A Dissertation

Entitled

Student Engagement for College Students with the Hidden Disability

of Orthostatic Intolerance

By

Beverly Lynn Karabin

Submitted to the Graduate Faculty as partial fulfillment of the requirements for

The Doctor of Philosophy Degree in Higher Education

_____
Advisor: Lynne Hamer, Ph.D

_____
Anne Hornak, Ph.D

_____
Blair Grubb, M.D.

_____
Jane Ransom, Ph.D

_____
Judith Herb College of Education

_____
College of Graduate Studies

University of Toledo

December 2009

An Abstract of

Student Engagement for College Students with the Hidden Disability

of Orthostatic Intolerance

Beverly Lynn Karabin

Submitted to the Graduate Faculty as partial fulfillment of the requirements for

The Doctor of Philosophy in Higher Education

The University of Toledo

December 2009

This study described the factors that contribute to engagement patterns of college students with the hidden health-related disability of orthostatic intolerance. Specifically, it used a qualitative methodology and collective-case study design to explore the categories of campus physical, institutional, academic and social engagement from a student perspective. Guided by theories from college student development, student engagement, and identity development in both disabled and non-students with a disability, the research also examined student self-disclosure, self-advocacy, and identity. The data collection method consisted of two in-depth interviews with five undergraduate

college students over one semester and participant observation of each student in their college setting over several on-campus site sessions. Findings from the study indicate that these students encountered a number of barriers affecting all categories of engagement. Themes included lack of student centeredness, roommate difficulties, rigid institutional and classroom policies, curriculum pressure, financial penalties, lack of understanding of hidden disability, perception of lack of legitimacy of the disorder among administrators, faculties and peers, social isolation, conflicting values from peer regarding parties and alcohol use, and limited physical energy to engage on all levels. Factors that played an important role in student engagement included self-disclosure, self-advocacy, integration of disability identity, and positive faculty interactions. Although this study is exploratory, it makes clear that students with hidden disabilities need assistance from higher education officials, high school counselors, and health care professions in order to have a successful campus engagement experience.

God who created me, blesses me, and provides me with His grace is forever my

guiding light.

Acknowledgments

As I express my gratitude to the individuals in my life that allow me to dream, succeed, and support my doctoral degree, it is apparent that the old adage is true; words can't express how truly important you have been to me. Without saying, my children Shane, Casey, and Jessa Karabin have been extraordinarily patience in understanding that blending motherhood, education and a professional career is not a harmonious task. Even during their challenging adolescent years they accepted my journey, and I am thankful for their love and respect.

Thanks to my mother, Beverly Gerding, my greatest cheerleader and fan, who believes in me and provides unconditional love, and to my stepfather Hal Gerding, who I can always count on for support.

I owe thanks to Dr. Blair Grubb, my inspiration, mentor, and never-ending source of optimism, wisdom, and courage. I am eternally grateful to Dr. Kimberly Grieve, my dearest friend, doctoral colleague, and daily running companion who provides me with focus, balance, laughter, and direction.

It is with heartfelt appreciation that I thank the following dissertation committee members: Dr. Lynne Hamer, my committee chair and qualitative research guru who provided guidance and helped to pave the way in this endeavor. Dr. Jane Ransom, a "master" of structure, literary skills, and practical feedback, and Dr. Anne Hornak, for her higher education perspective, expertise, and positive insight.

This project could not have succeeded without my patients and the college students whose stories were the driving force for this project. Special thanks and greatest admiration to the president of the Dysautonomia Youth Network of America (DYNA)

Table of Contents

List of Tables

**Chapter I**

**Introduction**

This study evolved from my personal experience as a nurse practitioner working

in at a sub-specialty cardiology clinic for patients with disorders of the autonomic

nervous system. The cardiovascular clinic has a referral base that is composed of 70% of

patients from out of the state and 10% of patients from out of the country (personal

communication, Grubb, 2008). Thus the patients in the clinic who are college students

attend universities throughout the entire United States. The majority of the college

students in the clinic have been diagnosed with acquired disorders of autonomic

dysfunction and orthostatic intolerance in adolescence and young adulthood.

The autonomic nervous system is responsible for many body processes essential

for life itself, including regulation of heart rate, blood pressure, digestion, temperature

regulation, sweating, urination, and sexual function (Hamill & Shapiro, 2004).

Orthostatic intolerance (OI) is the hallmark of many syndromes in the autonomic nervous

system (Grubb & Olshansky, 2005).

Over the years, and after thousands of patient encounters with students afflicted

with orthostatic intolerance syndromes, I discovered that many of the students and

parents were concerned about education and college attendance. It is undeniable that this

dissertation topic developed from the student stories. Not surprisingly, some of the

educational research findings on college students with disabilities are similar to the

student stories I heard. for instance, the students reported to me tales of discrimination,

hardship, negative interactions with faculty and administrators, and numerous barriers in

the college environment, which are common themes found in the education literature on

students with disabilities (Bento,1996; Fichten, 1988; Hindes, & Mather, 2007; Hermes, 2008; Kravets, 2006; Leyser, Vogel, Wyland & Brulle, 1998; Malakpa, 1997; Murray, Wren & Keys 2008; National Center for the Study of Postsecondary Educational Supports, 2000; National Council on Disability, 2003; Nichols & Quaye, 2009; Norton,1997; Rao, 2004; Ryan, 2007; Sunderland, 2008; Walling, 1996; Weber, 2002). Frustration over "not being believed" was a common emotion frequently expressed by the students I encountered with hidden orthostatic intolerance syndromes. Some students were told by professors that they "didn't look sick," or that they "looked too good" to have a disability. The students wearily detailed the struggles they encountered with faculty and administration who challenged their requests for accommodations. Some students lost scholarships because they were too ill to take full-time classes. Several were forced to withdrawal from their majors because they were told by the deans in their departments that they would "not make a good teacher" or should "never work in health care." Many were forced to withdraw from classes due to strict attendance policies.

One student reported the hardship she endured because she was not allowed to live in student housing. Only students enrolled in classes full-time were allowed live on campus, and she attended school part-time due to the illness. Instead, she had to commute 60 minutes to the campus, drive 30 minutes to a relative's home to rest between classes, drive 30 minutes back to campus to complete her classes, and then make the long commute back home. She did this several days a week because she could not manage full-time hours. The example given is important to this study for two reasons. First, one wonders if after all of the driving the student had any energy left to engage in campus activities, and second, living on campus and attending classes full-time has been found to

be associated with higher levels of student engagement than living off campus and attending classes part-time (Kuh, et. al., 2006a).

Yet another student reported the physical trauma she experienced as a result of an incident with a professor who accused her of "faking" her disability. The student became ill during class and requested permission to leave the class early. The student reported she believed that the professor was skeptical of her story; thus, regrettably she struggled through the class, and finally left feeling very ill. As bad luck would have it, after gathering her books, she experienced lightheadedness, fainted, and subsequently fell down two flights of concrete stairs. Sadly, the student suffered a concussion, but fortunately no permanent damage. In terms of student engagement, one wonders if the experience of the student in this example has prevented future engagement of the student with faculty members. Granted, the examples of the above student stories are fairly dramatic, and paint a negative picture; thus, it is important to study what the engagement climate is really like for these students. My bias as a clinician-advocate for this group of students is understandable, so the purpose of this study was intended to let the students tell their stories without my biased interpretation. A closer look at their stories will help individuals working in higher education and health care providers understand what factors help them engage, or enjoy a full college experience, and what they would like to see done differently on the campuses.

My interest in the disabled population is timely: over the last few decades, the number of students with a disability attending college has increased three-fold, and the majority of these students are diagnosed with hidden disabilities (Henderson, 1995). Students with hidden disabilities are recognized as a subset of students with a disability

with distinct needs. Hidden disabilities encompass learning-students with a disability, those with disorders of attention deficit, and students with health-related disabilities (Kravets, 2006).

The college student with a hidden disability is virtually unrecognizable from the non-student with a disability on campus. Because of the invisibility of the disability, many students may not be given the same consideration for their disability that a student with a physical disability receives. It has been suggested that the "playing field" for this distinct cohort of college students is not level (Kravets, 2006, p.20). This argument, although not fully substantiated by the research, is a plausible one to consider given the fact that students with a disability in general have worse postsecondary outcomes on several indices when compared to non-students with a disability including retention, persistence, participation, and degree completion rates (Belch, 2004/2005; Getzel, 2008; Getzel & Wehman, 2005; Malakpa, 1997; National Council on Disability, 2003).

Fortunately, there seems to be greater attention given to assessment and provision of services and accommodations for students with hidden disabilities in educational settings in the last several decades, especially learning disabilities (Walling, 1996). College student mental health disorders are hidden disabilities, and disorders such as depression and anxiety commonly receive widespread consideration in the media and education literature in the past few years (The National Center on Addiction and Substance Abuse at Columbia University, 2003). Indeed, I discovered over 800 articles in a search of the educational database ERIC (2008) using the words "depression" and "college."

**Orthostatic Intolerance: A Hidden Disability**

Aside from learning disabilities and mental health disorders, examples of some of the more commonly recognized health-related hidden disabilities include asthma, diabetes, multiple sclerosis, HIV/AIDS, and seizure disorder (Walling, 1996). Uncommon or obscure disorders also cover the spectrum of health-related hidden disabilities. Of interest to this study is the student with the syndrome of orthostatic intolerance.

