2: 2805). This dichotomy, being intelligent and having a disability, provided insights into the complexity of disability identity, especially when being intelligent is valued and any difficulties with learning are not.

Another dilemma for Luke was the realization that his disability may affect him beyond the educational environment. Luke revealed an experience that was difficult for him and challenged how he perceived himself. The experience pertained to completing a job application, and the way his disability affected that process which left him with the impression that he may not be able to achieve independence.

I would have to say, umm, [pause], umm, like, a lot of my self-perceptions that I have had, umm, basically, umm the same throughout the years. One of the things, [pause], like the last year I realize, that umm, I can't be as independent, umm not totally independent. [silence] I have to, [pause] I have to have some help with things, [pause], like things, like, I don't know [silence]. Umm, like this summer applying for jobs, going to work, that was one thing that that was intimidating, writing down a job application because I was worried about my spelling and grammar and writing in general. You know, like when they look at the job application, umm, [pause] when they look, [pause], that is, what they are perceiving, what kind of person you are and umm, that, umm, like spelling errors on the job application, and, umm, so, I don't know, that was kind of a little hard to take, umm, I want to be fully independent, like, I don't know, it's [silence]. (L1: 1083)

Luke struggled with the telling of this experience, and it appeared that this realization that he may not be as independent as he would like due to the disability, was of significant concern. In listening to Luke, he appeared to be very conscious of the learning disabilities, struggling with how he was perceived by others and

how he viewed himself. The struggle with communications, in addition to the realization that he was smart, yet frustrated at not being able to study and complete homework assignments, was taking a toll on his self-esteem. This was especially true when he reviewed his history of academic success compared with his current level of achievement. Luke was struggling to find strategies that would work for higher education.

I could say I either lost it, or haven't really found it yet for a college situation. Umm, like in grade school and high school and stuff like that, umm, I did fairly well, umm, and I guess you say that dealing with thing, doing, like work, and steps and stuff, I don't know, [silence]. I haven't really had a fully successful term here yet, and I'm trying to figure out how to do that. (L2: 2129)

It should be noted that fall term was Luke's fourth term at the university.

While he was not close to suspension, he had withdrawn from several classes and often completed less than twelve credits per term. Luke was beginning to evaluate his decision to stay at the university.

When asked if disability was part of his identity, Luke stated in the first individual conversation that his learning disability helped to define him (L1: 116). When asked how it defined him, Luke replied "Well, (silence), I don't know. Like, umm, I say, [pause] this is hard" (L1: 1120). Luke was not able to articulate what he meant about how the learning disability defined him. In the first group conversation, when asked if individuals had a disability identity, Luke did not state "yes" or "no," rather he responded that it was a part of him, but he did not really think of how he learned as a disability. Luke stated:

Umm, I don't know. I, umm, well, I was diagnosed when I was real young and so I spent most of my life knowing that, I guess you'd say, like, I learn differently than most everybody else, umm, but I usually get what I'm learning, what I'm suppose to be learning. And, umm, [pause] I don't really think much of the disability. It's just something that's, [pause] that, umm, I have that's different than most everybody else" (GP1: 1702).

I found it interesting that in the first conversation, he said that his disability defined him, yet in a group setting, he stated that he does not really think of how he learns as a disability. But I believe that he is beginning to think more about the functional impact of disability, which might be why his responses to this question were conflicting. In the second group conversation Luke did not actively participate in the discussion. In the second individual conversation, Luke again had difficulties with responding as to whether or not disability was part of his identity. It was in the third individual conversation that Luke articulated that disability was part of his identity but that, at times, it was difficult to accept. "I guess you could say that I do recognize myself with a disability, but at times, I don't like to, like it or like to, umm, but I do know that's a part of me, and it's actually a big part of me, it's kind of helped shaped my life" (L3: 3235). There appeared to be some movement in Luke's awareness that the disability was part of his identity. Perhaps Luke's struggle with incorporating the disability into his identity was revealed in his description of how he viewed his disabilities. When asked how he viewed his disabilities, he replied, "as a blessing and a burden" (L3: 3245). He indicated that the "burden" part of his disability was in organization. Accomplishing the day-to-day tasks that need to be completed; sitting down to study, starting a writing

assignment, or expressing his ideas, was extremely difficult. Obviously, this area of his disability had significant impact on academic performance.

The blessing for Luke was that the disabilities made him think about things differently. "... approaching problems differently, and I guess finding ways to approach problems other than a conventional way, I guess you could say, and, I don't know, it sometimes does manage, [silence] it's rewarding to know that you come through and solve the problem in a non-conventional way than what everybody else has done. And solving that is kind of rewarding. (L3: 3326). Perhaps, the blessings of the disability were diminished in the higher education environment because the burden part of his disability substantially affected his performance. As in the summary of Jill, Luke was struggling with melding a disability into his identity. On one hand, the disability defined and shaped him, yet on the other hand he does not perceive the way he learns as a disability. As Luke struggled with understanding the disability and the functional implications on his life, he experienced difficulties with disclosing his disability and utilizing services.

Because Luke's community was small, the fact that he had learning disabilities was common knowledge. "Well, I come from a really small town, so most people already knew my parents so, like some of my teachers knew me quite well personally, beforehand. I think that made a difference if I didn't understand in class like my different needs and stuff" (L1: 1038). Consequently, when Luke arrived at OSU, he did not have much experience discussing his disability. In the conversations, having to speak to others about his disabilities was uncomfortable.

“Back home, the people that you were around, knew your history and knew your background, and so, umm, a lot of times they would judge you on that, you know, first impression and that kind of stuff” (L3: 3096).

Coming to a new environment, Luke was more aware of his difficulties with communications. He expressed concerns about how others interpreted his language difficulties, and he did not want to be viewed as less intelligent.

I guess you could say I still have problems in that and [sigh]
[silence]. I don't know, I feel like, I could probably, umm [silence].
I don't know, I mean, umm, I guess I have difficulties trying to
overcome that, [pause] overcome the difficulties of expressing
yourself, and umm, [pause] viewing myself as, umm, well, I just
want to not worry about, umm, what, if I, umm, what I say [sigh].
(L2: 2272)

His concern regarding how others, who do not know his background, would perceive him made it difficult to speak to faculty. “...and then like talking to a professor or something, and they don't really know, like, who you are and much of your identity or anything like that, you're judged by what, umm, how you present, umm, I mean just talking to them when you first meet them and, I don't know, it's a little intimidating...” (L3: 3107). However, when discussing disclosure to his friends, Luke stated that he does not have difficulties with disclosing to them, nor does it appear to bother him to answer other students' questions as to where he was during a test or why he had a note taker. It was understandable why he would feel comfortable in speaking to his friends about his disabilities as they had already come to know him and perhaps were not as likely to judge him. It was interesting to note that he was comfortable with answering other students' questions about the

services he received from the SSD office. Luke also implied that he was not bothered about others perceptions of why he needed services. However, Luke's assertion that he had no difficulties with disclosing to other students was perplexing when he discussed how difficult it was to ask another student to be a note taker.

Luke compared asking someone to take notes as being similar to asking the professor to assist with alternative testing. When asked about the differences in how comfortable he was in disclosing to some and not to others, he stated that it had to do with not wanting to feel he was a burden to others. "Like I talked about, umm, like they're going out of their way for me, and I don't know, [pause], sometimes I feel that can be like, umm, a disadvantage, umm, like, [pause], I usually don't like to ask people for help and stuff like that" (L2: 2184). In the second group conversation, Luke again expressed this concern. "For me what's hardest, umm, is knowing that you're going to put all the responsibility on someone and so you're asking someone to, umm, for a lot of responsibility to take notes for you..." (GP2: 2593). In addition to not wanting to feel like he is a burden to someone else, Luke also appeared to be struggling with the need to use services and trying to maintain societal standards.

I hold myself up to the same standards as other people in terms of, [pause] I guess, [pause], like you know, I should get this done in the same amount of time or, umm, it should come to me as easy as it does to other people [silence]. I guess you could say that I should do as well as other people, but a lot of times that's frustrating. Because to realize that also, it's a whole lot harder to reach that standard..." (L3: 3162).

The need to maintain standards, lack of both motivation and organizational skills, coupled with difficulties in communications appeared to impact Luke's participation in working with other students in his classes to understand the material. In most cases, Luke studied alone. Additionally, when the group discussed the amount of time needed to learn new material, Luke agreed that his disability had turned him into a hermit (GP3: 3186). To a certain extent, Luke appeared to experience isolation from his peers in the academic arena, but attempted to maintain more of a social connection through his participation in the cycling club.

Luke's story revealed an individual who was struggling with his perceived lack of success in higher education, while knowing he was intelligent. Additionally, the impact of this disability on how he might be perceived by others was a source of concern. Luke did not appear to have difficulties with disclosing a disability to others, unless the reason for the disclosure was to receive accommodations. Much of Luke's angst appeared to be connected to his concern that the functional impact of his disability may hamper his ability to achieve the societal values of independence and self-reliance. In terms of identity, Luke does not embrace the label of disability, but rather perceived the disability as a learning style. He experienced a feeling of shame or being a burden when he used accommodation. With respect to disclosure, Luke did not have any difficulties with disclosing to friends. The problems arose when he had to disclose in order to receive services.

In the second group conversation, I introduced the concept of having a safe place to go, a place where having a disability was accepted and disability issues were freely discussed, a disability community, or for lack of a better term: a disability cultural center. With respect to the issue of community or center, Luke did not participate in that part of the conversation. It was during the second individual conversation that Luke addressed the question of whether or not having a community would be of value. He responded, “I don’t know, [sigh], I’m not sure, but [silence], probably not. I mean, yeah, it’s great, [pause] it depends on the person, but not for me. I don’t know, [pause], yeah, I can’t see how that would be beneficial for me “ (L2: 2292). In the third group conversation, when the group was discussing the issues again, Luke suggested that he thought there would be reluctance to going to the community or a center for persons with disabilities because it would be difficult to be out and open about the disability (GP3: 3539). It was in the third individual conversation that Luke appeared to have changed his opinion on the value of having a community. Part of this change may be a result of the research, which provided him the first opportunity to discuss disability issues with other students with disabilities.

Well, I think it’s also helped that, umm, we were sitting there talking about, [pause], realizing that it was nice, you know. Getting that type of stuff out in the open and talking more about your disability, [pause], talking with other people, I’m just realizing that that’s helped. And, umm, as you go through that, umm, [pause] I guess you could say at the beginning, I had a real hesitance, [pause], still trying to hide from that, umm, [silence]. And umm I guess you could say that I was feeling very isolated and that type of stuff,

going to a place where people know you and identify with you, it definitely would be helpful (L3: 3276)

Thus, it appeared that Luke had moved from his original position of not finding value in having a community to one that he would find value in having a community. In discussing what college student services professionals could do, Luke agreed with the group conversation of having an Odyssey class for student's with disabilities. Regarding what social and institutional changes could foster students' integration into the university, he did not participate in the group conversation on that topic, nor did he have any comments in the last individual conversation.

George

I don't think of myself as having a disability. It's just how I learn (G1: 1162)

George is thirty-five years old and a sophomore majoring in Engineering. He indicated that he had a great family life and that his parents tried to do everything they could to help in a positive way. His support systems are his family and his wife. Beginning fall term 2001, he quit his job so he could focus on school full time. He indicated that he does not participate in other student activities at the university as he spent most of his time studying. Even though he spends considerable amount of time studying, he does manage to volunteer some of his time with the Boy Scouts as well as ensure that he enjoys quality time with his wife. At the time of the data collection, George was not concerned about his

grades. However, George acknowledged that his grades do not accurately reflect his knowledge of the material. George was engaged in the interview process throughout and offered a different perspective from the previous two cases.

George was diagnosed with a learning disability, communication disorder (stuttering) and ADHD in the first grade. He classified his learning disability as moderately severe. George's learning disability affected reading and processing speed. His accommodations were textbooks on tape, note takers and extended time on exams. With respect to the ADHD, George does not believe this diagnosis was a factor at this time. When he was first diagnosed with ADHD, he was placed on Ritalin but because he experienced side effects, his mother took him off the medication and placed him on the Feingold diet, which eliminated sugar, food dye and other unnatural ingredients from his diet. George testified that this diet worked well for him, and that to this day, he attempts to eat mainly organic foods while limiting his intake of processed foods. His difficulties with stuttering were also no longer a problem.

It appeared that George experienced difficulties in learning and interacting with his peers beginning in the first grade. When asked if the disabilities had an impact on him growing up, he stated.

Oh, I definitely think so. Because some people, [pause], like I had friends, some people didn't really care. I was just somebody else and they treated you fine, but some people treated you like you were dumb, or you just weren't a smart person. And you were the outcast. Also partially because of the ADD and the communication, I used to stutter really bad; a lot of times I couldn't get the words

out, so there was definitely a break in communications involved in that.
(G1: 1022)

Although George stated that he does not have a lot of memory about that time in his life, he mentioned several times throughout the individual interviews that by having the disabilities, he felt that others did not perceive him as being intelligent.

I remember being teased about the stuttering, and people thought I wasn't very smart because I couldn't talk, because I was stuttering instead of talking. [pause] That kind of thing. So it went along with the [pause], and who knows how interrelated they are and what causes and effects they had on each other, but besides the other reading problems I had, which again are either interconnected or not interconnected, umm, you know, at least my perception I had from some of my peers is that they thought I was dumb. (G2: 2058)

George indicated that throughout elementary and secondary education he did not perform well academically. After high school, he attempted community college, but he quit due to academic difficulties. Because of his difficulties with education, he entered the work force where, through a variety of jobs, he proved that he could be successful. In his last position, George was a fleet supervisor who managed the ownership and maintenance of state publicly-owned vehicles for a local city. Having performed well in this position as well as others, he developed a level of confidence that is not evident in the previous two cases.

Well, I think I'm a very confident person. Umm, I used to be very unconfident and I gained confidence probably through lots of different ways. Having a good childhood and good parents; doing lots of different things in my life and being successful and overcoming my disability in everything I've tried to do, which now includes going back to college and getting my degree. So, I think I exude confidence. And I actually think people wouldn't interpret someone having a learning disability as being confident. (G1: 1065)

There were a number of interesting messages that appeared in the above quote, such as overcoming the disability and the perception that others would believe that confidence and learning disabilities were mutually exclusive. George also stated that he had not always had confidence in his abilities and that perhaps this lack of confidence stemmed from his struggles with the educational system. In reflecting back on his disability, George indicated that perhaps his age does play a part on how he perceived his disability.

I think ten years ago, I was a confident person, but I wasn't a confident person in the same way that I am today, and I don't think I would treat the disabilities the same as I do now, in telling people and getting services. I think that I would be a lot more nervous and secretive about it than, even than I am now (G2: 2147).

As George continued discussing his disability, he disclosed that, prior to his success in the work place, he viewed himself as being mentally unhealthy because of dealing with the impact of the disability and others' perceptions about people with disabilities. "...maybe 15 years ago I probably was a lot less stable as far as being comfortable about my disabilities, and worried about what people thought" (G2: 2410). It was interesting to hear about his perceptions of when he was younger and dealing with disabilities issues compared to where he is today. It appeared that maturity might affect acceptance of the disability.

In discussing his decision to go back to school, it became apparent that the emotions he wrestled with as a child regarding his learning disability resurfaced. George revealed his emotions about returning to an educational environment when he stated:

Scared, scared that I wasn't going to be able to do it. You know. But I didn't do very well in school, really, and then after school, I tried community college for a year and I did really bad. So I was scared to come back, wondering how people would treat me if I approached them with having learning problems and wanting help and just afraid that I was possibly going to fail (pause). Definitely a lot of doubt. I was confident in myself, I knew if I wanted to do it, I'm sure I could, but not sure what obstacles I was going to run up against or maybe if I really could or not. (G1: 1218)

It was interesting to note that while George indicated self-confidence in ability, he also revealed self-doubt as he returned to an environment that was not conducive to his learning style. Reconciling his ability to be successful in work and unsuccessful in education had been difficult process. Thus, it was not surprising how George responded to the question of disability identity.

In response to whether or not he identified with having a disability, George stated that he does not. "I guess I don't think of my disability as part of my identity, just because, I guess, because it's been part of me forever, I don't even think about it, does that make sense?" (G1: 1156). "Even when I'm reading a textbook; getting books on tape, I don't think of myself as having a disability" (G1: 1162). In the first group interview George reiterated that he did not believe he had a disability. "I think I'm smart in general, as anyone else, we're all smart people, and so I don't consider I have a disability" (GP1: 1606). As with Luke, George had difficulties with reconciling that he was intelligent with societal messages that individuals with learning disabilities are not intelligent. I also found it interesting that something that had been a part of who you were, had shaped how you respond to the world, was not viewed as part of your identity. But by the second individual

conversation, George began to evaluate his learning disability and the societal label, disability.

I identify as having a disability maybe in the definition of a disability, because I am different than the norm as far as my reading ability and spelling, my basic nonverbal language issues [pause]. I don't know exactly how they define my disability, and I'd probably disagree with how they define it if I knew how they defined it. But, you know, I think it's a hard thing to define. But so I think if you are talking about comparing me to the norm, I would say I have a disability, but I also think in some cases the definition of having a disability is only relevant to society's standards and not [pause], does this make sense? So, it's a relative thing. (G2: 2163)

George appeared to be struggling with the label "disability" and believed that it is more of a way for society to classify him as not falling within the norm. In the third individual conversation, George maintained that his disability label was created due to the system or environment. "If the system needs, [pause] if you need to read so fast and I can't read so fast, then according to the definition, I have a disability" (G3: 3253).

At that time, George appeared to be comfortable with who he was and how he learns, even though he still does not view his disability as an identity marker. Although George does not believe that disability is part of his identity, he did articulate the positive attributes of having the disability.

I think it's made me a better student. And maybe it's because I'm older, I don't know, but I've definitely changed how I approach school now and how I approached school 18 or 20 years ago. [pause] And so, maybe it's because I didn't do good than, and I made a decision that it's something I didn't want to do, or maybe it's because I've admitted I have a disability and I'm willing to do

what it takes to overcome the disability and get the services that I need. But, I think it's made me a better student. (G1: 1665)

George also believed that because of his disability, he knew what his limitations were, which he believed was an area of strength. "I think a lot of people don't know what their limitations are, and so you know, they don't use that as a basis for making decisions. One of my limitations is reading, you know, so I just know that, and it doesn't [pause] you know, I just do what ever I have to do accordingly, you know, in situations"(G3: 3064). George's case provided insight into the complexity of constructing disability identity. He oscillated between denying the disability to cognitively acknowledging that he had a disability. I say cognitively, because it appeared that he kept it separate from how he perceived himself. "It is not a disability, it's just how I learn" (G1: 1162). But being comfortable with who you are may be more difficult when disclosure to others can lead to potential devaluing of self.