OI syndromes occur due to a disturbance in the autonomic nervous system (Grubb & Kosinski, 2001; Grubb, 2005a). The autonomic nervous system (ANA) is a highly complex system that is responsible for regulation of many important body processes, including heart rate and blood pressure, temperature regulation, bowel and bladder function, and sweating (Hamill & Shapiro 2004).

Autonomic regulation of heart rate and blood pressure is necessary for an individual to remain upright (Grubb, 2005b). In syndromes of OI, the individual experiences a constellation of symptoms due to the inability of the body to adjust to upright posture. Normally, when an individual assumes an upright posture, gravity pulls almost 1/3 of the blood into the abdomen and dependent extremities (arms and legs), which causes a fall in blood pressure, and ultimately cerebral circulation. As a consequence, the autonomic nervous system must then mediate a series of responses that help to propel the blood back to the heart and brain (Grubb, Kanjwal, Karabin & Imran, 2008). Individuals with disorders associated with OI, they are unable to offset the effects of gravity on blood flow, which result in a variety of symptoms that occur just remaining upright (Grubb & Kosinski, 2001). Some of the more common symptoms include

lightheadedness, fatigue, dizziness, blurred vision, trouble thinking and concentrating, headache, sweating, nausea, rapid heart rate, clamminess, exercise intolerance and anxiety (Low, Opfer-Gehrking & Textor, et. al., 1995).

Unlike congenital disabilities, disorders associated with orthostatic intolerance are frequently acquired disabilities and usually begin during junior high and high school, and extend into the college years (Grubb & Friedman, 2005; Rollinson, 2005). The term "acquired disability" refers to a "broad array of disabilities resulting from trauma or disease" (Dunn & Brody, 2008, p.413). Students with orthostatic intolerance disorders not only experience the burden of adjustment to college like many of their contemporaries, but also the added adjustment of coping with a sudden-onset, perplexing medical condition.

Needless to say, the syndromes associated with OI can have profound effects on individuals' physical, cognitive, and mental functioning (Grubb, 2008). Individuals with these syndromes, especially those that result in near fainting and fainting, experience significant limitation in daily activities (Linzer, et al. 1992; Linzer, et al., 1994) including driving (Linzer et. al., 1994; Van Dijk et al., 2006). Several researchers have found an increase in anxiety and depression in individuals with syndromes associated with OI when compared to those without OI (Giada, et al. 2005; Linzer et al. 1992; 1994; McGrady, Kern-Buell, Bush, Khuder & Grubb, 2003). In addition, quality of life is significantly impaired in these individuals when compared to the general population (Baron-Esquivias, et al., 2003; Giada, et al. 2005; Rose, 2000; van Dijk et al., 2006). The diminished perception of quality of life in individuals with OI has been found to be comparable to individuals who suffer from epilepsy (Santhouse, Carrier, Arya, Fowler &

Duncan et al. 2007), lung disease, and heart failure (Baron-Esquivias, et al., 2003). Orthostatic intolerance may affect daily functioning. Thus, many of these teenagers and young adults face significant challenges as they maneuver through the growth and developmental stages of late adolescence and young adulthood (Grubb, et al., 2008; Grubb & Friedman, 2005).

**Identity Development in College Students with OI**

One of the more important stages in the growth and development of adolescents and young adults is the development of identity (Erkison, 1959, 1980; Arnette, 2000). The concept of identity development is conceptualized as an evolving process that places a personal sense of self within a socially ascribed milieu. Among teens and adolescents with an acquired disability, the development of an identity is complicated by the addition of a "disability identity" (Shakespeare, 1996). This new identity, superimposed on an undeveloped sense of self, makes these emerging adults particularly fragile. In essence, individuals who suffer from the illnesses associated with OI may find their world profoundly disrupted during a vulnerable developmental period. This unexpected interruption in the developmental process may affect many tasks considered necessary for healthy identity formation (Erikson, 1959, 1980) and college student development (Chickering & Reisser, 1993).

Students who attend college with the hidden disability of OI will need to renegotiate their identity in ways that may be unfamiliar to them, and this may affect the developmental journey through college. In its simplest form, college student development refers to the changes and growth that take place in the student while attending college (Chickering & Reisser, 1993; Torres, Howard-Hamilton & Cooper, 2003). Accordingly,

7

student growth and development encompasses a holistic perspective that includes the development of identity, social relationships, cognitive/intellectual functioning, and moral development (Evans, Forney & Guido-DiBrito, 1998).

A number of researchers have looked at identity development in diverse groups (Torres, et al., 2003) including women (Josselson, 1987), African American women (Taub & McEwen, 1992), Asian Americans (Kim, 1981), minorities (Atkinson, Morten & Sue, 1979; Phinney, 1990; 1992), African Americans (Cross, 1991; Johnson, 1997), Native Americans (LaFrombise, Trimble & Mohatt, 1990), and Latino/Hispanic Americans (Ferdman & Gallegos, 2001). Each of the preceding models and theories helps add to the knowledge base of college student identity formation in different cultural communities (Torres, et al., 2003). However none have looked at students with HD or OH as a unique group.

More recently, disability researchers have begun to address the topic of disability identity formation (Gill, 1997; Weeber, 2004). Well understood by disability advocates but not so prevalent in the medical and rehabilitation fields (Ong-Dean, 2005), much of the discussion on identity development in the disabled seeks to address the negative view of disability in our society (Putman, 2005). Disability identity scholars have begun to reject the well-entrenched medical or "sick" model of disability (Ong-Dean, 2005), described as "monolithically and oppressively imposed on disabled people" (p.141), in favor of a positive collective self-identity (Swain & French, 2000).

Developmentally, college age students are at the heart of identity formation (Erikson, 1959, 1980; Arnette, 2000), yet little research exists on disability identity formation in this group (Buggie-Hunt, 2008). Disabled college students with hidden

disabilities, described as "another diverse population" (Kravets, 2006, p.18) may be at risk for delay in identity development especially if they are limited in their ability to participate or engage in activities during college.

**College Student Engagement**

In the preceding discussion of identity development a fundamental contribution to the discussion involves the interaction between the individual and the environment (Erikson, 1959, 1980) and the student with the college environment (Chickering & Reisser, 1993). Implicitly understood in student development literature is that involvement in the campus experience is one factor related to student development and success (Astin, 1993; Evans, et. al., 1998; Kuh, 2001; Pascarella & Terenzini, 2005).

One of the more salient theories in higher education that has been linked to a successful college experience is the theory of student involvement described by Alexander Astin (1984). The foundation of student involvement is based on the assertion that students learn by participation in the campus experience. Student involvement, as defined by Astin, refers to "the amount of physical and psychological energy that the student devotes to the academic experience" (p.518). Astin uses several phrases or words to capture the meaning of involvement including "participate in, engage in, join in, and devote one self to and take part in" (p.519). Regardless of the term used, the idea that engagement is fundamental to student success has led more recently to scholarly inquiry into the assessment and measurement of this construct. One noted assessment tool designed to assess student engagement in college is the National Survey of Student Engagement (NSSE). Developed in 1998, this tool allows administrators and faculty in higher education to improve educational practices and student outcomes in college

9

(National Survey of Student Engagement, 2001). The NSSE is described in detail in the next section.

George Kuh, one of the lead researchers involved in the NSSE design, later developed a framework of student engagement called the Framework for Student Success based on the principles germane to Astin's theory of involvement (Kuh, Kinzie, Buckley, Bridges, & Hayek, 2006a). Student success is defined by the researchers as "academic achievement, engagement in educationally purposeful activities, satisfaction, acquisition of knowledge, skills and competences, persistence, attainment of educational objectives and post college performance" (p.6). The Framework for Student Success posits that engagement patterns in students are related to personal attributes and behaviors, interactions with peers, faculty, and institutional engagement. (p.7). Engagement is also linked to feeling validated, accepted, or supported in the college environment (Kuh et al., 2006a). Individuals are more likely to engage in activities if they feel welcomed by their environment. Acceptance positively influences their connectivity to the campus. Higher education literature (Astin, 1993; Kuh, Kinzie, Schuh & Whitt, et al., 2005; Kuh, et al., 2006; Pascarella & Terzini, 2005) strongly demonstrates that student engagement in the college setting is positively correlated to a number of postsecondary outcomes including persistence and academic success.

**The National Survey of Student Engagement**

Because student engagement in the campus experience has been noted to be an aspect of the college experience connected to student success, educational research in the field of student engagement has exploded in part due to the development of a survey used to measure not only student factors that contribute to engagement, but also institutional

factors that are necessary to foster student success. Simply put, the survey is interested how the students engage and how the institution enables or inhibits engagement.

Developed by a team of leading educational researchers including Alexander Astin, Gary Barnes, Arthur Chickering, Peter Ewell, John Gardner, Richard Light, Ted Marche, Robert Pace and led by George Kuh, the survey is given to hundreds of undergraduate students annually throughout the United States who attend four-year colleges and universities (National Survey of Student Engagement, 2001). The NSSE is intended to assess how well students participate in education processes that are "strongly associated with high levels of learning and personal development" (Kuh, 2001, p.10). Five categories of "effective educational practices" measured by NSSE include; a) the level of academic challenge, b) active and collaborative learning, c) student faculty and peer interaction, d) enriching educational experiences, and e) a supportive campus environment (Kuh, et. al., 2005, p.10-13).

Although the NSSE survey has been widely used with diverse students, a review by this author of over one hundred research articles and presentations of the NSSE in the last decade since its inception reported on the official National Survey of Student Engagement web-site demonstrates no survey use with students with a disability, including students with hidden disabilities (National Survey of Student Engagement, 2009). One explanation for this omission is that students with a disability normally do not self-identify themselves in college surveys and admission applications due to laws on confidentiality (Kravets, 2006; Lynch & Gussel, 1996). More importantly, the issues of college students with disabilities are rarely addressed and "largely ignored" in higher

education (Nichols & Quaye, 2009, p.39). Even the widely used NSSE survey may be limited in its design for students with a disability.

The NSSE instrument may not accurately capture the student with a disability engagement patterns because some of the questions to measure engagement behavior require physical ability and stamina. A review of items from the survey reveals that many of the questions are based on the ability to physically maneuver the campus environment, as well as participate in off-campus activities (National Survey of Student Engagement, 2001). For instance, activities such as study abroad, tutoring other students, community-based projects, internships, working for pay on or off campus, and extra curricular activities, to name a few, may be difficult for students with a disability, especially those with health-related issues.

The NSSE survey is a Likert type scale with approximately 85 questions, and many of the questions ask about the frequency of engagement behaviors with responses that range from "very often, often, sometimes, never"; "very much, quite a bit, some, very little"; and "hours per week." Students with disabilities, even hidden disabilities may consistently score lower on the frequency of the desired engagement behaviors. College students who have physical and hidden disabilities suffer from cognitive and physical difficulties that may effect engagement. Also, the survey doesn't self-identify students with disabilities.

Many questions from the survey ask about the student relationship with faculty and peers. The responses in students with a disability may be different because the higher education literature reports that students with disabilities including hidden disabilities frequently encounter barriers to social interactions (National Center for the Study of

Postsecondary Educational Supports, 2000). If the survey does not self-identify the student with a disability, questions concerning social engagement on the survey may not reflect this information.

It is known, and goes without saying that students with disabilities value a trusting, open, and honest dialog with faculty and peers (National Center for the Study of Postsecondary Educational Supports, 2000). Fortunately, a few studies report that faculty attitudes toward the student with a disability regarding the provision of accommodations are generally favorable (Murray, Wren, & Keys, 2008; Norton, 1997).

On the other hand, many students with a disability report tenuous relationships with faculties (Malakpa, 1997). In students with hidden disabilities, this may be even more problematic. For instance, in a qualitative study of 26 learning disabled (LD) students, the majority of the students expressed significant anxiety over meeting with their college professors due to the assumption that the faculty are "uniformed and unconcerned" about their issues (Hadley, 2006, p.14).

Not only do some students with a disability view faculty as uninformed and reluctant to provide needed accommodations, the faculties are described as inconsistent in issues related to students with hidden disabilities. For example, in a recent correlational study by Murray, Wren and Keys (2008), 192 faculty members in a large urban private institution were surveyed on their attitudes, beliefs and practices towards learning disabled (LD) students. The findings indicated that faculty support of LD students, willingness to provide accommodations to LD students, the actual provision of accommodations, and performance expectations of LD students is generally positive. However, from the study, and reported as consistent with previous research, the faculty in

this study were more likely to favor minor rather than major accommodations for the LD

students. Further, the researchers explained that that this attitude may be due to the belief

that major accommodations somehow "compromise academic program quality" (p.110).

In another recent study by Hindes and Mather (2007) of teacher and student attitudes

toward disabled post-secondary students in a single Canadian university, the participants'

attitudes were more negative toward students with hidden disabilities (psychiatric and

attention disabilities) than physical disabilities (language, motor, and sensory

disabilities).

The student-faculty relationship may also require student self-disclosure of the

disability. From the literature, students who do not disclose their disability status are

more likely to have difficulties in the educational setting than students with a disability

who do disclose (Lynch & Gussel, 1996; Milsom & Hartley, 2005), and it is known that

many students do not disclose their disability. Thus, as the research would suggest, a

student with a hidden disability may not feel comfortable enough to approach their

college professors and perhaps even disclose the disability. It follows then that it may be

quite likely that this aspect of student with a disability engagement (faculty-student

interaction) may be different from the non-student with a disability.

A review of the disability literature indicates that an inclusive college

environment that encourages participation for students with a disability is paramount to

their success (Heiman, 2006; Graham-Smith, S. & Lafayette, 2004; Sunderland, 2008;

Wilson, 2004). That said, little is known about the social and academic engagement

patterns of students with disabilities. A student with a hidden health-related disability

may not have the physical or social resources to participate as fully in the college

environment as the NSSE would envision. Perhaps if we know more about the disabled group, we may better serve their engagement needs. It may be necessary for institutions of higher education to rethink educational engagement practices that primarily address the dominant able-bodied culture.

### Student Engagement in Diverse Groups

Recently there have been a number of studies that examine student engagement in diverse students using the NSSE (Bridges, Cambridge, Kuh & Leegwater, 2005; Filkins & Doyle, 2002; Harper, Carini, Bridges & Hayek, 2004; Kuh, Kinzie, Cruce, Shoup, et al, 2006; Pike & Kuh, 2005; Pike, Kuh,,& Gonyea 2007). These studies have demonstrated that diverse students benefit from active engagement on the college campus, and in some instances, even more so than the dominant culture. For instance, Filkins & Doyle (2002) reported on a large study (n=1,910) that reviewed NSSE data from six urban institutions of higher education for two sample populations that included first-generation, low-income students and second-generation, middle to high income college students. Both groups demonstrated gains in cognitive and affective growth through college if they engaged in effective educational processes (active collaborative learning and interactions with faculty).

Another large study (N=11,000) by Kuh et. al., (2006) looked at the relationship between NSSE results, pre-college experiences, college grades, and persistence to sophomore year for freshman and senior college students at baccalaureate-institutions including several minority-serving institutions (MSI). One of the more significant findings reported was that although students from all ethnic backgrounds benefit from

engagement, students who have been historically underserved achieve even greater benefits in terms of grades and persistence to 2nd year.

The literature on student engagement demonstrates a positive association between institutional practices that support high levels of student engagement in underrepresented groups, and this is encouraging (Wasley, 2006). However, as stated, lacking in the literature on student engagement and student development theory are any studies that address students with a disability, including those with hidden disabilities (Web-search: Educational Full Text; Educational Research Complete; EBSCO Databases; ERIC; MEDLINE 2003-2008; MEDLINE (PubMed); National Survey of Student Engagement (NSSE) web-site; Psychological & Behavioral Sciences Collection; Proquest Nursing & Allied Health 1986-present). Clearly the research thus far demonstrates the benefits of engagement for students who are not of the dominant culture. What are not clear from the literature are the engagement needs of the student with a disability.

Student with a disability Engagement: From a review of the disability research, there are several studies that discuss student with a disability participation in the educational environment. Findings from this research have reported that students with a disability are more likely to flourish if they feel accepted by faculty, education officials, and peers (Bruno, Giordano & Cross, 1996; Marom, Cohen & Naon, 2007; McDougall, Dewit & King, 2004; Praisner, 2003; National Study for the Center of Postsecondary Educational Supports, 2000). For students with a disability, a sense of belongingness or inclusion in the campus setting is associated with positive educational experiences (Curtin & Gill, 2005; Graham-Smith & Lafayette, Wilson, 2004). In addition, student with a disability beliefs about adjustment to college (Shaw-Zirt, Popali-Lehane, Chaplin

16

& Bergman 2005), quality of life with disability (Brown, 1997), self-disclosure of the disability (Lynch & Gussel, 2001; Milsom & Hartley, 2005, Stage & Milne, 1996), and self-advocacy skills (Pocock et. al., 2002; Test, Fowler, Wood & Brewer, et al, 2005) are important underlying concepts in the literature that may influence engagement or participation.

**Statement of the Problem**

An understanding of how students with hidden disabilities such as orthostatic intolerance engage in the physical, institutional, academic, and social environment of the campus is important for policy, theory development, and practice in higher education. Similar to other diverse underrepresented groups, engagement in students with hidden disabilities is more likely to result in persistence through college.

The medical community can also assist higher education officials by providing legitimacy to the syndromes associated with orthostatic intolerance and other hidden disabilities to help explain how the syndrome may affect the student's ability to engage in the campus experience. Both disciplines must understand engagement patterns in this diverse group of students because each discipline contributes to the success of the student campus experience. Too often there is a fragmented approach to understanding special needs students; health care is situated at one end of the continuum, and higher education at the other end. Unfortunately, many students get "stuck" somewhere in the middle, and many must navigate through a critical developmental period alone. They need our combined assistance, understanding, and advocacy.

**Overview of Study**

The aim of the study was to describe the factors that may contribute to engagement patterns of college students with the hidden disability of orthostatic intolerance. The study used a qualitative method of inquiry to explore the issue from a student perspective. The qualitative method is ideally suited for research on little known issues or phenomena. One of the assertions on which qualitative research rests is that it is a fundamentally interpretive method, and is based on an individual personal experience in the natural setting (Marshall & Rossman, 2006). Thus, the study provided a rich source of first-hand information about the engagement of a student with a hidden disability in the context of their college setting. To the researcher's knowledge, this is the first study to address student engagement in college students with hidden disabilities.

The study used a collective-case study design. In a collective case study, the researcher is interested in exploring one issue or phenomenon of interest and then selects multiple cases to show different perspectives on the issue (Stake, 1995). For this study, data collection methods consisted of two in-depth interviews with five college students over one semester and participant observation of each student in their college setting over several on-campus site sessions. Data was also collected via document analysis. Thus, this study collected multiple sources of data to show different perspectives on the problem.