George's prior experiences with others viewing him as less intelligent explained the difficulties he had with disclosing his disability to others. Although he indicated that when he told friends about the disability, he did not believe that he was viewed as less than, however, he does not disclose to other students because he was concerned about their reactions.

It's one thing to feel okay of or in yourself, but it's another thing not to want to deal with people's reactions. You know, I think I'm fine, you know I don't care, but maybe I don't want to tell people about

my learning disabilities because I don't want to deal with their reactions" (GP2: 2422).

In the second individual conversation, George reiterated his discomfort with disclosing. "Maybe that's why I don't want to tell people today I have learning disabilities. I'm afraid that they'll react in the same way that those school children reacted back then. Maybe, that they'll think I'm dumb. And I don't think I am. I'm, I just learn in a different way than they do" (G2: 2068). As George wrestled with the issue of disclosure to his peers, he also had difficulties with disclosing to his faculty.

Requesting alternative testing required George to disclose a disability to his professor. In this situation, George admitted that speaking with his professors about his learning disability was difficult. "When you first talk to your faculty member, at first you're always wonder what they're going to think or what they're going to say. You don't know if they're going to be trying to help you, or think you're a hassle, or maybe they're going to think you're trying to cheat the system. So far, I haven't run into that, but it's always something you have think about when you're going in" (G1: 1229).

Although dealing with the reactions of others was of concern, utilizing services did not appear to be an issue as it was in the previous two cases.

I think people with learning disabilities, umm, have some issues they have to come to terms with. I know that I can't read as fast as other people, so, I have to come to terms with that. I can't read in a situation the same as other people. Whereas some people can go

into the library sit back, and read a book, you know, an hour before class, I can't do that. I have to be in my own quiet environment, and because I use services to help my disability, I basically have to do it at home. (G2: 2095)

There are two issues in the above statement that deserve further comment.

First, the use of accommodations appears to hinder participation in a group setting. Because he had to have a quiet environment to study, participating in study groups was not conducive to his learning style. Another issue for George was time. Having to listen to the text on tape was often a slower process than reading which lengthened the time needed to complete the reading. Time as an issue became clearer in the first group meeting.

You asked about how we think our disabilities affect our personal lives. I think the only way my disabilities affect my personal life, is that I have to spend so much more time reading and studying, that it takes time away from my personal life (all others in the group agreeing) more than I think it does for other students (GP1: 1480).

Although George appeared to spend considerable time in studying, isolation does not appear to be an issue. Perhaps this was due to his wife's support of George's educational endeavors. Additionally, George perceived that he does not have the same type of issues related to disclosure as the other participants because he was at the university for his education and not for social reasons.

Like I said, I think some of the young people in the group are battling with the social issues. They're trying to have a social life, which, if you're a young person going to a university is probably an important part of going to a university. [pause] I think it would be tough to be in a situation like that and trying to fit in, and to have a

disability, and trying to decide to tell people or not to tell people. Because on the one hand, if you tell people, it gets it out in the open and it does relieve some pressure. But yet if you do tell people, and then you find out that, you know, they do think you're stupid, or they take it the wrong way, then that's the exact reason why you didn't want to let it out... (G2: 2183)

It was interesting that George separated disclosure between academics and social situations. Perhaps it was because George was an older-than-average student that he did not feel the need for the social aspect of the university. But, it appeared that George did face similar issues about disclosing in order to receive accommodations. Another difference in George's story as compared to Jill and Luke was that George had come to terms with the fact that he could not study in a group. Because of this realization, he did not view himself as isolated.

George's case was compelling in that he was confident in his ability to be successful, but had mixed feeling about the educational environment because of the need to manage the reactions of others. George had not melded a disability into his identity, but believed that the environment contributed to the definition of a disability. His constant theme throughout the interviews was one of, I am smart, confident and I do not have a disability, it is just the way I learn. In terms of identity, George does not accept the label of disability. He does not disclose his disability to friends at the level seen in the other participants' stories. He too, experienced difficulties with disclosure for the purpose of receiving accommodations. However, George experienced no problems with using services

George's perspective on the disability as a separate part of him influenced his perspectives on the issue of community. In the second group conversation, I introduced the concept of having a safe place to go, a place where having a disability was accepted and disability issues were freely discussed, a disability community, or for lack of a better term: a disability cultural center. In this conversation, George recognized that the peer mentoring class that was offered the previous spring term was a nice opportunity to meet other people, but that it was not necessary for him to feel like he was part of a group or a community. Later in the conversation, he provided more information about having a disability community.

I think most people wouldn't go. I think it would be a good thing if they went, it would be healthy for them, and I think they would enjoy going too. But I think that most people wouldn't go, either because they felt they were too busy or they were, again not wanting the stigma of having a disability or nervous that somebody else would see them going into that room (G2: 2273).

In the third group conversation, George reiterated to the group his perspectives that even if there was a disability cultural center for people with disabilities, he still did not believe that individuals would go to such a place. But later on in the discussion he suggested that if the university did develop a disability cultural center, that it would be best if the center could be incorporated into the SSD environment that was already established. There appeared to be agreement about this concept from the group. In the third individual conversation, George

expounded on why he felt it would be necessary to have the community connected with using services.

I think most people wouldn't go to an organized group. Especially the people who were already fighting with the idea of whether they had a disability or not, and didn't want people to know they had a disability. They're the people who would need the group the most. I think they would be the ones that would hesitate the most to go, because in their mind, they're trying to say they don't have a disability so why should I go to a disability group" (G3: 3319).

It appeared that, for George, the stigma of having a disability, and the general dissonance students with disabilities experience, would make the formation of a community difficult.

In terms of what college student services administrators and the institution could do to foster the integration of students with disabilities into the campus, George had several ideas. George agreed with the others that there should be a special Odyssey class taught for students with disabilities. For the Odyssey class, he believed that there should not be a class offered for people with hidden disability only, but combined with students with physical disabilities. George also believed in the need to educate faculty regarding disability issues. It appeared that George believed that the university should require faculty to receive training on disability issues. He indicated that if it were not required, then by simply having a forum, only the instructors who were already willing to assist would come. "The ones that are going to be obnoxious and are going to think dealing with me is a waste of time and that, think I'm getting an advantage over other students, are the ones that aren't going to come anyway, unfortunately" (GP3: 3824). In terms of what social and

institutional changes could foster students integration into the university, George presented the idea that a class regarding disability issues should be offered as part of the baccalaureate core requirements. The class, perhaps offered as an option for the cultural diversity requirement, would be one that all students could select to take, not just students with disabilities (G2: 2309).

Sally

*There is more to me than the disability.
It's not up there on the number five slot, you know. (S3: 3217)*

Sally is a twenty-two year old junior majoring in general science. She is the eldest of two children and the only one identified with a disability in her family. Her support systems were her family and her boyfriend. Although she stated that her family had always been supportive of her, she also implied that her parents did not understand the disability or its impact on her education. Sally also indicated that while her boyfriend had also been supportive, he too, does not understand her disability. Sally stated that she had a part-time job but did not participate in other student activities at the university as her time was divided between work and school. At the time of data collection, Sally was concerned about her grades but had confidence that she would graduate. Sally actively participated in each group and individual conversation.

Sally was diagnosed with ADHD and a reading disability. She classified both of her disabilities as somewhat severe. Sally's story began when she was in

second grade and was having difficulties with school. She had always struggled in school, and her early memory of school was an emotional one. Having been diagnosed at an early age, Sally commented that she neither understood the implications of the diagnosis nor was it explained to her.

I didn't understand it. I mean, you're off in your own little world in a way. In my experience, I always knew that I was different from other kids, 'cause I was always in the 'slow' group, you know, the other kids would call it 'you must be in the stupid group'. I knew I was different, but I didn't know why. I didn't understand, [pause]. It was like 'here take a pill'" (S1: 1014).

The early influence of being placed in a "slow" group and the subsequent peer teasing impacted her self-esteem. Sally stated "...my self-esteem has just been horrible growing up, you know, and I think that has a lot to do with some of my other mental illnesses" (S1: 1132). Sally's early experiences with special education and her peers had affected her perceptions, and influenced her subsequent concerns regarding disability issues. Some of Sally's perceptions regarding students with disabilities might reveal how she thinks about disability issues. While telling her story about her experience with special education, her tone implied anger and contempt of this system.

And I remember those special ed. teachers. They catered to those people, and they were so playing the teachers, you know. And the teachers were babying them. And it really ticks me off. And these are people that society has told can't do this, and can't do that, and but yet, the teachers aren't helping; they're just handing them everything (S1: 1102)

Sally believed that the attitudes of society and more, specifically, the special education teachers fostered students' belief that they do not measure up to the same standards as their non-disabled peers.

...so they accept that they're going to be second rate and they're not going to be smart enough, and it just really bugs me because somebody has crushed who they are to the point where they're just going to accept it, and they're not being challenged. (S1: 1133).

Sally was passionate when she spoke about the special education system and how the system actually diminished success and fostered learned helplessness. In each individual and group interview, Sally brought up her concerns about special education. Perhaps her concerns stemmed from her own perceptions that students just like her, were not trying. In discussing her early interactions where she was a teacher assistant in a special education class, she stated,

But the thing I found with these classes (special education), they're just too easy for people who are in the medium, they're not severe, like you know, where they belong in these Special Ed classes, they're not quite up to speed to be in the regular classes, they're in that medium, and that, [pause], it makes the work for those people too easy. Easy where, [pauses] it's hard to explain, and [pause], this is what I had a real problem with people I considered just like me, they just didn't try. (S1: 1092).

Later in the first interview, her concern regarding effort was further revealed when she discussed the impact of special education. As the system does not motivate or challenge students with disabilities, Sally interpreted the message as "you can use your learning disability as a cop out; as a scapegoat" (S1: 1113). Perhaps Sally's concern was that if she perceived that students with disabilities

were using the disability as a scapegoat, others might have similar beliefs about her. By the second individual interview, the concern that she might appear to be using her disability as an excuse was exacerbated because of difficulties with explaining the disability. “Because I have a really tough time explaining to people, and I feel that when it comes out, I don’t know, I feel when I try to talk about it, I’m not verbalizing it right, it’s just not coming out right. I feel like it sounds like I’m using it as an excuse” (S2: 2133). Sally wrestled with her own perception of others with similar disabilities and, because of her own standards of working hard, she distanced herself from the definition of disability.

Sally also revealed another issue she had regarding the media portrayal of people with ADD/ADHD and the appearance that this disability was being over diagnosed.

I’m mad at the media, in a way, for publicizing all this. It’s like, ‘oh if your kid is a little unruly and it makes you want to pull your hair out, here, bring them to one of these doctors and they’ll put them on one of these drugs that will mellow them out and make them comatose’. That’s what I really feel a lot of parents have been doing [pause]. Not all parents, because my parents did not fit the norm, and because of the media doing that and [pause] essentially abusing it, I’ve found people to be very cynical towards people that really do have learning disabilities [pause], truly do. I’ve had some people be kind of cynical to me. (S1: 1157)

It was interesting to listen to Sally’s opinion of the media’s portrayal of ADD/ADHD and her belief that lack of parenting skills was the reason behind the significant increase in the number of diagnosis of ADD/ADHD. However, she was quick to note that her case was different, as her parents were not in that category.

Regardless of the reasons for the increase, she appeared to be experiencing the backlash from other individuals who discounted her disability. Thus, it appeared that incorporating a hidden disability into one's identity was complicated by societal implications that the disability does not exist or that it is an excuse for unruly children. Regardless, Sally entered into the conversation about disability identity with the perspective that students with learning disabilities did not try very hard, used their disability as an excuse for not performing, and contended with the notion that society appeared to be skeptical about ADHD diagnosis.

Another twist regarding identity development in Sally's story pertained to the issue of medication. Sally's story was unique, as she was the only one who was on medication consistently while growing up. Jill did not start using medication until she arrived at OSU. Both George and Luke were placed on medication but both discontinued the medication within in a year and Helen did not start using medication until she was a junior in high school. But for Sally, the issue of medication seemed to have had a profound influence on her identity. Sally described the difficulties with taking medication that appeared to alter her personality.

You have certain people that like you when you're on it, and you have people that like you when you're off it. It's like you have these two different groups of friends. You have these people who like it when you're wild and spontaneous, and everything, and just say what comes out; whatever you're thinking. And then you have these other people who can't handle those kinds of people. They think you're obnoxious when you're not taking the medication. So you question who you really are. 'Who am I?' 'Who are my true friends?' (S1: 1031--1036)

The issue of medication and its impact on identity development was fascinating and one that was not discussed in the literature.

Additionally, Sally struggled with socially prescribed behavior for a girl. “It’s tough being a girl, too; [pause] I’m sure it’s tough being a boy, but it’s like okay for a boy to be loud and obnoxious and be disruptive and that is fine. But if it is a girl doing that, it’s sad, you know, [pause], unacceptable” (S3: 3485). Based on her experiences, Sally inferred that she had emotionally “closed off” while growing up as a way of not letting herself get hurt from the comments of other people.

The issue of intelligence, a concern of the other three participants was also a concern for Sally. Societal beliefs that grades reflect knowledge and intelligence conflicted with Sally’s belief that she, too, was intelligent, just not able to show her intelligence given the design of the educational system.

My perceptions of myself deal with peers growing up and being known as stupid because I was in the slower groups, and [pause], that had an impact on me later in life, proving to myself that I’m not stupid, and the only way I could prove to myself that I wasn’t stupid was through grades. I’m having problems with the grading system now, but, you know, it doesn’t necessarily show your intelligence, [pause], level of grades don’t. And even still it affects me that I have to prove to myself that I’m smart (S1: 1048).

Because of the negative experiences she endured early on in education, Sally worked very hard to get out of special education. Sally believed that she was fortunate because her family moved several times when she was young, so when she entered junior high school she did not disclose a disability to anyone. In fact,

she believed that the ADHD had gone away because she had found strategies that reduced or eliminated her struggles with concentration and time management. During her first term at the university, Sally experienced significant difficulties with reading, studying, and testing. She was re-tested and submitted the documentation to the Services for Students with Disabilities (SSD) in order to receive accommodations. However, using services brought back emotions she had previously experienced when she was in special education. Because of her negative experiences, Sally's response to disability identity was not surprising.

In response to whether or not disability was part of her identity, there was evidence of her wrestling with this concept. In the first individual interview, Sally stated that she never associated herself with the term "disability". "In my mind when I heard people say the word disability, I never thought of myself. I always thought of somebody who was in a wheelchair or somebody who had an appendage missing, somebody that was physically disabled, not mentally" (S1: 1081). In the first group interview, when participants were asked if disability was part of their identity, Sally responded "No, I don't. I don't want to think about it" (GP1: 1597). But then added "Well, it is part of my life, and it's not part of my life" (GP1: 1601). I found the statement that disability was part of her life and not part of her life, intriguing. It appeared that she separated her identity from her disability. Later in the first group conversation, Sally attempted to rationalize her responses, "I do think differently than other people, but I don't really think of myself as different than other people; I mean everybody's different in their own way" (GP1: 1682).

Perhaps the stigma of having a disability was why she described the disability as simply being different and not a disability. Sally did not participate in the second group conversation about disability identity nor did she want to engage in that conversation in the second individual interview.

In the third individual interview the question of disability identity was once again asked, and the response was “I don’t know, [pause], I feel that if I was going to list off things about me, disability would be down on the list. There’s a lot more to me than just that disability. It’s not up there on the number five slot, you know” (S3: 3216). However further on in the interview in discussing the impact of the ADHD, Sally stated the disability had a profound impact on her, as indicated in the exchange below:

Sally: ...and I’m realizing the way I perceived the world; different stages in my life I perceived the world in different ways, but ah, it all plays back to, [pause], which is so funny, because it all plays back to my learning disability. Not necessarily my learning, just what people, you know, what their perception was of people with learning disability. You know things that happened as I grew up, the peers and the impact that they had on my, [pause], just my outlook on life and the world, has changed. And it’s kind of funny because I don’t think that at certain times of my life, I would have looked at the world as negative as I did if I did not have learning disabilities; if I was part of the crowd, I wouldn’t have looked at the world the way I did. And I still might have a different perspective even today, if I didn’t have learning disabilities, of the world. It’s kind of funny how it kind of plays back to that.

Tracy: But you’re just now realizing that it has had a huge impact on how you...?

Sally: Uh Huh.

Tracy: How? Emotional or...?

Sally: Everything, everything, everything, It's weird. One little thing, [laugh], one little thing, it affects your whole life, life perceptions, feelings, types of things. (S3: 3464)

It was an interesting journey to watch Sally struggle with not identifying as a person with a disability, to reflecting that the disability had significantly impacted her life, and subsequently, her identity. However, while it seemed that she was coming more to terms with who she was, the issue of dealing with other people was still problematic. In college, her experience with dealing with her learning disabilities and ADHD had been difficult. Utilizing accommodations has unique challenges in terms of disclosure, and requires the students with the disability to manage his or her own emotions as well as negotiate the emotions of others in terms of disbelief, fairness and effort.

In order to receive accommodations, disclosure to other individuals is necessary. When asked about disclosing the disability, Sally presented conflicting messages. In the first interview, she stated "When I was younger, it didn't [pause], I didn't tell people. It was not okay in my mind; people would look at me as being weird" (S1: 1056). At college though "it doesn't bother me and I feel if people have a problem with me discussing my disability and the medications I'm on and why I'm on it, that's their problem" (S1: 1063). But, in the second interview, she commented "you don't go around just telling everybody. And the learning disability is just one of those kind of things. I mean, you tell who you want to tell if it comes up in a conversation, I have no problem telling whoever I'm talking to

that I have one” (S2: 2080). Although Sally does not actively disclose a disability, she implied that she had no difficulties with telling others about her disability. But there appeared to be a difference between disclosing to one’s friends about a disability and having to disclose in order to receive accommodations.