**Topic and Purpose of the Study**

Many factors contribute to the academic, social, and emotional growth of college students. One factor related to college student development is the role of student involvement in the college environment. Research in the field of student involvement has

demonstrated that positive involvement behaviors in students are linked to academic success (Astin, 1993; Pascarella & Terenzini, 2005). Astin (1984) believed that student involvement in the campus environment is essential for students' growth, development, and learning. It is known that college students with disabilities experience less success in postsecondary outcomes on many levels when compared to the non-student with a disability. What is not known is whether engagement barriers contribute to this discrepancy.

The number of college students with disabilities, especially hidden disabilities continues to climb in the last three decades. In fact, hidden disabilities comprise the majority of students with a disability on college campuses. College students with the hidden, health-related disability associated with orthostatic intolerance, like other similar late-onset disabilities, may be at risk for poor postsecondary outcomes due to engagement barriers in the campus setting. It is not known how students with disabilities, including hidden disabilities, participate in the college setting.

Engagement of students with hidden disabilities is important because participation is intricately related to college student identity development. Disability researchers have recently begun to explore identity development in the disabled individual. Despite the increase in recognition of diverse cultural groups in student development theory, as of yet, there is no research in the student development literature on the development of identity in students with hidden disabilities. The importance of the relationship between student identity development and student engagement and participation cannot be understated. Thus, the purpose of the research study allowed students with the hidden

disability of orthostatic intolerance to tell their stories about their engagement patterns in the college setting. This information also provided a glimpse into their identity formation.

Information on identity in college students with hidden disabilities and their engagement behavior is essential for college students with these issues. The newly student with a disability with orthostatic intolerance may use the information found in this study as a catalyst to help construct a positive sense of "self," despite the recent changes in physical and cognitive function. An important part of embracing a positive disability identity is the construction of self that is internalized as separate from the negative "disability identity" or the identity that is defined by the dominant culture assumptions, values, and beliefs about what it means to be disabled.

Faculty and administrators in higher education may use the knowledge gained from this study to better understand the issues faced by these diverse students. In order to increase the likelihood that the student with a disability will be successful in college, institutions of higher education need to create effective educational practices for the student with a disability. The institutions need to discover how the student with a disability engages in the campus environment because their stories will help educators to provide opportunities and learning experiences to keep the student connected to the campus. Indeed, for those who work with students with hidden disabilities such as OI, this study may provide insight into the students' world.

**Theoretical Framework**

An understanding of the growth and development of students is essential for higher education and health education. The idea that a student's sense of identity or self-growth is cultivated throughout the college years is "widely accepted" in higher

20

education (Torres, Howard-Hamilton & Cooper, 2003, p.3). Early theories of identity

development in college students focused primarily on white males (Evans, Forney, &

Guido-DiBrito, 1998; Torres, Howard-Hamilton & Cooper, 2003). However, the increase

in access to higher education for students with diverse backgrounds created a gap in our

understanding of how these students develop their sense of self during the college years.

In a monograph for The Association for the Study of Higher Education (ASHE)

and the ERIC Clearinghouse on Higher Education, researchers Torres, Howard-Hamilton

and Cooper (2003) noted the importance of identity development in diverse groups:

"Because not all students are alike, it is important that we understand their identity

development process rather than make over generalized statements about group

membership" (p.2). Further, they stated, "if higher education is sincere about creating

positive learning environments for all students, then each person who works with diverse

populations must also value these diverse developmental issues" (p.7).

The recognition of student diversity was quickly cultivated by student

development theorists such as Chickering and Reisser (1993); Cross (1991), Josselson

(1987), Phinney (1990, 1992), and Schlossberg, Waters & Goodman (1995), to name a

few. These theorists contributed to the vast field of student development in diverse

groups. A healthy sense of identity in college students is integral to participation in the

campus experience (Torres, Howard-Hamilton & Cooper 2003). Higher education

officials and health care providers need to understand the developmental issues of

students with a disability because "the consequences or outcomes of the developmental

process may have implications for the individual's level of adjustment as well as for the

quality of the interactions in which he or she engages and for the environment" (Helms,

21

1993, p.306 as quoted in Torres, Howard-Hamilton & Cooper, 2003, p.3). Engagement is intricately related to a student's development or growth through college. However, as noted, no research on student development or engagement in students with a disability, including those with hidden disabilities such as orthostatic intolerance exists.

It is important to understand how students with a hidden disability of orthostatic intolerance engage on the college campus because this may influence their ultimate success in college. In order to provide an environment that is conducive to student growth and learning, faculty and administrators must be aware of the student with a disability's developmental and engagement needs. With this awareness, they are more apt to design policies and programs that contribute to a healthy college climate for these individuals. When students with a disability feel valued and understood by faculty, peers and administrators in higher education, they will likely respond to the challenges in the college environment and their illness with positive adaptive behaviors. An inclusive environment enhances student critical thinking skills, problem-solving skills, and communication skills that effects engagement behaviors and ultimately translates into student success.

**Research Questions**

The research study explored the question, how do students with the hidden disability of orthostatic intolerance (OI) engage in the campus setting? Sub-questions focused on the factors that contribute to: a) engagement in the campus physical environment, b) institutional engagement, c) academic engagement, and d) social engagement. Topics of the sub questions were defined as follows:

Campus Physical Engagement: Physical engagement included behaviors or activities that rely on structural or architectural accessibility on campus, e.g., dormitories, parking, classroom locations, food service location/process, and location of student lounges, student union, and other structural accommodation issues.

Institutional Engagement: Institutional engagement referred to behaviors or activities that relate to campus policies, e.g., registration, scheduling, testing procedures, accommodations, and grading. Institutional engagement included activities that relate to institutional programs or services such student services, disability services, counseling services, and student health services. In addition, institutional engagement included financial aid factors that contribute to student involvement such as grants, scholarships, tuition costs, and penalties for withdrawal. Finally, institutional engagement encompassed the relationships between students and administrative staff.

Academic Engagement: Academic engagement included behaviors directed toward learning activities and interaction with the faculty, e.g., participation in practicum, internships, field experience, research, and clinical assignments. Further, academic engagement included activities such as participation in service learning, study abroad activities, arts and performances, and community-based projects. In addition, academic engagement included student use of electronic technology to complete assignments including accommodations to aid academic success, e.g., note-taking, computer software, texts on tape, study partners, tutors, and faculty mentors. Closely aligned with academic engagement is the student's feeling of acceptance and ability to work with the faculty.

Social Engagement: Social engagement included behaviors directed towards activities with friends and other classmates, participation in co-curricular activities such

as clubs, sororities, fraternities, committees, orientation, student-life activities, and recreational activities. Social engagement also included a campus climate that cultivates positive relationships among diverse groups on campus, including the student with a disability. Social engagement included a description of barriers or support that hindered or enhanced social activities and social relationships between students and their peers.

Thus, potential themes cutting across all areas of engagement centered on the following research questions: a) How do college students with orthostatic intolerance describe their ability to engage in the physical structure, institutional, academic and social campus environment? b) What experiences do students with orthostatic intolerance perceive as helpful in promoting participation in the campus environment? c) What obstacles exist in the campus environment that prohibits engagement for students with the hidden disability of orthostatic intolerance? d) What kind of behaviors and skills do students with orthostatic intolerance perceive to be necessary to achieve successful engagement in the college environment? e) What kind of campus support exists for students with hidden disabilities? f) Do students with hidden disabilities perceive the faculty, peer group and college personnel (disability services, student services staff, etc.) as supportive and accepting of his or her condition, and do these perceptions affect their ability to engage in the campus environment?

Although the research questions were used to structure this study, these issues are "etic" or "outside" issues that the researcher brings to the study of the case(s). But according to Stake (1995), issues and research questions in qualitative case study research evolve. Other issues emerged that were important to the participants in this study. These are called "emic" issues. The research questions did not change significantly

throughout the interviews. Additional questions were developed during the interviews that were not initially foreseen. This modification helped to provide greater understanding of the issue. This is a term called "progressive focusing" (Parlett & Hamilton, as quoted by Stake, 1995, p.9). A detailed list of questions used to guide the interviews is found in Appendix C.

**Significance of the Study**

College attendance affords benefits to disabled and non-students with a disability alike. But students with a disability who do not obtain a college degree are twice as likely to live below the poverty level. Participation in college for students with disabilities lags behind the non-student with a disability. The majority of students with a disability on college campuses have hidden disabilities. Hidden or invisible disabilities pose significant challenges for students in college and individuals in higher education. The presence of these students on campus requires a greater understanding of hidden disabilities, and a look at factors that can contribute to their success. Student engagement is a construct associated with success in college. How students spend their time and energy on academics, social relationships, and participation in the institutional culture of the campus influences persistence, retention, and satisfaction with the college experience. An understanding of how students with hidden disabilities engage or participate in college may help educators and health care providers identify and respond to their unique needs.

Benefits of College for Disabled Individuals: The completion of a college education provides many opportunities for individuals, and the value of a college education in today's world cannot be disputed. It is well known that completion of the

baccalaureate degree is associated with higher earning power (Pascarella & Terenzini, 2005). Indeed, college graduates earn almost 70% more on average than high school graduates (Pennington, 2004). Individuals with college degrees add to the "civic health" of our nation. College educated individuals vote in higher numbers than less educated individuals (Pennington, 2004). Today, more than ever, it is necessary for individuals to attend college to acquire specialized, knowledge-driven skill sets because this will increase employment opportunities (Duderstadt, 2004). College attendance figures for disabled individuals are improving, but are still inadequate. In a large sample of U.S. high school youths reported by Fairweather and Shaver (1990), only one-fourth of all disabled high school students were participating in postsecondary education. Like non-students with a disability, students with a disability who do participate in higher education are more likely to benefit than those who don't.

In terms of employment opportunities and sustainability, students with disabilities who obtain four-year degrees compare favorably to non-students with a disability (National Council on Disability, 2003). However, the research demonstrates that the statistics are much more sobering for those without a college education. In reality, two times as many individuals with disabilities live below the poverty line compared to individuals without disabilities, and the majority of disabled individuals lack professional degrees, work part-time (Hotchkiss, 2004), and work for minimum wage in positions that usually lack health benefits and job security (National Council on Disability, 2003). In a study that looked at employment outcomes of 500 learning disabled (LD) students who graduated from three postsecondary institutions in the United States, Madaus (2006) found employment outcomes of full-time status, benefits, and salary earned compared

favorably to the American workforce. In the same study, however, the same employment outcomes were not so favorable for LD students without four-year degrees; they lagged behind LD college graduates in all outcomes. The consequences of low participation by students with a disability in higher education have profound implications for the individual, the future work force, economy, and society.

### Student with a disability Participation in College

The ability of our post-secondary educational system to help students gain the knowledge and skills necessary for success requires institutions to be mindful of our diverse students. Widespread creative initiatives in higher education in the last few decades have created a rich, diverse population of students. This diversity has also created challenges for educators because educational teaching and learning environments have had to change to meet the needs of different groups. Even though higher education has opened access for many disabled individuals who may not have attended college years ago, many of these students experience less success in college outcomes when compared to the dominant culture.

Students with disabilities (physical, mental, and learning disabilities) have increased threefold on college campuses since 1970 (Henderson, 1995). According to the US Department of Education, National Center for Education Statistics (2006), 11% percent of all undergraduate students reported having a disability in 2003–04. Among these students, 25% reported an orthopedic condition, 22% reported a mental illness or depression, and 17% reported health-related disability. In 1998, almost all public institutions of higher education (98%) enrolled students with disabilities (National Council on Disability, 2003).

Students with a disability have enjoyed greater access to postsecondary institutions in part due to federal regulations designed to reduce barriers to admittance. Following the heels of the civil rights movement in the 1960s, the passage of Section 504 of the Rehabilitation Act in 1973 and the Americans with Disabilities Act (ADA) in 1990 mandated structural and architectural changes in our institutions of higher education to support the physically disabled. ADA legislation mandates that colleges and universities must make "any reasonable accommodation that may be necessary for those people with an identified disability to have equal access to the educational opportunities and services available to non-disabled peers, if requested" (PL 101-336; PL 105-17).

The standards set forth by the legislation make it illegal to discriminate against the disabled, but "reasonable accommodation" has become more and more difficult for college disability resource centers to provide (Hermes, 2008). This may be due to the fact that the definition of disability today has changed significantly in the years since the ADA legislation. Greater numbers of students are being diagnosed with hidden disabilities. Unlike physical disabilities, students with "hidden" or "invisible" disabilities are not readily apparent, and are more likely to be misunderstood (Wolf, 1999).

Although college students with disabilities have increased access to higher education from three decades ago, this cohort lags behind those without disabilities in terms of postsecondary outcomes. Students with a disability in postsecondary education experience inferior outcomes in academic preparedness at the secondary level, participation in college (Fairweather & Shaver, 1990), persistence and retention, and degree completion when compared to their non-disabled peers (Belch, 2005; Malakpa, 1997; National Council on Disability, 2003). Students with disabilities take twice as long

to finish their degrees than non-students with a disability, without any financial mechanisms in place to help them (National Council on Disability, 2003).

The college setting can be quite challenging for the disabled, and barriers exist that leave students with a disability frustrated and disenfranchised (Taylor, 2004). A number of factors have been attributed to less successful college outcomes for students with a disability (National Council on Disability, 2003). One factor cited in the literature is the inconsistency of student support services or disability services among institutions. These services can be valuable resources to help assist students with a disability in their journey through college. Although the services have grown considerably over the years, they are known to vary greatly from campus to campus (Scott, 1996). The type of accommodations provided for students on each campus may range from comprehensive to minimal or even non-existent (Malakpa, 1997; National Council on Disability, 2003; Scott, 1996). The scope of disability services for students in post secondary education is described as uncoordinated, fragmented, understaffed and inconsistent (Scott, 1996). Many students with a disability are unaware of the services provided by disability support services and believe that more information and outreach should be available to them (National Center for the Study of Postsecondary Educational Supports, NCSPES, 2000). This is unfortunate because more than 80% of disabled college students require some sort of institutional support to manage the college environment (National Council on Disability, 2003).

In addition to lack of standard disability services from campus to campus for disabled college students, another factor that may contribute to poor postsecondary outcomes in students with a disability is that educators and administrators in higher

education may not even be aware of a student with a disability's needs (Lafayette

Graham-Smith, 2004; Malakpa, 1997; National Center for the Study of Postsecondary

Educational Supports, NCSPES, 2000). This is particularly true in students with "hidden"

or subtle disabilities. Findings from a large, national qualitative study using focus groups

of students with disabilities support this fact (NCSPES, 2000). Students with a disability

reported that the faculty lack understanding of their disability issues, treat them unfairly,

and don't provide equal accommodations to students with hidden disabilities compared to

students with obvious physical disabilities (NCSPES, 2000).

Participation for Students with Hidden Disabilities: Students with hidden

disabilities make up the greatest rise in disabilities on college campuses. According to

2006-2007 data from the National Center for Education Statistics (2006), hidden

disabilities, including specific learning disabilities, and health-related disabilities,

encompass the majority of individuals served by the Individuals with Disabilities

Education Act (IDEA). However, in college students that are diagnosed with a hidden

disability, many choose not to disclose their disability (Lynch & Gussel, 1996), and are

frequently first diagnosed and identified at the postsecondary level (National Council on

Disability, 2003). Thus, the prevalence rates of college students with hidden disabilities

are likely an under-estimate of the actual number of students.

If we examine a cohort of students with a disability, we know that students with a

disability in general have unique educational needs, and may encounter difficulty in the

campus setting based on the distinct nature of the disability. It goes without saying that

students with a disability, similar to non-students with a disability, are not homogenous.

Students with a disability are not a "one-size fits all" entity; indeed, they are quite

diverse. However, often our perception of a student with a disability is that of an individual with an obvious physical impairment. In reality, the disability spectrum is quite broad, and encompasses physical disabilities (hearing impaired, sight impaired, speech, orthopedic), emotional-behavioral disabilities (depression, anxiety, obsessive-compulsive disorder, schizophrenia), health-related disabilities (diabetes, HIV, seizure disorder, asthma) and learning disabilities (autism, disorders of attention deficit), to name a few.

As stated, students with hidden disabilities are a diverse group that includes learning disabilities, attention deficit disorder, and other health-related disabilities (Kravets, 1997). Students with hidden disabilities may experience difficulty navigating through college more so than their physically disabled and non-disabled peers because of the invisible nature of the disorder.

These students don't appear ill, and may be treated as such. Kravets (1997) suggested that students with hidden disabilities may be underrepresented and perhaps discriminated against on college campuses:

> The bad new is that the climate for individuals with hidden disabilities appears to be making a U-turn back to being less sensitive, more skeptical, and less agreeable to giving students accommodations. While more students are being identified and labeled, more eyebrows are being raised from disbelievers (p.19).

Kravets (1997) reported that many students with learning disabilities are required to substantiate the existence of a disability yearly. The requirement for documentation may subject the student to unnecessary, time-consuming, and costly testing. Imagine a person with a chronic condition of diabetes or asthma that is required to undergo

31

extensive testing yearly to reconfirm a diagnosis. Given a scenario like this, it is not

unreasonable to raise the question "how level is the playing field for this diverse group of

students?" (Kravets, 1997, p.20).

Another example of inequity for college students with hidden disabilities is

described by Madaus (2000) in a 50-year historical snapshot of disability college support

services. Madaus (2000) referred to the recent "backlash" of some university

administrators against students with hidden disabilities. In his article, he reports that

students with hidden disabilities frequently encounter "doubting" administrators that

question the legitimacy of disability qualifications and are hesitant to provide

accommodations for students with a disability due to the concern that the integrity of the

academic programs is at risk (Madaus, 2000).

Skepticism from faculty was encountered by students with hidden disabilities in a

large qualitative study of students with a disability from ten universities that examined

their experiences and perceptions concerning access and participation in postsecondary

institutions, educational supports and postsecondary preparedness for transition to the

workplace (National Center for the Study of Postsecondary Educational Supports, 2000).

Findings indicate that an "accommodation stigma" exists for students with disabilities,

especially those with hidden disabilities. Non-disabled peers and faculty often question

the legitimacy of the illness and accommodations (p.13).

Examples of discrimination of students with hidden disabilities are found

peppered throughout the literature in education (Ferri & Conner, 2005; Gray, 2002;

Weber 2002; Wilson, 2004). Findings by Cook (2001) demonstrate that teacher rejection,

defined as students that teachers would be relieved to have removed from their classes,

was significantly higher for students with hidden disabilities compared to students with obvious disabilities. In 2004, four learning-disabled medical school applicants filed a lawsuit against the Association of American Medical Colleges for discrimination. The class-action suit claimed the students were denied test-taking accommodations for the Medical College Admission Test or MCAT (Mangan, 2004).