In discussing the use of services for her disability, Sally indicated that she actively sought out institutions that had accommodations. When the group was discussing the feeling associated with using services Sally did not indicate any shame or burden with using accommodations. “I’m going to use it [accommodations] to my full ability. I’m going to get out of here one way or another” (GP: 2287). But using services and having to assist with finding a note taker in the class was an issue. In the second group interview, Sally discussed the difficulties with asking another individual in class to be a note taker. “The reason we don’t do this is because I don’t want to deal with ten million questions or a snotty attitude, [pause], you just don’t want to deal with, [pause], pretty much anything. You don’t know how the person’s going to react (GP: 2589). But it was in the third interview that she revealed the complexity of emotions associated with disclosing to receive assistance, oscillating between having concerns about other people’s reactions in the past, back to not caring about others’ reactions, to indicating that a specific mood is required to handle the interaction.

In the past, it was like that. I didn’t want to deal with their reactions, but right now, I mean I can sit around and go ask ten people the same thing, I mean, to take notes for me, and I’d blow off their reaction. I don’t know, it just depends on what mood I’m in, I

think, if I'm, [pause], if I'm ready to handle it; if I'm not ready to handle it, I think it just really depends on my mood. (S3: 3320)

When asked for more of an explanation on the type of mood that was needed, Sally stated “ I guess, just, you know, kind of putting up the shield of anything that would hurt, you know” (S3: 3347). Again, it is interesting to see the conflicting messages of having no problems with disclosing, to expressing difficulties with disclosing. Another impact of the disability connected with academics was the amount of time needed to study, resulting in limited interactions with others or in being isolated. In the third group interview, when the group was discussing the impact of the disability, social isolation was identified as an issue. Sally stated in the conversation, “I'm just a hermit. I really am. I study all the time by myself” (GP3: 3169). In the third individual interview, Sally expanded on this issue. She stated,

I can't do study groups like everybody, and that's how people get to meet other people is their study groups, and they get friends that way. You don't do it in class; you do it in study groups. I don't do study groups, so I'm very isolated, I don't have really any friends in school. I study and study and study, but I don't get, you know, what I think I deserve on the tests. (S3: 3163)

Sally's case was similar to Jill and Luke with respect to their emotions about being isolated, or not having the same opportunities as other students to develop relationships. Perhaps all three students differ from George because of the support he has from his wife.

Sally's case revealed elements of the first three cases with respect to having experienced negative societal messages regarding disabilities, the struggle

with developing an identity inclusive of a disability, and wrestling with finding a way to accept all facets of one's identity. In terms of identity, Sally has not melded the disability into her identity, but as her case revealed, she was beginning to be aware of and understand how her disability had shaped the person she was today. However, she has limited disclosure to friends and experiences difficulties in disclosing in order to receive accommodations. She does not experience any difficulties with using accommodations

In the second group conversation, I introduced the concept of having a safe place to go, a place where having a disability was accepted and disability issues were freely discussed, a disability community, or for lack of a better term: a disability cultural center. Regarding the issue of community or a center, Sally commented that having a community would have helped more in secondary education than in college. She stated that she felt isolated in high school and junior high because there did not appear to be anyone else like her that she could talk with about how she was feeling. So, she always felt alone (GP2: 3082). Sally then stated that in college everything was different and she did not feel the need for a community or others to talk with about disability issues. However, in our second individual conversation, she believed that by participating in the research, having the opportunity to talk with others had been beneficial.

There's some things that I think have been really nice about the group that I thought that, [pause], you know, that certain feelings that I had, I thought is was just kinda me, and it turns out that everybody kind of has them, at least in the group, being isolated and kinda lonely, you know and [pause], I realized that was the most

uplifting thing I could've gotten out of the group, you know, like, hey, you know, I'm not the only one (S2: 2026).

Sally appeared to oscillate between whether or not having a community would be beneficial. In the third individual conversation, there was additional discussion about a community or center. Although Sally recognized the value of having the opportunity to meet with other students and discuss issues related to the disability, she still believed that having a community or perhaps an orientation would be of value more for incoming students, rather than students like herself, who had been at the university for several years. Regarding an orientation for new students, she implied that SSD should move beyond the discussion on how to obtain services to providing the opportunity to bring people together, to create a warm welcoming environment for new students. "It would just be nice if it was more of a homier, group kind of feeling" (GP3: 3301). To me, this would border on the development of a community, supportive of disability issues.

In terms of what college student services administrators and the institution could do to foster the integration of students with disabilities into the campus, Sally proposed the creation of an Odyssey class for incoming freshman instead of a cultural center for people with disabilities.

I know that I would have taken an Odyssey class for people with learning disabilities, so I could meet other people. Because you're just coming out of that high school structure, you're insecure as it is, and college is about finding yourself in a way. Now we're all pretty comfortable, but when you get here as a freshman, I think the majority of the people aren't real comfortable with themselves [pause], and right now, yeah, maybe I'd go to a cultural center, but it's taken me a lot of years. And I just think that's where the people

who are freshmen are, versus where the people are who have been in college for a few years, you are at total different places” (GP3: 3551).

Sally also agreed with the other participants about the need for faculty training. However, she suggested that a class on disability issues should be created and that professors should be required to take the class as a prerequisite to teaching. There appeared to be support for the idea but, in general, the group realized that this might not be possible. In terms of what social and institutional changes could foster students’ integration into the university, Sally agreed with George’s suggestion regarding adding a class pertaining to disability issues as part of the baccalaureate core requirements, perhaps in the cultural diversity requirement.

Marie

“C students run the world, because we work hard” (GP1: 1409)

Marie is a twenty-four year old junior majoring in engineering. She has one brother who is autistic. Interestingly, she stated that she was the only one in her family with a disability. When questioned about this statement, she paused and then responded that she did not think of her brother as having a disability, and if she did, it was a mental disability, not a cognitive one. Her support systems include her family, her boyfriend and the guys that she studies with in engineering. Although she has a boyfriend, he, too, is majoring in engineering and most of their time together was spent studying. Marie indicated that her boyfriend does not understand the disability. She also stated that while her family was supportive,

they too, do not understand the disability. Marie is not involved in any campus activities and stated that going to school is the only thing she can do at this time. At the time of the data collection, Marie was concerned about her grades in the fact that they do not reflect her knowledge. Marie had participated in a number of summer internships and believed that she will be successful, once employed.

Marie's learning disability is related to processing speed and reading. She characterized her learning disabilities as moderately severe. Marie's story about the disability appeared to start when she was tested for a learning disability in her freshman year of college. She was studying 14-16 hours a day and barely making C's. But as revealed through the research, her story actually began earlier, although it is unclear as to when she was diagnosed. In reflecting on her educational experience, Marie stated that she always had difficulties with school. In the first individual conversation, the school personnel in elementary school thought she might have had a disability, but nothing was ever diagnosed. She remembered that someone once "told my Mom I would probably never make anything higher than a C. I'd probably never go to college" (M1: 1020). Marie was held back in the 5th grade due to her marginal academic performance. Interestingly, her previous diagnosis came to light in the last group conversation, when we were discussing IEPs. Marie stated that she had been on an IEP in high school, but she thought everyone had one and did not realize that she might have been classified as having a disability at that time. I find it perplexing that this information was not shared with her family or if so, that her family did not share the information with Marie.

Marie appeared very confused about having an IEP, yet never told that she had a disability.

Despite this new information, Marie started college without the knowledge that she had a disability. Because the amount of time she spent studying in college was not reflected in her performance, she decided to get tested. She wanted to know what was “wrong” with her. When she was given the results of the testing, she said that she “cried for like, two days” and “thought it was the most awful thing in the world” (M1: 1030). Marie also conveyed emotion of anger and relief from having the testing.

It was a relief in a way, but in a way it was kinda anger, you know. You get angry because you find out, all these years growing up, you always felt like you never wanted to read in front of class, you always felt like you were kinda dumber than all the other kids and stuff, and it was just cause you were learning differently. (GP2: 2369)

Regardless of when she was diagnosed, for all intents and purposes, Marie had only been aware of the disability for a couple of years. As Marie struggled with the diagnosis, it appeared that her parents had some difficulties with having a daughter diagnosed with learning disabilities.

Marie stated “my family’s probably more embarrassed that I am, to tell you the truth. My dad’s a professor at a university, and I know it’s kind of embarrassing to him” (M1: 1039). When asked what behavior led to this conclusion, she stated, “well, he just kind of keeps hushed about it with the other professors, he doesn’t really say anything, I’m pretty open about it, though. He’s

always telling me to shut up about it” (M1: 1045). She explained that perhaps her parents were worried that society might attack them because they did not raise or educate her appropriately; blaming them as “well this is your fault, you probably should have made her read more when she was a kid, or something like that, (M1: 1228). It was interesting how Marie interpreted her parent’s reaction to her diagnoses and then stated that she could understand their reactions because of how society views disabilities.

Marie also discussed some of the subtle messages she received regarding how her friends perceived her learning disability. She explained how her friends always apologized when she told them she had a learning disability. She laughed, and said that she would tell them not to be sorry; that finding out was actually beneficial. Her thoughts on why people apologize or believe it should be kept quiet are that:

We always tend to perceive a weakness as being bad, and I think when you tell you have a learning disability, they take that as a weakness, and we always try to hide our weaknesses. [pause] I guess that when they find out that you have a learning disability, people think of you as being kind of dumb in a certain way and stuff, as being [pause], like a weakness, I guess, that’s what I always thought it was and I think that’s what most people think it is. (M1: 1078)

It was interesting to note that Marie imparted that she always thought of a disability as weakness. I believe that she struggled with her previously held beliefs regarding disability and was now having to re-evaluate that misconception in light of her own learning disability.

Marie's story was unique in that she had always struggled with a learning disability, but the overall tone of her story at first was one of secrecy. Nothing was explained to her by school professionals or her family. It seemed that what Marie understood about disability issues was her interpretation of societal messages about individuals with disabilities and normality. Her parents' embarrassment and their request to not tell others about the disability as well as the apologies from others when she discloses, impart that there is shame about having a disability. Given the negative messages about having a disability, developing a disability identity might be challenging.

When asked if disability was a part of her identity, Marie's response in the first individual conversation was "I don't see myself as being identified as a person with a learning disability, I'm just a person that has an obstacle" (M1: 1106). Her first response implied that she does not have disability as part of her identity. This is very interesting because in the first group conversation, she responded to the question of having a disability identity with "I do, I think it's an obstacle in my life that has made me a strong person" (GP1: 1605). It was a little confusing as to whether or not she had disability as part of her identity or she merely perceives it as an obstacle. Later in the first group interview, she provided clarification on this issue.

Yeah, [I identify as a person with a disability]. I almost think of it as a gift, because it's made me learn how to work. Because my hard work is going to get me somewhere. I'm not like the "A" student that can put in minimal time and get straight A's but I've learned

how to work hard and I think it's made me a stronger person, and identify as a disabled person; it's part of my life. (GP1: 1657)

Based on this statement, not only does she identify as a disabled person, she also perceived the disability as a gift. However, I think Marie was still wrestling with the concept of disability identity, because of subsequent statements that she made in other group conversations. In the second group conversation, Marie provided clarity on how she struggled to maintain what she perceived as the gift of the disability and the functional impact of the disability in higher education.

I view it as a weakness now, I don't know, I try to view it as a strength, but sometimes it's hard when it messes with your test scores [laugh]. I think that's the biggest confidence shooter; you see it more as a weakness. If you got a high test score, you would see it more as strength, right. But it is not. But it will never be strength. Maybe making us a stronger person, but not academically. We have to be strong to go through this. (GP2: 2772)

Marie recognized the difficulties with having a disability in the current educational environment. In the third individual conversation, when asked the question on identity again, she stated that her identity was "being an engineering student and doing what I can to get through it, I guess that's my identity. I guess my disability is probably one of the obstacles you got to overcome, but it's also an obstacle that's going to make you stronger in other areas" (M3: 3094). It appeared that Marie does recognize the disability and at times, views it as a gift as well as an obstacle. But I am not sure that disability is part of her identity. Perhaps in the areas of disclosing and using services, a clearer picture might emerge about where she is in the process of developing a disability identity.

In terms of disclosing her disability to others, Marie indicated, “Everybody knows. People ask me why I’m not in the room with the exam; I tell them. I don’t really hold anything back. I think I used to, but now I don’t really care, I guess” (M1: 1123). When asked what changed in her life that made disclosure easier, she replied, “I guess I am just more comfortable, my grades went up, you know. You’re here to go to school, you’re here to get good grades, you’re here to get the degree, you know, my grades are going up and it’s helping (laugh) that’s all I care about” (M1: 1131). Having the positive reinforcement of obtaining better grades appeared to provide the impetus to disclose. However, it seemed that Marie did not always disclose her disability readily. “When I first found out I had a disability, I’d kind of choose who I told, but I didn’t tell everybody (GP1: 1154). Later in that same conversation, Marie concluded that she made a conscious decision to be open about the disability. But having made that commitment, she imparted that there were emotional difficulties with disclosing. “I guess because I always chose to be open with it. I felt, it’s kind of shaming sometime, is sometimes perceived as a weakness, but that’s how I deal with things, I just talk about it” (GP1: 1159). Marie believed that if the topic of learning disabilities was more out in the open, discussed publicly, the stigma would not be as great. “Yeah, I made a decision to be open about, because you want to be true to yourself, and what type of person you are... Usually I tell people. I kind of feel that the more open we are about it, the more people get used to it, and it’d just kind of like, be a normal thing, you know” (GP2: 2477).

Marie appeared to be very open with having a disability, but this decision to disclose might have been influenced by necessity rather than by acceptance. This is because of her major and her gender. “[B]ecause I’m a girl, I stand out, you know. So if I’m not in a test, you know, people notice. So they come up to me and say ‘how come you weren’t in the test’” (GP2: 2478)? In Marie’s case, being one of only four women in a classroom of 50 or more men, her absence was more notable than for the other students, perhaps forcing a response to explain why she did not take an exam. Additionally, because of her gender, Marie has had to develop other coping strategies to assist with her survival in the engineering program. “I feel like I have to put an act on every time I walk into a study group or go into a classroom. I have to feel kind of cocky, you know [laugh]. I guess that’s just how I hold my own or something, I don’t know. You can’t really be yourself in there [laugh]” (GP2: 2452). Overall, Marie’s disclosure of her disability to others did not appear to be an issue, even though disclosing had resulted in several negative responses from her peers. Marie shared a story that “a really good friend of mine told me one day that he thought it was bullshit; he thought it was an excuse” (GP1: 1728). Another comment from a student implied that students with disabilities should not be allowed in the engineering program. “Like one guy said to me the other day, he’s like, if a guy’s not tall enough to play basketball on the NBA term, we shouldn’t give him special privileges. Why should a kid be allowed to go through the program with learning disabilities when they’re not getting the same advantage as everybody else” (M3: 3056). Although her peers

are not saying the words that she is less intelligent, it is implied that the disability is an excuse, or that she is not really worthy of being in the major. Marie indicated that she worked hard to ignore these types of messages and attempts to maintain a positive attitude. Additionally, she would rather have these comments said to her so she can talk about the disability rather than said behind her back.

With respect to utilizing services, Marie provided conflicting responses. She stated that she was going to use the services because she needed the accommodations to survive in college. Yet in the second group conversation, Marie indicated that

I always feel like I'm always a burden when I take services. Because you have to do alternative testing and that takes time out from the professor. You have to go see them, and if they have to give you your test, they have to fully, like reschedule their time and stuff for you to take the test. And then, you have to have a note taker. The person taking notes is getting paid for it, but you're always thinking that they're wondering why does this person not take notes. I always feel like I'm kind of a burden when I take services. (GP2: 2606).

I find that I was surprised by Marie's response, given her responses to disability being part of her life and that she had no problems with disclosing the disability. It appeared that much of her concern about being a burden was due to the fact that the environment had to be specifically modified to accommodate her. It also appeared that some professors resisted or resented having to make special arrangements. Thus, the interactions with others and having to deal with their reactions complicated how comfortable she was with her disability.

The use of services, especially additional time on exams, brought Marie in conflict with her peers. Because Marie is in a highly competitive field, engineering, the issue of extended time was perceived as unfair. In fact, other students have suggested that it was unfair that she got an “A” on an exam because she was not competing the same way as everyone else. This has forced her to starting hiding her test results. “I hide my grades now. I don’t tell the guys what I get; if I get lower than them, they think I’m stupid; if I get higher than them they think it’s because of the learning disabilities and the extra time, so I just don’t tell them” (GP1: 1073).

It seemed that Marie was caught in a no win situation with respect to her peers in the engineering program. This was especially upsetting to Marie when she discussed how she had given up having a social life, and other relationships outside of school, in order to become an engineer. “Because people, [pause], they study, and they go out and have fun and stuff. But pretty much when you have a learning disability, you really don’t have, [pause], really a social life, because you have to study a lot more” (GP2: 2078). “I feel like sometimes I sacrifice so much and you don’t get anything out of it. You get like a 68 or 69 on an exam, when you sacrifice all that time” (GP3: 3111). Although Marie indicated that she did not have interests outside of school and did not participate in any other extracurricular activities, she did have a strong support system with several other students in the engineering program. Additionally, Marie believed the disability to be situational and would not have an impact on her once she graduated. “When I get out there,

and I do go to work, I don't, [pause], I mean, I don't have a learning disability. There's no such thing; it doesn't affect me" (GP1: 1441).

Marie's story was informative because it provided another view of the multiple influences that shape our identity. Marie presented herself as a confident individual who had wrestled with disability issues connected with her brother's and her own disability. In terms of identity, she appeared to have accepted the disability, but was still struggled with melding the disability into her identity, which was not surprising given her educational environment. However, in terms of disclosing the disability, Maria was significantly different than the other participants as she openly expressed to friends and classmates the disability and the need to have accommodations. Even with that attitude, but she experienced difficulties with using accommodations because she perceived that she was a burden.