In interviews with college students diagnosed with learning disabilities, Ryan (2007) reports that the student participants expressed a lack of disability support services, lack of belongingness in the higher education environment, and experienced feeling a lack of credibility among faculty and peers, or that "their stories are not believed" (p.433). In addition, the students had difficulty asking for accommodations because they were too "embarrassed" felt "guilty" or "regretful" (p.439).

Key findings of a study commissioned by the UK Disability Rights Commission note that much of the discrimination towards disabled individuals in educational institutions is "more subtle, and often unintended" (Wilson, 1997, p.163). In the same study, a survey of 305 students with a disability (age 16-24) reported that 45% of the students had difficulty at their institution for reasons related to their disability (Wilson, 1997).

Hidden Disability of Orthostatic Intolerance: Students with orthostatic intolerance suffer from a health-related hidden disability. Disorders associated with orthostatic intolerance are characterized by intolerance in the upright position including symptoms of syncope (fainting), near syncope, lightheadedness, extreme fatigue, exercise intolerance, diminished concentration, headaches, nausea, tremulousness and memory difficulties that improve on resuming a recumbent or supine position (Grubb &

33

Olshansky, 2005; Grubb 2008). Recent NIH estimates suggest that approximately one million individuals suffer from some form of orthostatic intolerance (Goldstein et al, 2002). Further, this syndrome is frequently under-diagnosed by health-care providers, and thus many more individuals may be afflicted.

As stated, many syndromes associated with orthostatic intolerance (OI) are hidden disabilities not apparent at birth, and in fact, typically begin at adolescence and young adulthood. They are considered acquired disabilities, similar to an individual with a traumatic brain injury from an auto accident. Individuals afflicted with disorders that manifest as OI will grow and develop normally throughout childhood and the prepubescent period usually without any evidence of a health-related difficulty, developmental delay, or learning disorder. Unfortunately, these students are hit hard with a disorder during a critical developmental period, a very vulnerable time in terms of college student development. They must make adjustments to the demands of college at a time when they may be intermittently physically, emotionally, and mentally challenged.

The students afflicted with the syndromes associated with orthostatic intolerance must abruptly adjust to a new way of learning based on changes in cognitive function, which is foreign to their previous learning style. Because of the intermittent reduction of cerebral blood flow, these students suffer relapsing periods of cognitive and processing defects. The symptoms may vary from day to day, and this inconsistency may make interactions with faculty members and friends difficult. That said, they have to adjust to a new college environment and learning changes. They have to develop new coping skills. They must possess self-advocacy skills to assist them in their academic and institutional needs, but these skills may also be undeveloped (Pocock, Lambros, Karvonen, Test &

Algozzine, et. al., 2002; University of Washington, 2000). They must learn to adapt to new physical limitations that wreak havoc on their everyday tasks.

Students with OI suffer from an unpredictable illness; they may have good and bad days (DYNA, 2008). In general, the student with OI maybe more at risk for poor engagement patterns in college due to the acquired nature of the syndrome. They may be hesitant to disclose their illness and ask for assistance from faculty and friends. They may find that the campus environment is non-inclusive in terms of their ability to engage and participate. Emotionally, many of these students must come to terms with the fact that they are ill, and may feel too overwhelmed to participate. They may not participate in the campus environment because they believe that it is not "worth the effort." As such, they may have difficulty engaging or becoming fully involved in the campus experience.

According to survey data from The National Center for Education Statistics (2006), students with disabilities on the college campus have increased 8% to 13% over the past 30 years. From the survey, of the 13% reporting all disabilities, over 9% could be considered hidden disabilities. As stated, hidden disabilities such as learning disabilities, language impairments, emotional disturbance, and other health impairments make up the majority of the students with a disability.

Students with hidden disabilities, unlike their easily recognized disabled peers, struggle with the legitimacy of their disorders, and experience the stigmatization associated with the lack of credibility (Wolf, 1999). The obstacles encountered in higher education for students with hidden disabilities such as orthostatic intolerance syndromes may be negatively associated with persistence and degree attainment. In order to ameliorate the likely negative trajectory for these students, we must understand how they

engage on campus. Although the current trend in student engagement research had begun to look at students with distinct needs, much of the vast literature on this topic is devoid of any mention of student with a disability's needs (Astin, 1984, 1993; Kuh, 2001; Pascarella & Terenzini, 2005).

As stated, the theory of student engagement as we know it may need to be viewed from the lens of a student with a hidden disability. The students afflicted with the syndromes associated with orthostatic intolerance (OI) represent a unique sub-set of students with a hidden disability. These students, unlike other students, are at high risk due to the sudden onset of the disability during the teenage years. In order to assist these students, and students with other similar hidden disabilities, we must know about their world, from their point of view. In an article that summarized the key findings from research presented by the UK Disability Rights Commission (DRC), Wilson (2004) argues "the need for voices of young disabled people to be heard in research, policy and planning" (p.162).

To that end, the student "voice" provides us with a snapshot of their perspective on engagement in the college setting. Is the campus environment inviting, or does it inhibit successful engagement for the student? Do students with hidden disabilities in this study view faculty and peers as approachable and supportive? Or, rather, do they perceive the faculty and peers as untrustworthy and unaccommodating to their needs, especially in terms of engagement? Do the students' perceptions prohibit or encourage engagement? Do the students with disabilities in this study believe that they are integrated into the campus community, and if so, does this help them to engage? Are the opportunities for extracurricular activities realistic, or are they seen as too difficult to attempt, based on

their health restrictions? What aspects of the physical environment of the campus contribute to an engagement barrier? Do campus institutional policies or practices make engagement difficult for these students? These are some of the questions that were explored to provide a deeper understanding of the issue. The knowledge gained from this inquiry is important to faculty, student affairs personnel, and administrators who work in higher education. The information gained from this study adds to the research on the theory of student engagement, student development, and disability.

Not only is the study significant for higher education, but also the health-related disciplines. Health care providers are at the forefront in diagnosing, assessing, and managing health, psychosocial and environmental related problems in students with hidden disabilities. Health care providers have an important role in the dissemination of knowledge to university personnel about how many disabled conditions impact learning, mobility, communication, and socialization. Findings from a landmark study sponsored by the National Institute on Disability and Rehabilitation Research report the importance of a partnership between university personnel and health care personnel. This partnership will provide a seamless transition for the medical community to educate the educational community about a students with a disability' medical condition, how the condition affects the student learning, and suggestions necessary for the student to receive any accommodations needed on the college campus (National Center for the Study of Postsecondary Educational Supports, 2000).

Thus, in order to understand many of the challenges that college students with hidden disabilities face today, a variety of disciplines including education, nursing, medicine and psychology, to name a few, must share "common knowledge" to promote a

holistic approach to the student. Each discipline, in its own right, helps to shape our understanding of complex issues by the assimilation of its theories and research findings into practice and policies. However, too often there is a fragmented approach to problem solving, because the disciplines do not "speak the same language." In order to "speak the same language," we must understand the world from each discipline's perspective. The outcome for an individual will either be enhanced or hampered by the perspective. If, however, the respected disciplines communicate and collaborate to problem solve by sharing common knowledge, this approach is more likely produce a positive result.

It is important for students to participate fully in the campus experience. Thus, it is important for the disciplines of education, rehabilitative services, medicine, nursing, counseling, and psychology to understand the engagement patterns of students with hidden disability of orthostatic intolerance and other similar hidden disabilities. The knowledge gained from this research may help further understanding of student with a disability's engagement patterns and contribute to the fusion of shared knowledge between the disciplines. This approach is important for college student autonomy, self-advocacy, self-regulation, and participation in the campus culture and may ultimately assist and empower students with hidden disabilities to succeed in the college setting.

**Limitations of the Study**

Several limitations were identified in the following sub-headings; sample, methodology and data analysis. A discussion follows.

Sample: In terms of sample validity one limitation is that qualitative research is bounded by a specific is bounded by a specific context or settings (Marshall & Rossman, 2006). Participants in this study consisted of students with the health-related hidden

disability, orthostatic intolerance, and each student is bound by his or her unique college setting. This "bounded system" is a small subset of the larger subset of all students with hidden disabilities. For this reason, the results cannot be generalized or transferred to the larger group of college students with hidden disabilities, or disabilities in general. It is unknown if the findings are applicable to other college environments, because this study is limited to five student participants at four different campuses.

Although the use of multiple cases and participant observation may help increase the study's external validity, the study, as designed, limits transferability. Instead, the student chosen provided a glimpse into his or her world, yet qualitative research findings cannot be used to predict how others with similar disabilities are affected or behave. Nor can the investigator conclude that the results can be positively linked to other students' success in the college setting. Despite this limitation study in a qualitative context allowed a deeper understanding of this problem. The findings may support research on students with other hidden disabilities. The findings may add to student development and student engagement research.

Another limitation of the sample aside from the limited transferability to the general college population of students with disabilities is the homogeneity of the sample regarding racial/ethnic and sex. All the students were of White females. Although the sample was not representative of the larger US PYS, it was more representative of the racial make up of students who report a disability on college campuses. Almost ¾ of students with reported disabilities on college campuses are White and women comprising 60 percent of college students with disabilities (Nichols and Quaye, 2009). Finally, as noted, females outnumber males 5:1 in the disorder of orthostatic intolerance.