In the second group conversation, I introduced the concept of having a safe place to go, a place where having a disability was accepted and disability issues were freely discussed, a disability community, or for lack of a better term: a disability cultural center. With respect to the issue of community or center, Marie struggled with this concept. Although she indicated in the second individual conversation that participating in the research had been helpful, she did not see the need to have such a community. In talking about the group and how it has been beneficial, Marie stated, "'Cause we really talk in that group; you know, what they've all been through. They kind of understand because they have the same

prejudice that they go through and I think they understand other people and stuff. And if you have a learning disability, they don't look down on you" (M2: 2346). Given how much time she spent studying, she did not see the value of having a community unless there was a way to connect the community to incorporate tutoring services (GP3: 3265). Towards the end of the third group conversation Marie articulated that she saw similarities between the recently established Gay, Lesbian, Transgender and Transsexual Cultural Center and the issue of a Disability Cultural Center. "[B]ecause being gay and lesbian is a very open issue, and people see it and it's almost accepted in the community, they get their own center. But we haven't got our center, because it hasn't been accepted" (GP3: 3893). After a discussion on the difficulties this community had encountered in the past, Marie thought about her previous comment and then added "yeah, the gay and lesbian center, they probably had to go through a lot of issues. They probably had people who were afraid to walk in the door at first, and you know, and stuff. It's not really the same thing, but in a way, it is. Because I think it is sort of a stigma" (GP3: 3900). Her response suggested that she was beginning to make connections about how other minority groups benefited from having a community with having a community for people with disabilities.

In terms of what college-student services administrators and the institution could do to foster the integration of students' with disabilities into the campus, Marie focused on faculty training and the development of a testing center. Regarding faculty training, Marie stated, "I think they should go through a class, to

tell you the truth, because they're educators, they should know how to teach and stuff like that. They only teach in maybe one learning style, they should be educated on this, because they're the ones teaching us" (M2: 2088). In the third group conversation, Marie continued her thoughts on faculty training. She indicated that students with disabilities should rate instructors and if they obtained a low score, they would be required to take the class" (GP3: 3828). The other issue that Marie focused on was a testing center. In fact, she had written a report to a faculty member in the college of engineering on the need to establish a formalized testing center with a specified location instead of the current configuration of utilizing space throughout the university. Marie also believed that having an Odyssey course for students with disabilities would be beneficial.

In terms of what social and institutional changes could foster students' integration into the university, Marie supported the idea of a cultural diversity class that was focused on disability issues. She suggested that the class would have to be part of the baccalaureate core since engineers would not take extra classes in a different department, as they would not count towards the degree.

Allison

It's not seeing yourself as the problem, but seeing other people as the solution (A2: 2239).

Allison is 55 years old and a senior in the College of Business. She sustained a head injury at the age of 40 and within six months from the time of the

accident, she was terminated from her position. At the time of the accident, she was the personnel director of an entrepreneurial software-manufacturing firm. She was terminated because “I could no longer function at the level I was functioning before, which was 80 to 100 hours per week; I could only put in 40 to 60” (A3: 3014). After the termination, Allison successfully opened and maintained her own business for the last ten years, with the last couple of years on a part time basis due to school.

Allison has two brothers: both are younger, and her parents were no longer living. She indicated that she had minimal family support, and at the time of data collection, she had a very small support system. Lack of support system has been difficult for her. She stated that she felt “very, very isolated, and kind of like an alien” (A1: 1377). When asked to speak more about this issue, she replied “I don’t fit any place. Had I been here longer, I might have found a group. Either older women who are in school, or older-than-average students who are in school, or people who have disabilities that I would be able to relate more to, but I don’t feel very connected here” (A1: 1381). Although this lack of a support system and isolation did not hamper Allison’s success academically, it does provide insight as to why the peer mentoring class and the research, which will be discussed later in this section, were of value to Allison. Allison’s disability affected the opportunity to develop new support system because of the functional impact of the disability.

Allison’s type of disability limits her opportunity to develop new relationships because she has to have complete silence when she studies, therefore

participating in study groups was not an option. Additionally, because of difficulties with tracking and concentrating in a noisy environment, Allison indicated that other students have been frustrated with her level of participation. This was because the College of Business promotes completing projects in a team format.

They get on a team, and then [pause], we have to do things at different times in different ways, and I can't do them. There were about four conversations going on at once, I couldn't track any of them and then they'd come back to me and say what do you think about the first thing. And I'd say I don't remember. I couldn't do it, and there's one person that almost ended up not speaking to me. I apologized to them, I went up to them and said 'I'm sorry I couldn't track very well, it's just part of my disability'. I still don't know what my relationship is like with that person. I don't know if they were really offended, if they were really irked with me, it was very awkward. (A3: 3132)

Because of the amount of time spent studying and in team meetings, Allison was not actively involved in extracurricular activities on campus. She anticipated graduating in June and looked forward to one day attending Law School. Allison actively participated in the research, although she came toward the end of both the second and third group conversations due to scheduling difficulties. She provided a unique perspective on the research process, group dynamics, and the differences that she could see between her situation, (an acquired disability) compared to those who had the disability since birth.

Although Allison obtained a disability later in life, she reflected on how her family history and the messages that she received about people with disabilities influenced how she dealt with the head injury. Allison implied that she was raised

in a manner that made her feel superior and arrogant; that if you worked hard enough and it was understood that you were bright, then it was a given, that you were better than anyone else (A1: 1095). Allison was very bright, did well in school, and was athletic. She placed fourth in state in the hundred-yard dash. In reflecting on the message she received about people with disabilities, she stated that “they weren’t really working hard enough, they weren’t trying hard enough, it was their fault. I think that was the main message I got. Maybe there were some other messages I got, but the main message was (pause) they’re lazy” (A1: 1099).

Allison also reflected on the impact of her family values regarding disability issues.

I also had my family history, which I didn’t even acknowledge until being I think at Oregon State, the impact my family history had subconsciously on me of it not being okay to not be okay. And I thought as long as you weren’t strong, as long as you were not able to function at 100% that you were not okay. And part of that was my parents not even coming or writing or being concerned about me after my car accident. I think it reinforced that, but part of it was my childhood survival instincts. Is that as soon as you become weak, and weak means being a minority, being disabled [pause], being the youngest in the family [pause], you were seen as less competent and given less recognition (A3: 3066).

After the accident, Allison’s struggle with her disability was based on the message that people with disabilities were to blame for their own situation, or deemed as less competent and not “okay”. When asked about the impact of the head injury, she disclosed that it took her time to realize that she was not the same nor would she ever be the same, as she was before the accident. But even with that realization she had the attitude: “Well, I have a disability, but I’m going to be different from everybody else (she laughs) everybody else can be affected by it, I’m

going to have one and not be affected by it (laugh)” (A1: 1210). As Allison was successful with her business, she stated that she went another 10 years ignoring the head injury; in denial of having a disability, but successful in developing coping strategies to mitigate the functional impact of the disability. Allison believed that her head injury did not create a disability in employment and was not something she thought about. Because of her decision to come back to college to obtain additional education, she was forced to confront her disability, as she could not identify strategies that would allow her to work around the disability given the environment and the value of time.

Allison described the difficulties with being back in the classroom, at another educational institution, how problems with memory, timed exams and noisy background, resulted in emotional distress. One of her professors recommended that she contact the Disability Services Director to discuss the head injury. “So I did, and it opened a whole new world. I had no idea that this was like, not only recognized, but this was okay. It’s okay that people with head injuries struggle, it’s okay that they get emotional or whatever” (A1: 1234). Because Allison could not find records of her previous psycho-educational evaluation on how she processed information, she was required to obtain additional documentation of learning disability for Oregon State University. The information received from the testing appears to have been beneficial to Allison as she now had proof that the head injury had affected her cognitive processes.

I did get re-tested this summer, and it resolved any doubts I had about having any limitation in some areas that my family either thought I was making up, or I had trouble accepting myself. So, where am I now? I do have cognitive effects from my head injury, and having someone, who I know is very skilled at testing, tell me ‘you drop 80 IQ points when you’re tested under distraction versus testing not under distraction’, and having experienced the feelings around that and having debriefing around that; it’s hard to deny or ignore that. So that’s been part of the process of saying “okay this is not the worst thing that can happen to you by any stretch of the imagination, it is something that is real and ignoring it or denying it is not going to make it go away”. (A1: 1044)

Having this validation of the disability appeared to be very powerful for Allison, and aided her in coming to terms with the disability. However, she still struggled with melding the disability into her identity.

In the first group conversation, when asked if disability was part of her identity, she first responded “I don’t” (GP1: 1599). But then later replied, “I think I’m in the process of changing what I think about it” (GP1: 1603). After some additional dialogue from the other members of the group, Allison began to elaborate on why she was changing her opinion. “I said I didn’t think of myself as having a disability, but I do notice that in class; every single time I’m in class, that I can’t process the same way that other people process... So I think, I was re- tested this summer, and I do know, really know, that there’s a difference in my ability to work effectively. It doesn’t make it good or bad, I need to be alone” (GP1: 1648). Allison’s struggle with accepting the disability was reflected in the differences between her initial response and how she was beginning to recognize the impact of

the disability on her life. Realizing too, that the impact is neither good nor bad; it was just a fact.

In the second individual conversation, Allison continued to wrestle with incorporating the disability into her identity. She discussed how her participation in a peer mentoring class for students with disabilities and the Services for Students with Disabilities Office has assisted her in changing how she perceived the disability. “I am getting more comfortable with it. I know for sure the peer mentor group, being able to have a place to come, no matter what the rest of the world does, says or thinks, I have a place to get validated, I think has helped me mature in my disability acceptance, recognition, validation, you’re-no-different-than-anybody-else-process” (A2: 2174). Allison went on to state:

It’s disability pride. Which means that I’m so pleased with myself that I don’t care if people know or don’t know, and I don’t have to talk about it, but I’m successful. I’m not, I still do, but less, maybe 80% less, of beating myself up because I have a disability. I mean that’s a stupid way to live your life! It’s like you have a double disability. You have a disability, and then you have yourself beating yourself up about a disability. (A2: 2191).

It is interesting to note that Allison stated she would “beat herself up” because of the disability. This was similar to Jill’s case, but Allison moved beyond the continued self-flagellation to recognizing that negative self-talk was not conducive to being successful. Later in the second individual conversation, she again commented on the changes. “I don’t know what other people are like, but for me, I didn’t see it as part of real life: I saw it as something separate from me. Something to hide, or something to make sure everybody knew about, or make sure

nobody knew about it. But now, it's like part of my package..." (A2: 2246).

Although Allison believed that her disability was now a part of her identity, she admitted the difficulties of trying to integrate the disability into her identity given societal messages and her family background. One message that she wrestles with was the notion that she was intelligent regardless of the head injury. Having the results of the test document that she is in the above average range, bordering on superior played a major role in resolving this issue. But she still had difficulties with being intelligent, but not able to "overcome" the disability.

I also had always overcome anything that I needed to overcome, and I just assumed I could overcome this, and in many respects, I did. And some of that's positive, some of that's real persistence and strength, but some of that is an incredible path to becoming less authentic, less genuine, and less accepting, not only of yourself, but of others. (A3: 3073).

I found Allison's reflection on "overcoming" the disability exciting. She was the only one who implied that the concept of overcoming could actually negate who you were as an individual: less authentic, less genuine, less accepting. Allison's insight on her own struggle with disability identity and incorporating the disability into a previously established identity allowed her to have a more objective view of the process. Because of her previous experiences as a human resources manager, she was able to see similarities between people with disabilities and other minorities. But even with that experience, claiming the disability was still difficult.

You know, if my hair is blonde or blue or red or eyes are brown or blue or whatever, no one really cares, and can I think of my

disability like that? So if somebody doesn't like red hair, it's too bad, that's the way it is. If somebody doesn't like it because my skin is white or black or green, it's too bad, I can't change it. And I think in our society, we have developed along certain lines, so we have become more accepting of gender and then race, and disability may be the next frontier, but I would like to be able to say honestly, and I don't think I can do it yet, that no matter what somebody else perceives, says, signals they send off, whatever I'm perceiving that their perceptions are, I don't care. It's the way it is, I'm doing the best I can, and it's their problem. I am not there yet. (A3: 3159)

Allison's story was interesting in that, even with her willingness to embrace the disability as part of her identity, dealing with others was often problematic. In discussing the issues of disclosure and using services, Allison conveyed some of the same concerns as seen in the other cases. Allison indicated that when she first started back to college, she did not want to tell anyone about the head injury. Once it became apparent that she was not going to succeed at the community college, she started telling everybody about the disability. This was really the first time that she had disclosed the disability and she remembered the mixed reactions from others. "Some people, it was like, they really understand it, and some people, it was like what are you doing here, you're weird" (A1: 1252). After thinking about the issues of disclosing the disability, the need to disclose to receive service and protect yourself at the same time, Allison provides a very thoughtful response.

I think it's highly complex, it's just a very complicated issue and it has to do with peer pressure, peer-acceptance, self-acceptance, and just wanting to do well and be seen as doing well. And, umm, not knowing how other people are going to respond once they find out that you have a disability and caring a great deal about what that response is, especially in school, when you have very little power. There's a lot of peer pressure and professor power in school, and so

[pause], if someone doesn't respond well, it really can have an impact on you. (A2: 2123)

Allison indicated that she had become more confident in herself, and that disclosing to others, while still difficult, was becoming easier. Her self-confidence had also affected her ability to judge when to disclose. "In general, I think I'm getting better at saying 'when is it appropriate?' 'What makes sense?' 'What will help me be a better student and what will help the other person help me be a better student?'" (A2: 2237) But later, in the third individual conversation, her response regarding disclosure reflected that she was still wrestling with disclosure issues. In speaking about working in the team situation, having to deal with the functional impact of the disability and having to inform others appears to be of angst to Allison. "So I think I'm in this shame [pause], what's my fault. Umm, burden, how much do I disclose, when I do disclose it, does it sound like an excuse or does it sound like it's something valid? And it if sounds valid to me, and they don't believe me, why do I take on their doubt?" (A3: 3156) It should be noted that Allison was feeling anxious about one of the team meetings she was going to have that evening. She explained that individuals on that team were having difficulties with how the disability affected her participation. It appeared that the difficulties Allison experienced with disclosing are similar to other participants: dealing with the reactions of others. But it also appeared that she was attempting to move beyond her fears of how others would react, especially if she realized that she needed assistance in order to be successful. As Allison wrestled with her emotions

regarding disclosure issues, she also had conflicting emotions regarding the use of accommodations.

Using accommodation or services appeared to be difficult for Allison given her background. She did not want to be perceived as being lazy or accused of not trying hard enough to be successful. Allison shared her feelings about when she first started using alternative testing accommodations

...I started feeling like I was cheating, because I got distraction free testing, I got extra time, and nobody else did. And that started eating away at me. So, it became very important that I took the test in class as well as outside of class (laugh). So I would come in and take the test before class and then I'd take it with the class. He just didn't grade the one in class, and that way I wasn't singled out.
(A1: 1240)

Obviously in the beginning, the use of services and being singled out were of concern to Allison. I would have anticipated that as she had progressed with a disability identity, that she would become more comfortable with receiving services. However, it seemed that she was still unsettled by using services.

...I think people are thinking no wonder she has a 4.0, she has distraction-free testing, she has time and one half. We would all have 4.0 if we had that kind of time. So there's that voice inside me that says I know I work harder probably than anyone else in my class, [pause]. I deserve my grades but there's still that thought that says, "I don't want to slack off." (A1: 1311)

It was very interesting that even with Allison's cognitive understanding of her disability and how it affected the way she processed information, she was still concerned about how others would perceive her as not working hard enough or deserving of good grades because she received accommodations. Often, Allison

would rather go without accommodations than approach another student in her class for assistance. It appeared that even though one can come to an understanding of, even an acceptance of a disability, requesting the assistance of others or using services is difficult in our current western culture. I think Allison also recognized that requesting services at the university had been difficult for her. The reluctance in requesting assistance connected with the desire to find employment in her field was of concern for Allison. I found this interesting due to the fact that she had been successful in her own business. Her primary concern pertained to the environment and possible lack of opportunity to control her environment. Her concerns were complicated, perhaps, by her experiences from the last time she worked in a company.

I'm competent, I'm bright, but like there's this opposite side, the shadow side of the coin which is: How am I going to interview? How am I going to express the needs I have so I get into a work environment that is as compatible as possible. I haven't felt like I've done all that good at communicating that at school. When and how do I do that? What's my life going to be like once I get into the work world again, when I'm not a sole proprietor so I don't determine everything I do, but there'll be teams of people, and how am I going to deal with the distraction, the hours, the fatigue. (A1: 1390)

Allison's case was different from the other participants, except Luke, who believed that their disability would not affect them in employment. Allison had already experienced that her type of disability did impact her, and the impact was dependent on how much of an opportunity she had to control her environment. Allison's story was different from the other participants, yet at the same time,

similar. The most obvious difference is that she has an acquired hidden disability and the injury occurred at a time in her life when, according to identity theories, that she had already formulated her identity. But the messages that she received from society about the disability, difficulties with disclosure, and using services were very similar to the other participants, and indicative of the complexity of developing an identity inclusive of disability or modifying an identity to accommodate a new strand to one's identity. In Allison's situation, it appeared that she not only had to incorporate disability into her identity, she also had to make adjustments to her previous identity, which seemed to have been rooted in her work identity. With respect to establishing a new identity, Allison indicated that she was "a person who, because of her head injury has become much less concerned about material things, much more interested in spiritual connections and relationships, and trying to identify what it is, why we're here, and being able or courageous enough to pursue that, whatever that is" (A3: 3227). In terms of disability identity, Allison was beginning to accept the disability. But, she experienced difficulties with disclosing the disability and using accommodation.

In the second group conversation, I introduced the concept of having a safe place to go, a place where having a disability was accepted and disability issues were freely discussed, a disability community, or for lack of a better term: a disability cultural center. With respect to the issue of community or center, Allison was the only individual who commented in the first group conversation on the benefits of meeting with other students. After George and Jill commented that they

did not feel the need for a community, Allison stated that, in looking back at the experience of the peer mentoring course, she felt it was very beneficial as it lessened her feelings of isolation. “When we got together in a group and started sharing different stories... that helped me feel much less isolated. I thought okay, this is the way it is, this is the experience, this is normal. I really felt it helped me understand how it is to have a disability on this campus, how is it treated, what are other people’s experiences (GP1: 1140). In the second group conversation, Allison again was the only one who stated that, if there was a disability community or cultural center she would participate. “I would go if I knew and trusted the people there, and felt like I could, just do it for myself. Because I’m such a verbal processor, when I talk about stuff sometimes it just kind of solves itself” (GP2: 2945). In the second individual conversation, Allison provided more information on how being part of the peer mentoring program and this research helped in working with the disability. “Being able to listen to other people’s stories, listen to different people talk about how they handle situations, it’s hearing other people having similar situations and maybe handling them very differently. It’s getting my own sense of context with how I fit with the disability group and realizing that I’m not weird” (A2: 2250). After the end of this conversation, Allison wanted to add more to her comments regarding the issue of community and the research.

I am integrating my disability more into my life. Because in the group, not only are people sharing their stories, but denying things. When people deny that there really is a stigma against them, it makes me pay particular attention to my own process. So the group’s been really instrumental [pause], not only in hearing stories

about things that are similar and how people deal with it, [pause], that I have wondered if I was a normal disabled person or not when I'm dealing with this, but also when people deny, like not thinking a group was worthwhile or if there was a group, I wouldn't go to it. And I'm, like, but this has been critical for me. (A2: 2372)

It seems that by having the opportunity to hear how other students with disabilities wrestled with the complexity of an ablest society had been very beneficial in assisting Allison to integrate the disability into her identity. In the third group conversation Allison agreed that, if a Disability Culture Center was established, it should be part of the SSD office.

In terms of what college student services administrators and the institution could do to foster the integration of students with disabilities into the campus, Allison expressed the need for awareness training beyond the faculty, and targeting individuals in positions of power. "Making sure that all faculty, all administrators, and this is an impossible task, but in an ideal world, are as aware, as educated, as non-biased, as compassionate, as are aware of resources as is possible, so that there's not just one place that students have to come if they need feedback or validation, or help" (A2: 2341). In addition to training faculty and administrators, Allison believed that students with disabilities also needed training. This training would assist students to "the point that they don't feel that they're going to be, [pause], going to have less of a chance of success or some stipulation where they will be seen as being different or they're going to be singled out, if they take advantage of services or speak out" (A2: 2351).

In terms of what social and institutional changes would foster students' integration into the university, Allison stated that disability issues deserved the same type of recognition as the Women's Studies and Ethnic Studies departments. She advocated for a Disabilities Studies department.

Helen

"My disability gives me a different perspective on life, not a different life"
(personal communication, February 15, 2002)

Helen is a twenty-one year old senior majoring in Liberal Arts. She is the third child of four children. She has an older brother and sister, and a younger brother. She is the only one in the family diagnosed with a disability. Helen indicated her support systems were her faith, family, friends and her sorority sisters. Although her family was very supportive, she indicated that they do not understand the disability.

Yeah [they are supportive], but they didn't know and still don't really understand everything about it that I have to do. My mom is great, very emphatic, wants to be there, wants to understand, they all do, but the mental disability, kinda of like how to handle it, the situation, they all try to figure out what is going on. (H1: 1047)

Although her family did not understand the disability, they were very supportive and searched the literature to further their own understanding of Attention Deficit Disorder (ADD). Although Helen had the support of her family, she experienced difficulties with learning. Because of these difficulties, she

actively sought involvement in activities that played to her strengths. Thus, Helen was the only participant in the study who engaged in extracurricular activities.

With respect to extracurricular activities, Helen had worked on campus as a receptionist for the football office since her freshman year. She is actively involved in her sorority and was the Recruitment Chairman last year. She also volunteers with Court Appointed Special Advocates and is an ambassador for the College of Liberal Arts. Additionally, she found her experience of backpacking around Europe by herself a source of strength. At the time of the data collection, Helen was not concerned about her grades and firmly believed that grades did not define her.

Helen actively engaged in the research. In the individual interviews, she was very attentive, and at times, would request to turn off the tape recorder so she could think about her responses. It seemed that the group interview format was challenging for her, as she did not actively participate. In both the first and third group interviews, there was only one time that she offered information without being directly asked a question. Thus, part of Helen's responses originated from emails that I sent to her as a follow up to topics discussed in the group when she did not participate in the conversations. It was possible that Helen might have felt intimidated in the group conversation, as she was the only Liberal Arts major in the group. Another plausible explanation was that Helen was not wrestling with the topics that appeared of concern to the other participants, as her story will reveal.

Helen, unfortunately had to miss the second group interview due to attending a Job Fair to assist with locating a job when she graduates in June.

Helen's story began when she was diagnosed with ADD without hyperactivity in her junior year of high school. The disability affected her ability to concentrate in noisy environments, attend to lectures, and perform on timed exams. She characterized her ADD as moderately severe. The reason for being diagnosed was due to the difficulties she was having with academics in high school. She would spend hours studying, even had her parents help her study, but still she was not performing well in school. Helen disclosed that it was a difficult time in her life when she was first diagnosed. "It was really hard at first. But, umm, everything from starting to take medication, to confronting teachers and telling people I had a disability. It was extremely difficult" (H1: 1056). When asked at a later date, about the difficulties with being diagnosed in high school, Helen responded, "I felt like I was a crazy person, for having to speak with someone about how I was doing, handling the medicines and stuff" (personal communication, March 4, 2002). It appeared that Helen was very embarrassed about having to meet with a psychologist. "It was also embarrassing to tell coaches or teachers why I had to be late or leave early, if I had to see my therapist. I just told them I had doctors' appointments" (personal communications, March 4, 2002). Although I had thought the stigma of seeing a therapist had perhaps lessened over the years, it seemed that, at least for Helen, it had not. Helen then revealed some of her thoughts about telling others about the disability and medication. "As time

progressed, I was able to slowly tell a few of my very close friends about what I was going through, because for a while, I felt inadequate or dumb, like I had something missing in my head” (personal communication, March 4, 2002). In addition to struggling with the diagnosis, the issues of medication presented another challenge.

As with Sally, the issue of medication was often mentioned in the individual interviews as well as the personal communications through email. However, Helen tended to focus on the support she received from her friends. “They helped me feel comfortable with myself and my medication. We made jokes about taking ‘focus pills,’ like, if I was acting funny or delirious, they attributed it my needing my focus pill” (email 3/4/02). She also expressed her concerns about the medication and the potential for abuse. When asked to speak about other issues that had an impact on her development, she commented, “First thing I think of is medication and its side effects. That’s why people are abusing the medication for the same disability I have” (H1: 1196). She went on to relay a story about a time when she had been offered money for her medication, but that she declined because she did not want to be responsible for someone’s health (H1: 1199). She also disclosed how the medication “robbed” her of her desire to eat, and that she had to force herself to eat because of her concerns about being too skinny, or developing an eating disorder (H1: 1218). Helen was also worried about potential health risks from taking the medication and did not want to make any bad decisions regarding

her own health (H1: 1220). The issue of medication was one of the reasons why she had difficulties with the diagnosis of ADD.

I got extremely depressed. I remember walking around not wanting to talk to anybody, I was kind of angry I think. Angry, [pause], I had never taken medication like that before, it was Dexedrine. I don't remember [pause]. I mean four or five days, go to school and I would stare at my locker and I would want to just get out of there for the day and go home and be on the verge of tears. People don't understand what I am going through, people, [pause], I can't talk to people, because I don't think anyone else has it, so... (H1: 1137)

The statement revealed the difficulties with being diagnosed with a disability and being medicated, especially at an age when "fitting in" with your friends was very important. Another interesting piece of information was the perception that she was the only one to have been diagnosed. However, it appeared that as Helen began to disclose to others and received positive feedback, her anger and depression subsided; but from time to time, she admitted to feeling sorry for herself. "I was okay, but sometimes, I still felt such a struggle to do well in school and I'd feel sorry for myself, that I had to take medication in order to be 'normal,' so that's when I get depressed" (personal communication, March 4, 2002). Again, the reference to needing medication to present as normal implied that, while off medication, she was not normal.

Helen's story was intriguing. Even though she had the support and encouragement of family and friends, the words she used to indicate how she was feeling, such as inadequate, dumb or abnormal shadows the dominant discourse. However, it should be noted that Helen's story differs from the other participants as

she refused to accept that she is ‘less than’ because of the disability. She believed that her faith helped her through the difficult times.

I grew up socialized with religion. I was brought up in a really strong Christian home, and so they’ve always loved you for who you are. It’s like my mom says “God has a plan for you and God has, he made you special who you are. Not special good or bad, just he made you in mind for you. So in my family, we know that you are accepted and being loved for who you are. (H2: 2256)

Having this foundation, Helen philosophized on how society views individuals with a disability. “And people try and put down ADD and stuff, I just try and think, I don’t know, it’s not a bad thing to have ADD. It’s okay, lots of people have it and it’s kind of reinforced the fact the, umm, just that I’m fine with who I am and its part of my personality and stuff like that” (H2: 2263). In fact, Helen recognized the positive attributes of having the disability.

I think all those emotional steps I have had to take has made me a lot stronger person and given me a lot of confidence, [pause]. I have had to force myself to go up to people in uncomfortable situations and be humble about something to say, “yeah I am not perfect, I have something wrong with me, can you please help me,” so, I think that has made me grow as a person. (H1: 1068)

Although Helen presented as a very capable individual, I was intrigued by her word selection in that there is something “wrong” with her. It would seem that while she is accepting of the disability as part of her, she still perceives the message that there is something wrong with her. But, I think she has found strength in other areas of her life that offsets this message.

If asked whether or not she identified with having a disability, Helen’s reply is not a surprising one. In the first group interview, when others were mulling over

the question, Helen stated, “I say I have a disability” (GP1: 1641). But it was in the second individual conversation that Helen reveals the complexity of a disability identity.

Well, sometimes, I think, well, I do have a disability and so I can identify with having a disability, but at the same time it’s just the way I study and the learn things. It doesn’t affect every aspect of my life, and there’s other things I can do, and I don’t think of myself as having a disability. Sometimes I do and sometimes I don’t. Sometimes it’s a big deal because I’m stressed out, or it’s affecting me the way I’m studying, it’s just really frustrating. But at the same time, other times, [pause], I don’t know. I think I’m a normal kid, even though I’m sometimes not perfect, but I do some things different, or in a different way. (H2: 2061)

It was interesting to hear how Helen vacillated between having a disability and at times, not thinking of herself as disabled. Thus, disability identity, even when one appears to incorporate the disability into their identity, the issue of whether or not he or she perceives himself or herself as having a disability is questionable. Additionally, the situation or environment can contribute to the confusion. The educational environment is a source of pressure because of grades, and the future implications of having a mediocre grade point average.

I am hoping people understand how much effort it takes for me to go to school in general. They don’t understand that I got a 3.0, but to me it is a 4.0. I worked my butt off and I just spent numerous hours at the library. I mean closing it down five nights a week, I mean, study so hard and my grades never put out, that is huge, that is really pressure, and everything. When I go to find a job, my grades will not be good enough, do I have to explain to them that I have ADD or that learning is hard...? (H1: 1233)

Helen was not present during the second group interview where the participants discussed the issue of how much studying affected their personal life or

turned them into a hermit. But through other conversations, it became apparent that she too, studied more than other members of her sorority house did, but often received lower grades for her efforts. Although concerned about having to justify her grade point average, Helen believed that there was more to her being than grades.

...but there are so many other things on this campus that make me who I am; that I like to do. I like to be involved with people and my job's not really going to care if I don't have a 3.0, hopefully, or I'm toast. (H1: 1543)

Perhaps one of the reasons Helen participated in other extracurricular activities was to balance the stress and marginalization of the education system with other areas that she perceived as strengths. "If one aspect of my life is not, if I think I'm not succeeding, I'll find something that I can do well, and not really max it out, but I'll do that well" (H2: 2357). Being involved in areas outside of academics was where she could be successful and, thus, was willing to compromise her grade point average.

In the third individual conversation, I asked Helen if she would provide more information about how disability was part of her identity. Helen responded to the question by reflecting on the process of being diagnosed, on how much of a positive learning experience it had been, and on how it would shape her future.

It has been a learning experience, I think. I identify who I am with a disability and how the disability affects who I am. They kind of go together and umm, how that affects my future. [pause] What kind of things about the disability, [pause], when to disclose information, and get penalized if I do speak about things, and umm what kind of

career would be good for me, what kind of career I should steer clear from... (H3: 3042)

It appeared that Helen does recognize the disability as part of her identity, even though, at times, she still wrestles with this concept. Because of her foundation, that having a disability does not make her less than others, the issues of disclosure and using services were different from the other participants. In discussing the issue of disclosure, Helen indicated that she had no problems with telling other students in class and out of class about her disability. She also indicates that she had learned to articulate her needs in order for her to be successful. For example, one time at a large sorority rush meeting she stated,

I told the girls that I have ADD and I need you to not do these things, but it is not a big deal. I just need you guys to not be screwing around and having side conversations when I am talking with people because I can't, [pause]. I am not giving you my 100% attention because I am being distracted. So, and I am glad I did that and so people knew how I wanted them to behave. (H1: 1172)

Helen seemed to be confident with revealing her disability and had taken the initiative to manage the environment around her so that she could be successful. She indicated, though, that even in the supportive environment of her sorority, there were side comments about her disclosure. "Some thought it was kind of a joke, but I didn't care. I wasn't affected either way" (H1: 1181). This comment suggested that while other participants were more susceptible to negative messages, Helen was confident enough in herself that she was willing to risk disclosure, and potentially receive negative messages.

In using services, Helen also had a different perspective. When discussing the need for alternative testing, Helen first implied that she felt it was a privilege to take her exams elsewhere. “It’s so frustrating to hear someone talking everywhere, noise just drives me insane. It just needs to be real quiet for me to take [the exam], so I think of it as a privilege” (H2: 2199). But when discussing the differences between privilege and rights, Helen changed her mind. “I guess a right; not a privilege. It’s just something I think of as I should get to do because I have ADD and it is a need I have in order for me to do better” (H2: 2209). In discussing about disclosing to faculty in order to receive accommodations, Helen does not experience any difficulties. In fact, she believed that it was the professor’s job to understand different learning styles.

I’m not ashamed to tell a professor that I have ADD. I think that’s something that they should, they’re a professor at a college or university, they should be prepared for students to come out to them. That’s part of their salary to adjust to different student learning styles. So I don’t feel, [pause], hey that’s their problem, if they have an issue with it, they should go talk to the administration, or SSD or whomever. (H2: 2280)

Helen’s story revealed an individual, who at one time struggled with understanding and accepting her disability, but is now comfortable within herself. Whether it was due to her personality, faith, or other support systems, Helen presented herself as a person with a disability, and was comfortable in saying that the disability was part of her identity. In our last email (personal communication,

March 4, 2002), Helen ended with a statement that summed up her journey in accepting the disability.

My process of accepting my disability as part of my identity was possible, because I had the inner strength and faith in God to get through the difficult times and because my family and friends were there to support me and encourage me. Throughout college, I've become more and more confident in my personality and character, which enables me to accept all of my strengths and weaknesses as who I am. I know there are areas I can work on to improve and areas I need to be humble about. It's been very helpful over the years, to identify my strengths and excelled areas, to keep my mind steady and if I ever get a little depressed now, I know to remind myself about the great qualities that will get me through the tough moments.

In terms of identity, Helen accepted the disability, even though she still had difficulties with the label. She experienced no problems with disclosing the disability or using services.

In the second group conversation, I introduced the concept of having a safe place to go, a place where having a disability was accepted and disability issues were freely discussed, a disability community, or for lack of a better term: a disability cultural center. With respect to the issue of community or center, Helen's story differed slightly from the other participants. When asked about community and the opportunity to speak with other students with hidden disabilities, Helen indicated that she perceived the research project as a small community. "That's what I can interpret our meetings and class to be like. I can go with people who, we may not be the same people or, be exactly alike in lots of ways, but we have some things in common that a lot of other people don't have"

(H2: 2048). In the third individual conversation, she thought the opportunity to see others wrestling with issues that she had experienced was positive.

Yeah I think it is good to see other people grasping with similar things, talking about what they have been through and what were the issues sometimes and having them talk about their background, their personalities, the reason why they have dedicated to their school work. Seeing how other people have taken their diagnosis and seeing what they have done with it. It is encouraging, it has been a positive thing to be, [pauses], to check out people who have similar, well maybe not the exact same as me but similar, to kind of identify with. (H3: 3057)

Although Helen thought the research provided an experience with community, she had more difficulties with this concept when applied to the university setting. She believed that having a disability community or center on campus would be beneficial, but then implied that it might be difficult to form if students believed that the center was more of a location for group therapy sessions. However, Helen communicated that if there was a disability group on campus she would go to the organization, but she would not “go religiously, like for someone else who did not have an organization to be a tight knit group with” (H3: 3080). Perhaps the difference between Helen and the other participants was that she had already found a group that she identified with: her sorority. “Because of the sorority, for me on campus, I felt that I have a group I can connect with, I can disclose information and I can, well it’s a small group, a group of girls I live with, but I think that is very beneficial” (H3: 3078). While Helen acknowledged that the participation in the research provided opportunity to discuss disability issues, she commented that she had already had the opportunity to speak about disability

issues because some of the other women in her sorority have a disability. She indicated that having other people with disabilities in her house has been a source of support. It appeared that not only had Helen found a support system in her sorority, she had also had the opportunity to engage in a small disability community within the sorority. Perhaps her situation was different from the others because of the opportunity to have a form of a community, which might have aided her in disability identity development.

In terms of what college student services administrators could do to foster the integration of students with disabilities into the campus, Helen believed that a class should be offered to incoming students with a disability. She believed that the class could be part of an Odyssey course or perhaps a separate course solely dealing with transitioning to the university. She commented that “it would be really great to get people into it, explaining that [having a disability] is not such a huge deal and it is beneficial to talk with other people (H3: 3161). In terms of what social and institutional changes could foster students’ integration into the university, Helen suggested teaching a course on disability issues. “Teach a class that is, like a bac core class, like sociology or something like that, or a lower division class that is optional, but most people would take. Raising awareness, not in an embarrassing or in a discriminating way, but just kind of promote it, educate people about what they should [know]” (H2: 2370).

CHAPTER 5: DISCUSSION

In this chapter, I will share my understanding of the participants' stories. Of interest to me was the manner in which the participants constructed their disability identity. I will first discuss the variance that occurred among the participants' stories, and how these variances differed from traditional identity development theories. Then I will identify the issues that appeared to contribute to or hinder the development of an identity that included the disability by relating the issues that emerged from the study to a broader body of literature.