One specific limitation in the methodology used is the lack of a longitudinal approach for college student development and identity development. In order to view the student from a developmental perspective, the ideal study would track the student longitudinally from the diagnosis of a syndrome of orthostatic intolerance through the college experience and perhaps beyond. Engagement patterns from the beginning of college to completion would add to a developmental view. Assessment of student outcomes such as persistence, and degree completion would add to the research.

Instead of tracking one student longitudinally over time, the study chose to address the limitation by selecting five students from different class rankings (freshman-sophomore-junior-senior) to provide a glimpse of different developmental frames. This developmental view has limitations because it is based on self-reports and past memory of different experiences. Trouble with memory recall of the events could affect the accuracy of the data.

Data Analysis: Although this study addressed the problem via a holistic, exploratory perspective, the interpretative nature of the inquiry may be seen as a limitation. My analysis as a researcher may not have captured the meaning intended by the student participant accurately. My bias as a researcher may be related to previous experience with this type of student. In addition, the meaning may be compromised due to the fact that only one researcher ultimately reviewed and interpreted the data. To increase interpretive accuracy, the interview transcripts were sent to each student for member checking and verification. The reader is referred to in Chapter Three, where I address this bias in greater detail.

To increase internal and external validity, the study provided for triangulation of data. This method used multiple sources of data to study the problems in depth. Further, multiple case study design and participant observation with triangulation of data from multiple sources helped to strengthen external validity, so that results may be used to guide practice and policies in higher education.

**Definition of Terms**

The following three terms are defined for this study: a) student engagement, b) hidden disabilities and c), orthostatic intolerance syndromes.

Student Engagement: Student engagement is defined conceptually as a complex interaction of student behaviors with the campus environment (Astin, 1984; Kuh, 2001). The "student" is characterized by internalized beliefs, values, roles, behaviors, identity, and personal attributes. Pre-college characteristics also contribute to student engagement behaviors. The campus environment includes the academic environment (faculty, teaching pedagogies, student success courses, student learning, course expectation, schedules, grades), the social environment (friends, classmates, clubs), the physical environment or structure (space, accommodations, living arrangements, barriers, parking, transportation), and the institutional environment (schedule of classes, financial penalties or rewards, add-drop policies, scholarships). Further, for the purpose of this study, from the literature, concepts related to student with a disability participation in education are conceptualized as "student behaviors" in student engagement. The concepts include a) student perception of acceptance by faculty, education officials, and peers, b) student perception of belongingness or inclusion in the campus setting, c) student beliefs about

adjustment to college, d) personal perceptions of quality of life with disability, e) self-disclosure the disability, and e) self-advocacy skills.

Hidden Disabilities: Hidden disabilities refer to a "heterogeneous group encompassing major and minor psychiatric disabilities, attention deficit disorders, learning disabilities, traumatic brain injuries, and other neurocognitive disorders and chronic medical conditions that may compromise academic functioning" (Wolf, 1999, p.387). Many health-related disabilities are considered hidden disabilities.

Orthostatic Intolerance Syndromes: Orthostatic intolerance syndromes refer to a heterogeneous group of disorders of hemodynamic regulation characterized by insufficient cerebral perfusion resulting in symptoms while upright that are relieved by assuming a recumbent or lying position (Grubb, 2005). Symptoms include fainting and near fainting, exercise intolerance, lightheadedness, dizziness, nausea, fatigue, diminished concentration, headache. The syndromes associated with orthostatic intolerance are by and large hidden disabilities. The syndromes of interest that are associated with orthostatic intolerance include dysautonomia, neurocardiogenic syncope (NCS) and postural tachycardia syndrome (POTS).

**Summary**

Although it is clear that students with a disability experience less success in the college environment than their non-disabled peers, no research exists about students with a disability diagnosed with hidden disabilities such as orthostatic intolerance. The literature on college students with hidden disabilities primarily focuses on students with learning disabilities, but this research does not look at engagement. College students with orthostatic intolerance experience significant cognitive, mental, and physical difficulties

that may transcend to the academic environment. The qualitative inquiry with multiple case study design was an important methodological approach used in this study, because it presented the problem from the students' point of view. This approach was able to capture the complexities and unexpected experiences described by the students that are normally only found in the natural setting. The rich data gathered from this study would not have been possible via conventional surveys. This study adds to higher education research in student development theory, disability identity development, and student engagement theory. It may spur further research of the National Survey of Student Engagement (NSSE) and students with a disability. This research also adds to the health-related disciplines because individuals who work with these students may work collaboratively with higher education officials to promote student success.

In this study, the students were able to identify significant academic, institutional, financial, physical, and social barriers that affected their ability to engage in the college setting. As well, the obstacles encountered by this group of students appeared to be aggravated by the "invisibility" of the disorder. In addition to describing possible barriers to success, this study was important because the students were able describe aspects of the college experience that have been helpful in the transition to college life. This data could be invaluable to other college students with similar hidden disabilities. Other students, educators, disability services personnel, and health care providers may use this information to foster a successful college experience. The information gained from the study may add to our understanding of student development in college for this unique group of students.

## Chapter II

## Literature

Very little is known about how students with disabilities engage on the college campus, and there is no research that specifically addresses the topic. Due to the limited knowledge, the literature review provides research and support for the constructs central to student engagement in dominant and diverse groups including disabled individuals.

A description of the theoretical framework is presented. What follows is a discussion on identity development and college student development in the dominant culture. Of importance to the study, the discussion addresses disabled persons including those with hidden disabilities. In addition, the discussion will focus on college students with the syndromes associated with orthostatic intolerance. An exhaustive review of the literature regarding student engagement patterns in the dominant culture is then addressed, followed by a discussion of engagement in college students with disabilities and hidden disabilities. Qualitative research studies in the literature of disability issues will be used to illustrate the topic.

## Introduction

Although student engagement is the prime construct for this study, this section begins with identity formation in adolescents and young adults. While it is true that student engagement behavior enhances or helps to form a healthy identity, this study is interested in examining identity first. The students in this study experienced a profound disruption in their identity. As the literature demonstrates, adolescence and young adulthood is an important time to form identity. However, this researcher believes that

the effects of the dramatic change in self need to be examined because this disruption in identity is more likely to influence engagement.

Two pioneers in psychosocial theory development related to identity embrace the view that a person's behavior is strongly influenced by a sense of identity or "self" (Erikson, 1959, 1980; Marcia, 1980). This tenet is paramount to understanding one of the factors that may play a role in student engagement. College student development, including identity development, is tightly interwoven into the fabric of student engagement (Kuh, et al., 2005). Identity development can be viewed as a temporal, multifaceted construction of internal and external factors that an individual accepts or rejects as a part of self (Weeber, 2004). A person's sense of identity is believed to be a dynamic developmental process starting in infancy, but one of the most important periods for identity development is late adolescence and early adulthood (Erikson, 1959, 1980; Marcia, 1980).

"Emerging adulthood" is a transitional stage between adolescence and adulthood that has been more recently conceptualized by Arnett (2000). This developmental period mirrors the time a student typically spends in college and many of the college student identity theories address identity development in emerging adults. Taking this a step further, it follows then that a student's behavior in the college setting (including participation in the college environment) is associated with a sense of self.

Ergo, a compromised sense of identity in a college student may influence student engagement behaviors. Disabled college students are a subset of students who have different needs than the dominant culture of college students. In her monograph series on college students with hidden disabilities, Walling (1996) suggests a state of disconnect

between the robust "self-concept" (p.1) of the contemporary college student with a disability today, and the negative perception of the disability by society. The idea that the student with a disability's self perception has progressively improved over the years is attributed to greater support systems for the disabled, legal mandates for higher education, advances in understanding the nature of the disability, and technology. More importantly is the fact that many students with a disability see their disability as an "important part of their personality, not something to feel depressed or burdened about" (p.1).

Given the state of disconnect between a positive sense of self identity in a student with a disability and the negative perception of the disabled individual by society, it is likely that this situation frustrates the college student with a disability. Even so, it is possible that the most resilient disabled college student who has already developed a positive sense of self is more likely to withstand the traditional view held by society, that is, "identity equals disability." On the other hand, the same may not be said for the student with a disability that does not have a well formed sense of self. In all likelihood, a college student with a new-onset, acquired hidden disability like orthostatic intolerance may have difficulty adapting to the typical dominant culture image of disability. Accordingly, a student with a disability may enter the college environment with a disability identity that may be fragile, and adversely affected by the campus culture. The perception by a student with a disability that the campus environment is non-inclusive may shape his or her sense of self and perhaps influence engagement behavior.

The fact that an individual with an acquired hidden disability may be at risk for a negative self image is well illustrated by Walling (1996) in her description of the

46

dramatic changes in self-concept that occur in college students with newly acquired disabilities. In order for an individual to adjust to an acquired disability, "drastic lifestyle changes are demanded and new techniques for carrying out life skills must be discovered" (p.3). Student engagement behaviors in students with newly acquired hidden disabilities may be adversely affected, especially if the student has difficulty adapting to the dramatic changes in self.

**Conceptual Framework**

Student engagement has been integrated into the underlying conceptual framework of practice and policy that shapes many institutions of higher education. The goal is to promote effective educational practices that create a successful student experience. Student involvement, in other words, relates to positive postsecondary outcomes.

The conceptual framework for this study is based on the following model and theories; a) the model of student engagement (Kuh et al., 2006a), b) several identity theories including disability identity, and c) college student development theory. The components of the conceptual framework are fused together by this researcher to establish a framework that best represents college student engagement in students with hidden disabilities. Each of the components is presented next.