For examining disability identity, the stories were intentionally arranged based on my perspective of the degree to which the participants had presented a positive disability identity. As such, Jill and Helen represented opposite ends of incorporating their disabilities into their identities. Jill's story could be considered as one of denial. Because she did not believe that she had a learning disability, I felt that she often bordered on denying the learning disability. Because of this denial, she experienced difficulties with using services and disclosing the disability for the purpose of obtaining accommodations. I cannot state that she completely denied the disability, however, as she did not have any difficulties telling friends that she had a disability.

Helen, on the other hand, incorporated her disability into her identity most of the time, but still did not always see herself as having a disability. Thus, I do not believe that she has fully accepted the disability, or its label, but portrayed a

movement toward accepting the label. Other than difficulties with the label of disability, Helen fully disclosed the disability regardless of the relationship with the person to whom she disclosed. Additionally, she experienced no difficulty with using services.

Positioned between these two extremes were Luke, Sally, Marie and Allison, each one of their stories contained elements of the stories of both Jill and Helen. These four participants had varying degrees of accepting or dismissing the label of disability. George, however, presented a different position regarding disability identity. He denied the label “learning disability” by firmly stating that any problems with learning did not lie within him, but within society or the educational system.

As the stories revealed, there was no linear movement from denial to acceptance of the disability. Instead, each story contained elements of denying the disability and movement toward accepting the disability label. With respect to disclosing the disability, none of the participants had difficulties with telling close acquaintances or friends about the disability, but all of them, except for Helen, struggled with disclosing to others for the purpose of obtaining accommodations. Thus, there was no apparent relationship between the denial or acceptance of the label, “disability,” and disclosure. For example, Jill denied the label but insisted that she had no difficulty with disclosure; whereas Sally recognized the disability, but had significant issues with disclosing.

If utilizing accommodations was viewed as another measure of the outward manifestation of a positive disability identity, then again there was no apparent relationship between acceptance or denial of the disability. For example, George did not accept the label and did disclose, but he experienced no difficulty with using services. Marie, however, manifested some elements of disability identity and had no problems with disclosing but experienced feelings of shame or perceived herself as a burden to others when using accommodations. Helen and George were the only participants who felt comfortable with using accommodations. The other five participants expressed a range of emotions about using accommodations.

Another issue revealed from the participants' stories was how the disability affected them in different contexts. Specifically, the participants in this study believed that the context, education, contributed to the label of disability. All of the participants, except for Luke and Allison, felt that the learning disability was not an issue in other aspects of their lives, and did not believe it would be an issue in employment. This insight differed from Skolnikoff's (1999) study that indicted the impact of the learning disability was prevalent in all aspects of her participants' lives. Given the complexity involved with constructing and presenting a disability identity, I returned to the literature on identity development for possible new insights.

Identity Development Literature Revisited

Identity development as described in the literature, typically began with a stage of internalized oppression or identification with the dominant discourse and ended with a stage of self-actualization or capacity to appreciate one's own race, gender or sexuality as well as other races, gender or sexuality. Embedded in this progression was the notion that as individuals developed an identity inclusive of a marginalized status, he or she would become more self-confident, able to navigate societal oppression (Cross, 1971), confident in disclosing (Cass, 1979), and defined by personal values rather than stereotypes (Downing, 1985). Borrowing from the array of identity models, the initial internalized oppression stage and the self-actualization stage to frame disability identity were useful as they provided an idealistic range of identity development.

What was not present in this study, however, was the individual who completely denied the disability. This was understandable as the pool from which the participants were selected, all had self-disclosed a disability in order to obtain academic accommodations. The individual with internalized oppression would not identify as having a disability, disclose to others, or use the accommodations offered by Services for Students with Disabilities office. The opposite, idealistic self-actualized position in identity development was also not present in this study. The self-actualized individual in disability identity would be one who identified and presented himself or herself as having a disability, perhaps portraying pride (Cross, 1971, internalization stage) in having the disability. As an outward

manifestation of disability identity, this individual would not have difficulty with disclosure or using services. It was my impression that even though there was significant variance among these participants, further research would reveal even greater variability.

Although the literature on identity development was useful for framing the variance within disability identity for hidden disabilities, it was insufficient. I believe the limitations were predominantly due to adherence to labels to define specific categories of people. For example, there was no discussion on whether or not one belonged in a specific group (African American, Hispanic, Asian) it was implied and accepted. This binary categorization had implications for the participants with hidden disabilities (disabled or able-bodied). The participants in this study did not identify with the normative picture of disabled, yet because they learned differently, they did not see themselves as able-bodied either. Thus, I turned to the Optimal Theory Applied to Identity Development (OTAID) (Myers et al., 1991) model and the Multidimensional Identity Model (MIM) (Reynolds & Pope, 1991). The OTAID model was limited due to phase 3 (*I focus my energy on people like me*) which identified the need to engage with others in the specific community as a necessary element to achieve a positive identity. The participants in this study, except for Helen, had never engaged with other individuals with learning disabilities. The MIM (Reynolds, 1991) model was informative, but I had difficulties with the assertion that regardless of where one was located in the theory, that each position provided areas of pride and dilemmas to maintaining a

sense of self. Specifically the first two positions, identify with one aspect of self (society assigned-passive acceptance) and identify with one aspect of self (conscious identification) did not reflect the participants' struggle with disability identity development. The participants in the current study reflected both activities simultaneously. They did not passively accept the society assigned disability identity, but neither would I conclude that in all cases that they were engaged in making a conscious choice of self-identifying as disabled or non-disabled.

The disability identity models were informative too, but were limited in their usefulness because they did not fully explain disability identity development. Wilczenski (1992) theorized three stages of identity: denial, exploration and acceptance. I think the three categories do not accurately depict the participants' stories, and there was a mixture of the three categories occurring simultaneously. Additionally, there was no mention of individuals refusing the label, "disability." Gill's (1997) model of integration was also not reflective of the participants' stories because her model focused on individuals with physical disabilities. Specifically, the first two types of integration, which pertained to integrating into society and integrating with the disabled community, did not reflect the participants' struggles. The participants were not struggling with admittance into society at large, but with the learning environment. Additionally, none of the participants were attempting to integrate with the disability community.

The models that had relevance for me were the models proposed by Grant (1996) and Cass (1979). Grant's model (1996) had relevance because of the

diffusion/dysphoria stage in which individuals struggled with the dissonance between the way they viewed themselves and the way others viewed them. However, her model became less applicable because she, too, embedded the immersion stage (the need to engage in the disability community) as a path toward a healthy identity. Cass' (1979) model was relevant because of the hidden aspect of sexuality identity that was similar to the hidden aspect of learning disabilities. Cass' (1979) model was useful regarding the initial stage of Homosexual Identity Development identified as "role confusion". However, the marked difference between homosexual identity and disability identity was the legal requirement to disclose a disability regardless if one had accepted the label. There was no opportunity to become comfortable within one's "skin" first, progressing to disclosure to close friends, and finally engaging in a specific community in order to facilitate the forming of the disability identity.

The development of a disability identity did not progress through the classic identity developmental stages of internalized oppression, questioning the status, slowly reaching out to others, eventually becoming self-actualized. Rather, the development of disability identity was not the private internalized process as seen in the dominant discourse for identity development. Thus, I began to question whether or not using a developmental model of identity was applicable to formulating a disability identity. But if I had used the developmental identity model literature to explain the participants' identity, I believe that most of the participants would have been housed in the first stage of identity development --

either conformity, pre-encounter or foreclosure -- depending on the model. But this would be unjust to the participants, as the progression of disability identity was markedly different from identity development based on race and gender, and even sexual identity. Perhaps the lack of an accurate label explains the conflicting and often vacillating responses from the participants. In the absence of a reference group or societal "norms" for individuals with hidden disabilities, each participant had to find their own personal meaning of their disability. Understanding that the participants struggled with the ambiguity of their social positioning impacted my understanding regarding the difficulties with developing a healthy disability identity. This understanding has impacted my interactions with students with hidden disabilities and has impacted my practice.

As stated earlier, the purpose of this study was to inform my praxis. Having worked for seventeen years in the field of disability services, I had assumed that by the time the individual presented himself or herself to the Disability Services Office in order to receive accommodations, he/she had developed some acceptance of the disability. But as this study revealed, this was not the case. There were several issues that complicated the development of a healthy disability identity. Based on my understanding of the information collected in the conversations with the participants, the issues related to disability identity development for individuals with hidden disabilities were (a) identity confusion -- neither able-bodied nor disabled, (b) identity refinement -- perceptions of the other, and (c) identity reconciliation -- using accommodations.

Identity Confusion --Neither Able-bodied nor Disabled

Identity development in individuals with hidden disabilities can be characterized by confusion. This finding was not surprising to me. Through my work with students with disabilities, I recognized that students with learning disabilities did not consider themselves as disabled. However, the confusion over the label “disability” was so significant that I must address this issue as it was foundational for disability identity development. Although I knew students with hidden disabilities wrestled with this label, it was informative to note the amount of energy spent in the effort to find a space between the visibly disabled and the “normal.” In this study, all the participants appeared to have difficulties with the label “disabled”, as they did not consider themselves as having a disability because they did not meet the normative portrait of a person with a disability. Evidence of this subtle positioning between able-bodied and disabled could be found in the language used by the participants.

In the participants’ stories, there was evidence of identity confusion that resulted in denying the disability, denying the label, ambivalence towards the label or movement toward accepting the label. In comparing the two capstone cases of Jill and Helen, identity confusion resulted in two forms – denial of the disability or movement towards acceptance of the disability and the label. For example, Jill stated she did not have a disability in reference to the cerebral palsy. Although she denied having a physical disability, she then proceeded to state that she had worked

“very hard her whole life to be normal” (J1: 1071). This implied that she did not view herself as normal. Also noted was Jill’s reaction to being tested for a learning disability which appeared to have been very stressful, as she would have to admit there was something *wrong* with her, (J1: 1065) or that she would have to admit to having a disease (J1: 1068). Jill resolved the dilemma of being labeled as disabled by discounting the learning disability diagnosis. Thus, Jill positioned herself between society’s stereotype of disabled and society’s concept of a “normal” person. But Jill’s positioning reflected an internalized belief of the negative stereotypes of disability, resulting in self-flagellation for not meeting societal standards.

In Helen’s story, the struggle against the categorization of “disabled” status was also apparent. In the first interview when she discussed how she conveyed to her sorority sisters what she needed to participate in the organization, she stated, “I told the girls that I have ADD, and I need you to not do these things, but it is not a big deal. I didn’t say [pause], I am *so* a normal kid” (H1: 1172). Even when Helen firmly indicated that the disability was part of her identity, her next statement was, “But I am not abnormal” (H3: 3168). However, Helen’s resolution of her ambiguous status differed from Jill’s. Helen’s faith removed the “less than” status because to do otherwise would imply that God had erred. “God has a plan for you, and God has, ... he made you special who you are. Not special good or bad, just he made you, in mind for you.” (H2: 2257).

The other participants were again positioned between Jill and Helen with Sally's story revealing ambivalence toward the label of learning disability and George's story revealing a self-defined position. It was within Sally's story that the ambiguous positioning between the normative view of disability and the normative view of the average person was most evident. Sally stated, "In my mind when I heard people say the word, "disability," I never thought of myself. I always thought of somebody who was in a wheelchair or somebody who had an appendage missing [pause] somebody that was physically disabled [pause] or somebody with Down's Syndrome" (S1: 1981). Sally positioned herself in the able-bodied realm. But Sally's position as "not disabled" yet "not normal" was revealed in the conversation regarding her boyfriend and his disbelief that she had a learning disability. When asked if she had spoken with him about why he was denying that she had a disability, Sally responded, "Well, umm, he doesn't like it when I talk about it, you know. I think it bothers him when I'm not normal [pause]. He doesn't want to think of me as not being normal" (S3: 3371). For Sally, not being normal was influenced both by her experiences in special education where she believed her peers and teachers perceived her as "slow" or "stupid," and by not conforming to socially prescribed gender roles. Sally did not resolve this ambiguous position by the methods used by Jill or Helen. Rather, she acknowledged the differences, vehemently denied the label and portrayed more of an ambivalent attitude regarding her own ambiguous position. While all of the participants ranged between denial, ambivalence and a movement toward accepting

the disability, George found a different resolution: he did not accept the label, “disabled.” George did not believe that anything was wrong with him, but that the educational system labeled him because he did not meet the societal expectations of the average student. Thus, George self-defined his learning disability as not inherent but more situational.

Most of the participants did not deny they had difficulties with learning; they questioned the label, disability. However, as acceptance or identification with this label was foundational for disability identity, it behooved me to understand the barriers to incorporating this identity marker. Because the literature in CSSA did not provide this information, it was necessary to investigate additional literature that would provide assistance with interpreting the participants’ stories. As a social constructivist, I needed to investigate the influences of Western culture on disability. Because knowledge is constructed between the participants and their interactions with the external environment, identity development is “... located in the core of the individual and yet also in the core of his [sic] communal culture” (Erikson, 1968, p. 22).

In 1993, Irving Zola stated that: “The vast majority of people who are born with or acquire [disabilities] do so within families who neither have these conditions nor associate with others who do. They are socialized into the world of the ‘normal’ with all its values, prejudices, and vocabulary” (Zola, 1993, p. 16). Understanding the world of the normal or what constituted the “average person” or the “ideal person” provided the framework for understanding the participants’

stories with respect to identity, interacting with others, accommodations, and community. Beginning with the notion that we are socialized in the world of the normal, I investigated the literature on the binary categories of the normal - abnormal identity marker. Utilizing the participants' interpretation of their experiences, I attempted to identify the positions that individuals with hidden disabilities appeared to occupy and the impact on identity development.

In *Enforcing Normalcy*, Davis (1995) provided information on the construction of normalcy in Western culture by investigating the history of terms such as "normal," "normality," "average," and "abnormal." He found that the creation of the concept "normalcy" emerged in the nineteenth century, simultaneous with the statistical model of a normal distribution curve. The statistical model to identify the norm and subsequent variance when applied to humans began the categorization of traits that were deemed of value. "An important consequence of the idea of the norms is that it divides the total population into standard and nonstandard subpopulations" (Davis, 1995, p. 30). Identifying characteristics that could be identified as "normal" and by default, "abnormal," appeared to be an historical obsession, starting with Aristotle and culminating in the early nineteenth century with a positivist mentality. A positivist mentality adheres to the belief in the existence, as truth, of "the average person" construct. "The cultural dilemma regarding the extent to which individual variations could be tolerated within a society based on freedom and equality was solved by installing the average man [sic]...[that] embodied humanity's regularity

and stability, around which particularities ranged on a short leash” (Thomson, 1997, p. 64).

In positing what was considered the “average person” in American mainstream culture, the image was a “white, European, Protestant male who invariably was also a member of what was recognized as the middle class” (Naylor, 1998, p. 56). Goffman (1963), in his treatise on stigma, added college educated, fully employed, good complexion, average weight and height, and a recent record in sports to the “average person” list. Thompson (1997) refined Goffman’s list when she clarified that “...able-bodied superiority appears natural, undisputed and unremarked” (p. 20).

Utilizing the concept of normalcy to reveal characteristics previously unchallenged as the norm, and thereby establishing the “other,” is not a new practice. Revealing the hegemony of normalcy has been used by other marginalized groups who have been devalued due to variance from the idealistic norm, based on gender, race, class and sexuality (Davis, 1995; Thomson, 1997). In most cases, these “variances” pertained to physical appearances.

Establishing normalcy for individuals with disabilities was also based on obvious physical characteristics. Utilizing the corporeal form as the foundation for discrimination was the focus of Thomson’s 1997 book, *Extraordinary Bodies*. She utilized the concept of normalcy to compare the “ideal body” to the degradation of those individuals with physical disabilities who did not fit into this idealized concept. Thomson’s (1997) examination of America’s freak shows showed that by

defining what constituted “bodily otherness” reinforced normalcy. The freak shows “...offered to the spectators an icon of physical otherness that reinforced the onlookers’ common American identity, verified by a body that suddenly seemed by comparison, ordinary, tractable, and standard” (p. 17). Thus, the concept of normalcy provided the foundation of the socially constructed categories able/normal and disabled/abnormal. However, this binary construction appeared to focus on the physical body or behaviors that deviated from the idealized norm.

A review of the disability studies literature that pertained to the textual and visual representation of disability, revealed a wealth of material regarding physical disabilities, developmentally delayed or mental retardation and psychological disorders (e.g., Thomson, 1997; Shapiro, 1993; Wilson, 2001; Eiesland, 1994; Davis, 1995; Gartner & Joe, 1987; Hevey, 1992; Mitchell & Snyder, 2001). Although this was a useful methodology to deconstruct the notion of normalcy and disability, it also reinforced the stereotypical belief “...to think of ‘the disabled’ as the deaf, the blind, the orthopedically impaired, [and] the mentally retarded” (Davis, 1995, p. 8).

This normative view of “the disabled” complicated identity development for individuals with hidden disabilities. As students with hidden disabilities do not have a visible marker to denote their state, their status becomes contested. However, simply because the participants did not place themselves within the category of disabled, the language they used did imply that they realized that they differed from the “average person.”

To understand where students with hidden disabilities positioned themselves, it was necessary to look at the language the participants' used in describing the disability. Throughout the conversations, the participants used words, such as normal, abnormal, wrong, dumb, stupid, when discussing how they perceived the disability and how others perceived individuals with disabilities. Investigating the terms or stereotypes applied to individuals with disabilities exposes the underlying belief system in Western culture toward individuals with disabilities. Oliver (1996) indicated that "...to have a disability is to have a problem, to have a disability is to have 'something wrong with you'" (p. 129). Because of the "abnormal" marker ascribed to having a disability, it was not surprising that stereotypes and prejudices against people with disabilities exhibited the overwhelming theme that people with disabilities "are innately incapable; ... are naturally inferior..." (Bogdan & Biklen, 1993, p. 69). Eiesland (1994) proclaimed that people with disabilities had been named by medical and scientific professionals and that "[t]hese professionals considered disabled persons to be less intelligent, less capable of making the 'right' decisions, less 'realistic,' and less self-directed than non-disabled persons" (p. 25). In most cases, these stereotypes have been applied to individuals with visible disabilities, but it was evident that individuals with hidden disabilities confronted the same stereotypes, solely because of the label, disabled. The normative view of disability and the stereotypes regarding disabilities revealed the positioning or space that individuals with hidden disabilities occupied. It was within this space, where societal and cultural

experiences were intertwined, that the struggle to incorporate a disability into identity occurred. The participants' stories elucidated the ambiguous positioning between the able-bodied and "the disabled," which made the development of a positive disability identity difficult to achieve. In identity confusion, much of the angst pertained to the participants' attempt to find a position that would reflect his or her, own perspective. But in the midst of struggling with developing a disability identity was the influence of "the other," whether "the other" constituted other individuals or the educational system. Because of the difficulty with the ambiguous positioning due to the hidden disability and the substantial influence of the other on the participants (identity refinement), the term "identity development" does not accurately reflect how the participants formed a disability identity. As identity development implies an internalized process of forming a disability identity. From this point forward, I will no longer use the word "development" to frame the formation of disability identity but propose that the participants were engaged in constructing a disability identity which takes into account why the participants were so impacted by "the other." The struggle to construct a positive hidden disability identity became more convoluted and refined due to the interactions with other individuals. These external influences contributed to the next issue of disability identity construction, identity refinement.

Identity Refinement – Perceptions of the Other

The second issue that emerged from the conversations with the participants pertained to how others perceived them when the disability became known and how the participants' reacted to those perceptions. All the participants had disclosed the disability to friends and did not indicate any difficulties with this type of disclosure. It appeared, therefore, that perhaps these participants were in the identity acceptance stage (Cass, 1979). The participants, however, did not always have the option of selective disclosure. To obtain accommodations, the participants had to disclose that they had a disability, while still wrestling with how this label impacted their identity. Thus, the individuals with hidden disabilities had to publicly claim the label, "disability." It is within this public domain that the participants with hidden disabilities refined their identities, as they were both labeled and discounted as disabled by others. Many of the difficulties the participants in this study encountered with other individuals pertained to the same issue identified in identity confusion, which depended on the normative view of disability. How the participants' managed the perceptions of the other in constructing their disability identity appeared to result in three possible positions: other-defined, movement towards acceptance of the label and self-defined. These positions were exhibited in Jill's, Helen's and George's stories. The other four participants fell within these positions. For simplicity, I use the image of a triangle to depict the three positions. It should be noted that the participants might experience elements of all three positions depending on the context.

In Jill's story, her academic performance forced her to confront the impact of the disability. By accepting the need for accommodations, she had to present herself as disabled. Much of Jill's story pertained to how others defined and labeled her as disabled. In our conversations, Jill spoke about her family's negative reactions to her disability ("why take home something so bad") (J1: 1101), her negative interactions at school ("made me sit out...not play 'cause I was lazy") (J1: 1131), and her note taker's patronizing behavior ("she's really condescending of me and I'd like to kick her sometimes because she's really condescending") (GP2: 2255). Although she cognitively discounted what others implied about her as an individual (refusing the label of disabled) she appeared to incorporate the beliefs of other individuals regarding the disability. She internalized and reduced the actions and behaviors of others to one statement: "Like instead of saying, 'it's because I have a disability', I say, 'No, it's because I am not good enough'" (J2: 2075). Even, when again reviewing all of her transcripts, Jill did not appear to interpret any experience that pertained to her disability and interactions with others as positive, including participation within the study: "I think actually thinking about the disability stuff actually lowered my confidence level" (J3: 3134). Given her background and experiences, Jill expended a significant amount of energy in the attempt to refute being defined as disabled. Yet her story exemplified the internalization of others' perceptions. Jill's story was the only one that reflected this positioning; perhaps her story differed from the other participants due to the cerebral palsy.

Helen, too, identified some difficulties with how others perceived her disability, specifically as she attempted to articulate her needs to others. For example, when she disclosed to her sorority her disability and the accommodations she needed, they perceived the disclosure as a joke and did not really consider her request. Helen's interpretation of the experience was that her sorority sisters did not understand and was not that they were contesting that she had a disability. Perhaps this interpretation reflected Helen's acceptance of the label, "disability". Although she struggled with the term "disability" in the first group interview, she did claim or accept that she had a disability (GP1: 1641). This movement toward accepting the disability allowed her to view herself in a positive manner, freed her from the need to maintain secrecy, and allowed her to articulate her needs in a manner that would facilitate success. "And people try and put down ADD...it's not a bad thing to have ADD. It's okay, lots of people have it, and it's kind of reinforced the fact that...I'm fine with who I am and it's part of my personality" (H2: 2263). Helen's story demonstrated a movement towards accepting the label, and there was no evidence that she accepted the "less than" position. Rather, the ADD was another facet of her personality. Positioned between Jill and Helen were Luke, Sally, Marie and Allison.

The last position is the self-defined position, and George epitomized this position. Although George started developing disability identity as defined by others, his peers and special education, he appeared to have moved beyond that positioning. George resolved his identity confusion by denying the label

“disability.” He was not disabled, he learned differently from the norm. “I identify as having a disability maybe in the definition of a disability, because I am different than the norm as far as my reading ability...I also think in some cases the definition of having a disability is only relevant to society’s standards” (G2: 2163). Thus, George defined himself as learning differently but that the educational system’s adherence toward one learning style created the disability.

In Jill’s, George’s and Helen’s stories, the influence of “the other” was present, but it was within Sally’s and Marie’s stories that the difficulties with developing disability identity in the presence of others occurred. For example, in Sally’s story, she indicated that one of her family members stated that she did not really have a disability and that it was just an excuse. Sally’s understanding of her own disability, as either a disability or an excuse, was reflected in her perception that other individuals with learning disabilities were not trying or used the disability as an excuse. Although Sally stated that she was not using the disability as an excuse, I interpreted her concerns on this issue as a barrier to developing a disability identity. Thus, I perceived Sally as still trying to define the disability in a manner that made sense to her. She was neither other-defined, self-defined nor accepting of the societal label of disability. In reality, she was a mixture of all three.

Marie’s story revealed how contentious disclosing a disability can be, especially given the competitive nature of engineering. This was evidenced by the comment from a friend that he thought the disability was simply an excuse and

doubted that she had a learning disability. There were other comments regarding learning disabilities that Marie shared which indicated that she had to navigate others' skepticism regarding her disability. It appeared that for Marie having to defend the position of having a disability facilitated the movement towards accepting the disability label.

For all the participants in this study, the construction of a positive disability identity was complex and complicated due to the expectations or dismissive attitudes of other people. Yet, the only position that had a negative impact on identity as a whole was Jill's position as being "other-defined." The other two positions or a variation of these two positions - self-defined or movement towards accepting the label of disability - appeared to produce a healthy identity. Perhaps not in terms of a healthy disability identity, but the outcome was remarkably similar, producing self-confidence and high self-esteem. The "self-defined" label was noted in Ferri's (1997) dissertation where she stated that her participants made their own definition of the label "learning disability" in order to have a healthy identity.

In terms of a healthy disability identity, Allison and especially Helen were examples of the movement towards accepting the label of disability. Helen did not appear to wrestle with what the label "disability" meant to her. Rather, she focused on the fact that although she had a disability, she was not "less than" by societal standards. She did not portray disability pride, but her movement toward accepting the disability allowed more freedom in disclosing the disability which

was not the case when one decided to self-define the disability. Thus, the only indicator of difference between the two positions, “self-defined” and movement toward accepting the disability label, pertained to disclosure. Helen had no difficulties with disclosing because her acceptance of a disability as one facet of her identity removed the negative stigma. George, in contrast, had difficulties with disclosing, because his definition of a disability was more environmentally based and conflicted with the dominant perspective that disability was an individual experience.

As stated previously, the opportunity to construct a healthy disability identity was complicated due to the legal requirements of disclosing in order to receive accommodations. This forced disability identity construction into a public domain. The participants with hidden disabilities were both labeled and discounted as disabled by other individuals. In all cases, students were confronted with either the stereotypical portrayal of disability or skepticism. The participants’ stories provided numerous examples of being labeled as “dumb” or incapable of succeeding academically. This was especially true for individuals who were involved in special education.

Regarding special education, Corbett (1996) stated that: “...if we detach this word [special] from its anchor in ‘educational’ we can see that ‘special’ does not mean especially good and valued...it is linked to ‘needs’ which implies dependency, inadequacy and unworthiness” (p. 3). Additionally, given societal

perspectives about disability, which were mentioned under the rationale for identity confusion, external influences substantially shaped disability identity construction.

The process of identity formation with respect to individuals with disabilities cannot be understood without reference to the historical process leading to the formation of cultural images of disabled people. Cultural images have portrayed disabled people as less than or more than human and have been reinforced by professional conceptions of disability as adjustment to tragedy or the management of stigma... thus the disabled identity is not formed simply through internal psychological processes but may be externally imposed. (Oliver, 1990, p. 76-77)

Whereas the media has contributed to the cultural image of “less than” for individuals with obvious disabilities, it has complicated and shaped the discourse pertaining to learning disabilities and ADD/ADHD. The types of cultural images regarding ADD/ADHD and learning disabilities expressed to the public were imbedded with skepticism. For individuals with ADD/ADHD, the media has contributed to the controversy on whether or not these diagnoses are genuine (Nadeau, 1995; Robin, 1998). “The most radical reformulation of ADHD has been to deny its validity. Is ADHD a valid syndrome or entity, or is it somehow an invention of self-interested professionals, support groups, lobbyists, or businesses that stand to benefit from its existence? This question surfaces regularly in the media in the United States” (Robin, 1998, p. 41). Especially contentious was the issue that ADD/ADHD persisted into adulthood. “Many in the general public do not yet recognize ADD in adults as a legitimate disorder” (Nadeau, 1995, p. xiii).

Perhaps the level of skepticism regarding ADHD can be found in the following statement:

Because research now documents that ADHD symptoms tend to persist beyond adolescence, assignment of the diagnosis to adults has been transformed from a rare event just 10 years ago to a popular and seemingly sought-after psychiatric label. Also, a blizzard of media stories, editorials, books, and magazine articles has propelled ADHD to star status within the orbit of mental health disorders... It has been called a “diagnosis du jour,” a “boutique disorder,” and “psychofad.” (Gordon & Murphy, 1998, p. 98)

This type of review of ADD/ADHD unfortunately contributes to the controversy surrounding the diagnosis and exacerbates the belief that individuals with these types of diagnoses do not have legitimate disabilities.

Skepticism about learning disabilities has been encouraged by academicians and diagnosticians who argue amongst themselves regarding the reliability of diagnostic tools for identifying a learning disability (Brackett & McPherson, 1996; Brinckerhoff et al., 1993; Kelman & Lester, 1997; Lorry, 1998; Lyon, Gray, Kavanagh, & Krasnegor, 1993). “Indeed, there is little agreement among psychologists and educators about the interpretation of the definition of learning disabilities and eligibility criteria, as well as about which psychometric methods should be used” (Brackett & McPherson, 1996, p. 69). Beyond the problems associated with diagnosis, the media has implied that the creation of the category of learning disability (LD) was a means to explain why white, upper and middle class children were not successful (Kelman & Lester, 1997). If the general public, and especially peers and faculty in higher education, assume that the categories of LD

and ADD/ADHD are fictitious, merely masking poor academic skills, then it becomes clearer why the participants' struggled with disclosure and girded themselves for negative comments.

Disclosure issues have been discussed in the CSSA literature (Aune, 2000). Previous research (e.g., Lynch, 1996, Beilke, 1999) and recent research (Olney & Kim, 2001) on disclosure explained that the difficulty with disclosure was related to the fear of discrimination and the stigma associated with having a disability. Although the participants in this research did not frame their concerns with the words "discrimination" or "fear," their stories revealed how oppressive it can be to claim a hidden disability. For the participants with hidden disabilities, discrimination and stigma were the result of having to defend oneself against being stereotyped as "less than" if the disability was believed, or perceived as a fraud, using a fictitious diagnosis to obtain unwarranted accommodations, if the disability was not believed. Both of these perspectives contributed to the complexity of constructing a disability identity. These perspectives also explained the difficulties the participants' encountered regarding the use of accommodations.

Identity Reconciliation – Use of Accommodations

The last issue of disability identity construction pertained to the use of accommodations. I used the term, "reconciliation," because at minimum the participants had to cognitively accept that they did have a learning disability that impacted their academic performance. If the use of accommodations was perceived

as the outward manifestation of disability identity, then where the participants were positioned – other-defined, movement towards accepting the label and self-defined--- had consequences for how they viewed the use of services.

Jill and Helen were, again, the boundary markers for the variance found in how the participants viewed the use of services. Jill's story, consistent with her positioning in identity refinement, made clear that she had substantial difficulties with using accommodations. She berated herself because she believed that she should not use services. "I am just pissed at myself because I need to not have note takers and I need to not take tests [with additional time]" (J1: 1203). Jill's difficulties stemmed from her perception that if she used services her degree would be worthless: "I don't want to feel like my degree is less. That's it, and that's my issue. I don't want to graduate and be thinking that I didn't work as hard as everybody else is" (J1: 1262). Jill made this statement during the first group conversation, but she also appeared to recognize that she needed to re-evaluate her position. "But I have a real issue with myself that I don't feel, like, with receiving services that I deserve as much as other people and I have to change that thinking in myself" (GP1: 1341). Jill's story demonstrated an internalized self-devalued position.

Helen, on the other hand, did not have difficulties with using accommodations. She initially viewed the use of services as a privilege. But when pressed, she changed her mind. "I guess [it's] a right; not a privilege. It's just something I think of as I should get to do because I have ADD, and it is a need I

have in order for me to do better” H2: 2209). Helen did not exhibit any anxiety about using services or believe that the use of services devalued her accomplishments. The other participants were a mixture of Jill’s and Helen’s stories. What was not reflected in the stories of Jill and Helen were the participants’ emotions of guilt while requesting services and their apprehension about how others perceived their use of services. These emotions, although reflected in various degrees in all of the stories, were pronounced in Marie’s story.

Marie discussed two issues connected with using services, being a burden to others and the perception of others that by using services she was cheating the system. In the second group conversation, Marie stated, “I always feel like I’m always a burden when I take services” (GP2: 2606). This comment referenced the fact that her professors had to arrange for alternative testing and were required to reschedule their time in order to accommodate her. The issue of being perceived as a burden was present in Luke’s story as well when he discussed his concern with using note takers. “Like I talked about, umm, like they’re going out of their way for me, and I don’t know, [pause], sometimes I feel that can be like, umm, a disadvantage, umm, like, [pause], I usually don’t like to ask people for help and stuff like that” (L2: 2184). The participants also struggled with their own doubts with using services. For example, in Allison’s story, she began to feel that she was cheating because she had more time on exams.

In the midst of grappling with their own conflicting emotions regarding the use of services, the participants had to negotiate the opinions of other peers and

faculty. Marie highlighted the issue of being perceived as cheating if she received accommodations. Again, her comments were in reference to her professors and are apparent in the following exchange regarding her professors' willingness to accommodate her on exams.

Tracy: What about the faculty?

Marie: Oh that's been a challenge. Some professors I go into and they have the attitude, they don't want to give you time and a half, they don't want you to take your test by yourself or anything like that [pause]

Tracy: So do you think there's an underlying message that you get sometimes from faculty?

Marie: Yeah, yeah

Tracy: What message do you think they're sending?

Marie: let me try and think, umm, probably us as being cheaters; cheating by taking time and a half, where all the other kids are given an hour and we're given an hour and a half [pause]. I guess they just think of us as having an advantage over the other kids and stuff. M1: 1136

Marie's story revealed that other students and faculty maintained the perspective that receiving accommodations was unwarranted and should not be provided. This was further indicated by the comment from one of her peers that special privileges should not be awarded. This peer compared natural ability as the prerequisite to participating in the National Basketball Association (NBA) and implied that, similarly, natural ability should be the prerequisite to participating in the engineering program. Any deviance from this basic premise established an

inequitable system. This perspective was based on the belief in equality and individual achievement prevalent in society. Clearly, the participants themselves grappled with the issue of equal access due to the disability versus being perceived as receiving special privileges. It is important to note that the use of services in order to be successful in higher education appeared to complicate the issue of disability identity. Requesting accommodations often involved managing the stereotypes of disability and, because of the hidden aspect of the disability, the participants encountered skepticism about the validity of the disability.

Perhaps the stereotype prevalent in society that the educational system was established for white middle class America, might explain the angst in these participants with disabilities in using services and the perception that using services provided an unfair advantage over other students. Because I was specifically interested in why students with disabilities wrestled with using services, why peers made disparaging remarks about the use of services, and why faculty were reluctant in permitting accommodation, I returned to the literature in CSSA. Specifically, there were two volumes in *New Directions for Student Services* (Belch, 2000; Kroeger & Schuck, 1993) and one monograph from *the National Association of Student Personnel Administrators* (NASPA) (Ryan & McCarthy, 1994) that pertain to students with disabilities. The two publications printed in the early 1990s did not address disability identity or issues with disclosure and using accommodations. Belch (2000) does not deal with the issue of disability identity, but does include information about the difficulties with disclosing a disability. There was also

discussion about accommodations, this discussion centered on who qualified as disabled, and whether or not accommodations lowered academic standards. Beyond the legal implications of disclosing and accommodation, there was no discussion on the underlying rationale behind the problems with disclosing or using accommodations. A more recent article (Upton & Harper, 2002) indicated that students who were deserving of accommodations were the students with disabilities who were most dissimilar from the students without disabilities. This finding of “deservedness” was similar to the issue of normalcy and American individualism found in my research. The literature on faculty who resisted in providing accommodations (deservedness) does not identify the issue of normalcy of the learning environment, but, rather focused on the concern of maintaining academic integrity (Beilke, 1999; Scott & Gregg, 2000). Kroeger (1993) provided a rationale for faculty. “[S]ome faculty see them [accommodations] as intrusive, as giving disabled students an unfair advantage, as lowering standards, as interfering with academic freedom or as imposed on them by an administrator fearful of lawsuits” (Kroeger, 1993, p. 63). While the words infer that adherence to standards was the basis for faculty reluctance to provide accommodations, Kroeger (1993) did not address the ideology that contributed to this perspective in the first place.

I believe that the ideology of individualism provides the key to understanding the difficulties associated with requesting and providing accommodations. Individualism from the American perspective is where “the state assures individuals their freedom and rights, grants them security and protection,

but respects their autonomy by not interfering unduly in their personal lives” (Stewart & Bennett, 1991, p. 133). Thus, I have come full circle because much of the literature pertaining to disability issues holds that individualism is the root of oppression against individuals with disabilities. The literature on individualism, however, focused on self-government, self-determination, autonomy and progress (Albrecht, Seelman, & Bury, 2001; Davis, 1995; Oliver, 1990). Although this does in part reveal why faculty resented being told that they must provide accommodations (self-government), it did not reveal why the participants in this study as well their peers and the faculty wrestled with the provision of services.

Further consideration of individualism revealed that the major orientation or values of what constituted mainstream American culture were instrumental in explaining the problems associated with using accommodations and providing accommodations. “Mainstream American culture is what all the members of the culture believe exist... and strive to become part of, irrespective of their origins or other cultures with which they might identify. It represents the standard by which they will judge themselves and be judged by others” (Naylor, 1998, p. xi). Although there are a variety of values and assumptions by which Americans live, they tend to not be aware of them (Naylor, 1998). Spindler and Spindler (1990) indicated that the values of the American culture could be summed up as (a) equality – all [persons] are created equal, (b) honesty is the best policy, (c) anyone can be successful, if they work hard enough (achievement), (d) the individual is unique and supreme, (e) time is precious, (f) and there is no use “crying over spilt

milk” (p. 26). Although these values reflect mainstream values associated with the middle class, white male, they are the values that I believe influenced the participants and faculty. These values are present in higher education, because higher education has been structured around the philosophy of a liberal education: “The central idea of liberal education is therefore the idea of individualism and individual freedom” (Taylor, 1960, p. 10). For the purpose of this study, the values that were confronted within the context of higher education pertained to equality and achievement.

Relative to equality, “Americans tend to be suspicious of anyone who does not profess equality, meaning (in America) sameness and nonexceptionability... If one is an expert about anything in America, it is best to express humility and emphasize basic human commonness” (Spindler & Spindler, 1990, p. 29). Although Americans profess to value equality, albeit they know it does not exist, equality and commonness become more complex for individuals with hidden disabilities. They appear as “normal,” yet, in order to receive accommodations they must profess inequality or exaggerate their difference. The debate over the diagnosis of LD and ADD/ADHD and the lack of a visible disability seems to explain the reluctance of faculty to provide accommodations as well as the belief that students with hidden disabilities are not entitled to accommodations.

With the passage of the Section 504 of the 1973 Rehabilitation Act (Public Law 93-112), Individuals with Disabilities Education Act of 1975, (Public Law 101-457) (formerly Public Law 94-142, Education for All Handicapped Children

Act), and the Americans with Disabilities Act of 1990 (Public Law 101-336), individuals with disabilities were provided greater access to public and private facilities, programs, education, employment, transportation, and telecommunications. These laws, however, created complications for individuals with hidden disabilities with respect to “who qualifies”. For individuals with visible disabilities, “[the law] demands that one embrace an adverse label to qualify for protection. What could be more demeaning than having to earn one’s human rights by showing that one is eligible to receive ‘special treatment’ by virtue of being a member of a socially discredited group” (Bickenbach, 2001, p. 577)? For individuals with hidden disabilities, it is more demeaning to have their human rights contested because they are not perceived as being a member of a discredited group. Both the authenticity of their disabilities and the appropriateness of receiving accommodations are publicly debated. This situation would present a barrier for constructing disability identity, especially in a society that values equality.

As for achievement, “[a]chievers are always admired, and this serves to motivate most Americans. The ideal person is the hard worker...” (Naylor, 1998, p. 59). In each of their stories, the participants referred to their efforts and hard work to be successful. Effort alone for these participants, however, did not equate with achievement in the educational system. The societal value that the individual can succeed, despite adversity, drives the mentality of the need to overcome the disability. While striving for a goal is admirable, for individuals with disabilities in

the educational system it can be an exhausting and self-defeating endeavor. Linton (1998) stated that "...when disabled people internalize the demand to 'overcome' rather than demand social change, they shoulder the same kind of exhausting and self-defeating 'Super Mom' burden that feminists have analyzed" (p. 18). For all of the participants, except for George and Helen, this drive to "overcome" often left them isolated and anxious. It was evident that the participants grappled with the societal value of individual achievement. This explained why the participants, during all of the conversations, stressed that they worked very hard to be successful and feared that they might be perceived as charlatans for using accommodations. Use of accommodations was equivalent to not fulfilling societal expectations that achievement is an individual endeavor. Many faculty and peers without disabilities adhere to the belief that there is value in achieving without assistance. If assistance is provided, then it negates the achievement. It was a "Catch 22" situation in that the participants, faced with academic failure if they did not use accommodations were perceived by others as not being worthy to participate in higher education because they used accommodations. The value of achievement made it extremely difficult to construct a positive disability identity.

Tied to achievement and equality is the value of fairness. "[A]ll Americans want to believe that the opportunities for this [achievement] are available to them individually and no one is precluded, given special privilege, or treated differently than anyone else (equality) (Naylor, 1998, p. 59) The issue is then, that in order to

be fair all individuals must be treated the same. Not being treated the same seems to explain the reactions of the participants who felt they were cheating because they were given accommodations. "Fairness" also seems to explain the reactions of non-disabled peers and faculty who held the opinion that by being provided accommodations, individuals with disabilities were being given an unfair advantage over others. All of the participants wrestled with the value of fairness except for George and Helen. Helen believed that accommodations were at first a privilege, but then stated that accommodations were something she was entitled to because of the disability. George also did not perceive the use of accommodations as "unfair." He recognized that the environment created the problem because the system was constructed based on the normative view of learning. Unfortunately, the general public as well as most academicians does not recognize how the educational system has been unfair because it is based on normalcy.

While many progressive intellectuals have stepped forward to decry racism, sexism, and class bias, it has not occurred to most of them that the very foundations on which their information systems are built, their very practices of reading and writing, seeing, thinking, and moving are themselves laden with assumptions about hearing, deafness, blindness, normalcy, paraplegia, and ability and disability in general. (Davis, 1995, p. 4-5)

The fact that higher education was founded on the normative view of learning has created a contentious position for disability services providers. Much of our time has been spent, not in providing accommodations, but in wrestling with our own perceptions of equal access, warrantability and justification for the provision of an accommodation, and in discussions with faculty about their

perception of equal access and reasonable accommodations. Regardless of how others viewed the issues of equality and achievement, for the individual with a hidden disability the public debate over the diagnosis and the subsequent debate over providing accommodations provided insight into the complexity of constructing a disability identity. For me, addressing normalcy and American individualism and how these ideologies impacted and shaped the lives of individuals with and without disabilities provided the framework for understanding the difficulties with constructing a healthy disability identity for individuals with hidden disabilities.

CHAPTER 6: IMPLICATIONS

In this chapter, I will discuss the implications of the insights reported in Chapter five for me personally, for disability service providers and college student services administrators. Then, I will discuss the limitations of the study as well as make recommendations for future research.

The first insight for me was that the participants in this study did not engage in a linear progression of disability identity development as proposed by the developmental theorists of other identity models (Cass, 1979; Cross, 1971; Erikson, 1959). The noted difference was confusion about whether or not they were considered disabled due to the normative portrayal of people with disabilities. This confusion resulted in the participants' either denying the disability, denying the label of disability, having ambivalence towards the label or showing movement toward accepting the disability and its label. How the participants resolved their identity confusion was based on where they positioned themselves in defining the disability and the label. The participants presented three possible scenarios for disability identity construction: other-defined, self-defined and movement towards accepting the societal label. Both the self-defined position and movement toward accepting the label seemed to encourage positive self-esteem and self-confidence. On the other hand, denying the disability seemed to lead to being other-defined. Because I was interested in learning how individuals can become whole, the

“coming home” to that part of self that is disabled, the study revealed that most of the participants were still engaged in trying to make sense of the disability and its impact on identity. Even though the participants exhibited a variety of constructions of claiming the disability, that is identifying what the disability meant to them, the use of accommodations presented another dilemma. The difficulties with using accommodations were associated with negotiating the perceptions of other individuals. However, the participants who were self-defined or were beginning to accept the label did not internalize the negative perceptions of others as much as the other-defined position.

Another insight of this study that was tangential to disability identity formation was the issue of building a disability community to facilitate the construction of a disability identity. As revealed in the participants’ stories, all of them had difficulties with recognizing the value of having an organized community. In fact, when I first introduced the possibility of having a place to go in order to discuss concerns regarding disability issues, most of the participants envisioned a group therapy session. The underpinnings of this belief were disturbing and revealed the extent to which disability issues have been viewed from a medical model that assumes the individual must be fixed, either by rehabilitation, medication or counseling. However, by the last group conversation, the participants had moved from their original response of finding no benefit to having a community to seeing some potential of bringing individuals with hidden disabilities together. I interpreted this movement toward finding value in having a

community as indicative of catalytic validity. “Catalytic validity represents the degree to which research re-orient, focuses and energizes participants toward knowing reality in order to transform it; participants gain self-understanding and self-determination” (Lather, 1991, p. 68). Granted, it was possible that the participants believed that because I asked the question, that the issue was important to me. Their final suggestion to utilize the Services for Students with Disabilities Office in order to establish a community might have been an attempt to placate me rather than actually seeing potential advantages in having a community for themselves. All the participants except for Helen, however, expressed the sentiment that the study provided the first opportunity to discuss the similarities of their disability experiences, and all, except for Jill, seemed to have derived some initial benefit from having participated. It appeared that the need to immerse oneself into the disability community in order to achieve a healthy identity was not always necessary for the participants, but that having a community might lead to a smoother construction of a disability identity. Helen, who indicated that she had had the opportunity to engage in discussions about disability issues with other women in her sorority, exhibited characteristics that reflected what I believe to be a more positive disability identity. Based on the comments of the participants, developing a community would be beneficial, but because of the stigma associated with disabilities, difficult to achieve.

On the issue of how college student services professionals could assist students with integration into the University community, and what social and

institutional changes would foster this integration, the participants offered several suggestions that pertained to social and institutional changes. The participants cited the need to educate faculty, staff and peers regarding disability issues, not only in understanding the legal requirements and the different types of hidden disabilities, but also in recognizing the need to present the material in a variety of ways in order to be inclusive of diverse learners. To foster social and institutional changes and reduce negative social stereotypes, the participants recommend the creation of a Disability Studies program that would deconstruct disabilities, similar to the purpose of Women's Studies and Ethnic Studies. Additionally, the participants recommended that a course be taught to individuals with disabilities to provide the opportunity to develop network systems, reduce the sense of isolation and foster the belief that individuals with disabilities can be successful in higher education. The role of CSSA administrators was not explicitly discussed, but based on these stories, I believe there are numerous implications for the field of CSSA, which are presented later in this chapter.

As stated throughout this dissertation, the primary reasons for undertaking this research was to inform my praxis. Because of my interactions with the participants, I have more insights on the difficulties with accepting the label of disability, and the issues surrounding disclosure and the use of accommodations. While consciously I realized that students with hidden disabilities struggled with identifying as "disabled," I did not realize the amount of energy and the emotions involved in navigating the ambiguity of having a hidden disability, dealing with the

beliefs and perceptions of peers and faculty, and the confrontations involved in using accommodations. Although issues of disclosure have been written about, hearing from the students themselves about the difficulties associated with disclosing their disability influenced my decision to change some of the Services for Students with Disabilities' policies for obtaining accommodations. Through this process, I developed a better understanding of the reasons why students were reluctant to speak with faculty and peers about accommodations. Encouraged by this understanding, I began to investigate the development of a new course, titled "Peer Guides," co-taught with students who are enrolled in the SSD program. Students who wanted to co-teach the course portrayed a level of comfort with having a disability, disclosing the disability and using services. It is my hope that these "Peer Guides" will model to new, incoming students that students with disabilities can have a positive disability identity and can be successful in higher education. Additionally, I hope the class will provide an opportunity to discuss the difficulties associated with disclosing a disability and using accommodations. However, this class would focus on the needs of students with disabilities and would not address the desire of the participants that individuals without disabilities be educated about disability issues. Thus, I sought and received approval to teach a one-credit course for the College Student Services Administration degree program regarding disability issues. This course covered both the social construction of disability as well as the ramification of the laws in higher education.

Implications for the Field

There were several findings that had implications for disability services providers and the field of College Student Services Administration. The first implication of the study underscored the need for disability service providers to educate themselves on the emerging literature of Disability Studies. As most disability services providers obtained degrees in fields that were previously steeped in the medical model of disability (i.e. counseling, rehabilitation counseling and psychology), continued education regarding the social model of disability is needed.

A second implication for disability service providers pertains to the area of transition. Transition into a university was often discussed in terms of what the students do not possess – self-advocacy skills, self-esteem, understanding of the disability, study skills, etc. Traditionally, transition programs have focused on providing policies and procedures for requesting accommodations. Although a program to promote a successful transition is needed, it does not address the underlying issue of constructing a positive disability identity and navigating an oppressive environment.

A third implication of the study is the need to provide opportunities for students to discuss their disabilities with other students with disabilities. Disability service providers should provide opportunities for students with hidden disabilities to interact with each other and hopefully, through these interactions, reduce students' feelings of isolation. It is, however, important to understand that the

attempts to provide such opportunities will not be embraced until the stigma of disability has lessened in society. Disability service providers should not be discouraged when students with disabilities do not readily engage in or appreciate their efforts to form a community or support group. I also think that in time, having a formalized disabled community will benefit both the students and the University community. Because the development of a community will take time, it behooves disability service providers to develop courses that introduce students with disabilities to the history, social movement and culture of disability. These courses would also assist students in appreciating and accepting the disability as part of their identity, instead of denying or attempting to overcome the disability.

Another area that disability service providers need to address is the method by which non-disabled students, staff and faculty are educated about disability issues. This method must encompass more than the legal requirements to accommodate, because the law does not guarantee changes in attitudes and stereotypes. Realizing that the reluctance to provide accommodations is often based on a belief in the values of equality and achievement provides the basis for dismantling the argument against accommodations. Challenging faculty, staff and administrators to reflect on their own biases towards normalcy will be critical to dismantling the oppression.

The final implication for disability service providers as well as CSSA professionals and faculty pertains to the teaching/learning environment. Currently, the educational environment does not address the needs of diverse learners. For

example, educational printed materials are not provided from the publishers in alternative formats. Thus, not all students have the same access to the printed word. Additionally, exams are usually the only tool used for students to demonstrate their knowledge. The standards for how to teach are based on issues of normalcy. As disability services providers we need to engage in conversations with faculty about the need to incorporate elements of universal design when constructing a new course or revamping an established course. Universal design in higher education would take into consideration, the need to “present information in multiple ways,”... “[o]ffer multiple ways for student to interact with and respond to curricula and materials,”... and [p]rovide multiple ways for students to find meaning in the material and thus motivate themselves (Bowe, 2000, p. 4).

Changing how education is delivered and measured I believe will benefit all students. Although incorporating universal design elements into higher education might lessen the oppression of diverse learners, there is still the need to understand how a hidden disability impacts the construction of a disability identity. As changing the learning environment will not completely address identity construction for individuals with hidden disabilities, CSSA professionals should educate themselves about the issues mentioned in this study.

A key challenge for CSSA professionals is to understand the difficulties with constructing disability identity. This involves more than McEwen’s (1996) recommendation that student affairs professionals “learn how an individual with disability understands and conceptualizes that disability” (p. 205). In most cases,

the student with the disability adheres to the dominant discourse. As such, student affairs professionals need to understand what is embedded in the social construction of disability and how the dominant discourse of normalcy and American values have shaped the images, stereotypes and beliefs of the American public, inclusive of individuals with disabilities. This requires introspection in order to identify their own stereotypes and biases about disability issues. The recent ideas proposed by Belch (2000) addressed some of the assumptions individuals hold and how those assumptions affected their behavior towards people with disabilities. However, Belch's publication does not address how American values of equality and achievement were at the heart of discrimination against individuals with disabilities.

The results of this study were in part supported by other research that investigated disclosure and the negative attitudes held by faculty and staff as separate issues. However, these studies did not relate the findings to their influences on identity construction. It is disconcerting that in 2002, there appears to have been limited progress made in creating a welcoming environment in higher education for students with hidden disabilities. I believe that this is in part due to the focus on the legal aspects of disability and not the values inherent in American culture and sustained within the individual. Until faculty, staff and administrators are motivated to re-evaluate the impact of American Individualism on higher education, we may never see meaningful changes in the academy.

Limitations and Future Research

This study was not intended to provide a detailed account of the “reality” experienced by university students with hidden disabilities. Instead, it was my attempt to understand how students with hidden disabilities constructed a disability identity and the barriers to disability identity construction. This study also attempted to serve as a link between the emerging field of disability studies and college student services administration. Due to the methodology of the research, I cannot make inferences about all university students with learning disabilities as a discrete population. I cannot generalize the issues that emerged in this study to other students with hidden disabilities at OSU or elsewhere, because this type of generalization is dependent on the similarity between the participants in this study, each with unique social and familial context to participants in a future study, each with their own unique social and familial contexts (Lincoln & Guba, 1985). However, I can continue to “test” my understanding of the construction of disability identity as I continue to work with individuals with hidden disabilities in the future. This lack of generalization could be construed by others as a limitation.

There were other limitations to the study as well. One limitation was the lack of participants with multiple identity markers such as race, class, and sexuality. As there were only two participants classified as older than average, neither of whom exhibited similar characteristics, future research could investigate the influence of age and gender in disability identity construction. Another potential limitation of this study is the use of a broad definition of what constitutes

a hidden disability (learning disability, ADD, ADHD, head injury). Selecting individuals who were diagnosed at different times in their lives and with varying degrees of severity may be another limitation.

Future research could be done to investigate the impact of identity construction specifically for individuals with ADD, with ADHD and specific learning disabilities, instead of grouping these disabilities together under the category of “hidden disabilities”. Additional research could explore the differences in disability identity construction between individuals diagnosed early in their educational careers and individuals diagnosed while participating in higher education. Other areas for future research are the use of medication and its influences on identity construction, the influence of disability culture on identity construction, and how other identity markers influence the construction of a disability identity.

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