**The Model of Student Engagement**

The foundation of the conceptual framework for this study rests on "The Framework for Student Success", a model developed by educational researchers led by George Kuh (2006). This framework has its roots in the "Theory of Student Involvement" developed by Astin (1984). Student engagement posits that student involvement on

campus is both a physical and psychological energy investment. Engagement includes student behaviors and institutional conditions. In this study, college student development, identity development, disability identity, self-disclosure, self-advocacy, and quality of life are constructs influenced by student behaviors and institutional conditions.

Student behaviors include pre-college characteristics and demographics, and these influence campus physical, institutional, academic and social engagement. The pre-college experiences include previous experiences that affect student success in the college setting. These are background characteristics that include prior academic preparation, college readiness, family and peer support, motivation to learn, demographics-sex, race/ethnicity, socioeconomic status, family educational background, enrollment choices, and financial assistance and policies (p.7). The characteristics speak to pre-college preparation and educational aspirations. The onset of the newly acquired disability is included in this area. This disorder is what the student "brings to the table" that is different from other students, and not addressed directly in the Framework for Success (Kuh et al., 2006).

Student behaviors also include social and academic engagement. These categories address study habits, peer involvement, interaction with the faculty, and motivation. A supportive campus environment enhances engagement. Students who experience a sense of belongingness and validation are more likely to be involved in interactions with peers, faculty and campus support personnel.

Institutional conditions include the institutional environment and the physical campus environment engagement. These categories affect engagement and include institutional policies, support services, housing, and accessibility.

**Identity Theories in Dominant Culture**

Identity theory and college student development is related to student engagement in the college setting (Evans, 1998).The research on development of a disability identity has been gathering momentum in the last decade (Weeber, 2004). Although college student development theories have explored identity development in diverse cultural groups, no theory has been formulated specific to the student with a disability. For this study, identity development is a construct incorporated into the conceptual framework.

Erikson's Theory of Psychosocial Development (1950; 1980): The changes that occur in an individuals' psychosocial development over the course of a lifetime have been explicitly detailed in the theory of psychosocial development described by Erik Erikson almost 50 years ago. Psychosocial identity development theorists have used Erikson's theory as a starting point for discussion of theory development in countless amounts of college student development research (Torres, et al., 2003; Evans, et al., 1998). Why Erikson's theory holds such appeal to developmental theorists even today is well articulated in a statement by Berzoff (2002):

> His theory is the first, and still the strongest, to expand the discourse on development by adding the variables of culture, race, class, sex, and time to how a person develops a coherent sense of identity. While Erikson was constrained by his own cultural constructs and values, his era, and by a linear view of development, his work has provided us with a theory that takes race, class, and sex into consideration far more than any previous psychodynamic theory. His inclusion of the sociocultural surround in which individual identity develops makes a profound contribution to clinical practice. (p.124)

There are seven stages of psychosocial development delineated by Erikson seen

as necessary conduits for healthy psychosocial development. Throughout an

individual's lifespan, each stage is mastered sequentially for healthy ego

development. The stages tagged as important for traditional college age students

(18-25 years) include the adolescent stage of identity versus role confusion and

the young adult stage of intimacy versus isolation (Erikson, 1959, 1980).

Early identity development, as conceptualized by Erikson, is grounded in

adolescence, and includes relationship changes in self and with the social network of

peers and others. Erikson theorized that adolescents gain a sense of self or identity when

they can engage in positive relationships with friends, and gain independence in the

relationship with their parents. Adolescents learn to function with autonomy especially

with regard to decision-making. The peer influence and socialization that occurs is based

on the inclusion of the adolescent in a peer group that fosters shared participation in

activities. Self-esteem is enhanced when an adolescent is able to fully participate in

activities that foster a sense of belonging. Following the adolescent stage of psychosocial

identity formation is the formation of intimate relationships within the young adult. This

includes achieving a balance between relationships, peers, employment, families, and

schoolwork (Erikson, 1959, 1980).

Weeber (2004) finds fault with Erikson's theory from a disability perspective,

adding that the theory "assumes non-disabledness of the body" by the "linking of

psychosocial development to mastery of the body and its functioning" (p.24). A disabled

person herself, she argues that identity development in a disabled individual is not

synonymous with the disability and envisions identity as "bodiless in its abstraction"

(p.24). In order to "master" the stages necessary for healthy psychosocial development the way Erikson proposes, a disabled individual may not follow the same path, especially if the ability to achieve each stage is based on body function.

Erikson (1959, 1980) conceptualizes adolescence as a period of "separation" from the parental and family influences and an increase in connectivity to the peer group.Assumedly, in adolescents and young adults with new-onset disabilities, there may be greater demands placed on the family and considerable difficulties in the initiation and maintenance of the peer relationship.

Researchers have explored peer and family relationships in chronically ill adolescents, and in one study the sample is similar to this study. Kashikar-Zuck et al. (2007) report on social function and peer relationships of adolescents diagnosed with juvenile primary fibromyalgia syndrome (JPFS). Very much an acquired, adolescent-onset, hidden disability, the researchers report that adolescents with JPFS often have difficulty with peers and school activities including attendance, extracurricular activities, and sports. The study design included survey data collected from teachers, peers, and self-reports from 55 adolescents (ages 12-18) with JPFS, and matched with 55 adolescents without chronic illness.

Findings from the study indicate that adolescents with JPFS were perceived as being more isolated, less popular, less well-liked by peers, less often selected as best friend, and had fewer friendships than the control group of adolescents without chronic illness. The researchers note that contrary to previous research on other children with chronic illness, the youth in this sample had greater peer group and social functioning difficulties. As an explanation for the discrepancy, the researchers offer that JPFS may be

unique to other disorders in that the adolescents afflicted with this syndrome have higher rates of mood disorders and anxiety, perhaps secondary to lack of ability to obtain a definitive diagnosis (Kashikar-Zuck, et. al., 2007).

The autonomic nervous system syndromes associated with orthostatic intolerance behave somewhat similarly in presentation to JPFS in that they both are acquired disabilities in adolescence, present with multiple subjective symptoms and few objective findings, and are difficult to diagnose. Thus, the study by Kashikar-Zuck, et al. (2007) is significant to this study because it lends support for the importance of peer relationships in chronically ill youth, and the importance of participation in activities in school and with friends. The high school youth in the study are younger in age than most college students, and it is possible that college age students may have had more time to adjust to the new-onset disability. Nonetheless, the study provides preliminary understanding of the importance of engagement patterns of adolescents with the peer group in a new onset hidden disability (JPFM) that is similar to orthostatic disorders.

In another study that provides a view of student-peer engagement in disabled youths, Hodges and Keller (1999) examined peer acceptance and involvement in students with a disability using a qualitative design. Sixteen undergraduate students with physical disabilities were chosen to assess what the students thought influenced their social involvement on a college campus. Results from in-depth interviews revealed that perceived acceptance by peers and opportunities for participation in extracurricular activities was important to this group of physically challenged university students. Unfortunately, the students reported low expectation for social involvement. The themes identified as barriers to social involvement included inconvenience of accessing social

52

opportunities, perceived lack of acceptance by peers, transportation issues, problems with scheduling of extracurricular activities, and the need for assistive care. The study by Hodges and Keller is important for students with a disability with visible disabilities, but does not speak to hidden disabilities.

To reiterate, the conceptualization of the stage of identity vs. role confusion in adolescence by Erikson (1959, 1980) relies heavily on social integration and peer relationships. As stated, a student with a newly acquired, hidden disability may have difficulties with this developmental task because peer relationships may be challenging. It follows then that Erikson's theory of psychosocial development (1959, 1980) may have limitations for disabled adolescents. Although Erikson's theory has its limitations with the disabled, Weeber (2007), in her dissertation research on identity development in disabled individuals, notes that it is a "starting point for developing culturally diverse identity development theories" (p.30).

Arnett's Theory of Emerging Adulthood (2000): In accordance with Erikson's psychosocial development theory, Arnett (2000) more recently introduced a groundbreaking concept in the stages of development termed "emerging adulthood." Arnett conceptualizes this period as the prolonged identity development that occurs in individuals due to the postindustrial age dynamics of postponement of marriage, children, and transition into the workforce (Arnett, 2000; Schwartz, Cote & Arnett, 2005). Although not fully integrated into student development research, the period of "emerging adulthood" covers the time frame between adolescence and adulthood (18-25 years of age) and corresponds with college student development. Emerging adulthood is a "distinct period of life course, characterized by change and exploration of life directions"

53

(Arnett, 2000, p.1). Components of this transitional-like stage include refinement of identity, lack of stability, self-centeredness, and discovering choices.

The description of the stages identified by Arnett illustrates that this is a fragile time period for the dominant culture, and may be even more difficult for those with a newly developed or acquired hidden disability. Although Arnett does not specifically address identity in diverse groups, he acknowledges that not all young adults have the opportunity for life exploration, even in industrialized nations. Some groups historically lack opportunities, including minorities and culturally diverse groups, individuals from low socioeconomic status and, of course, the disabled. Many of the individuals from the marginalized groups may be forced into low paying jobs, unemployment, or the role of a single parent much earlier than a traditional college student from the dominant culture (Arnett, 2000). Employment outcomes are known to be bleak for adolescents with disabilities (Wolf-Branigin, Schuyler & White, 2006).

Students with disabilities, like students from diverse racial groups, have experienced exclusionary educational opportunities (Ferri & Conner, 2005), and subsequently this may limit an "exploration" of life choices. As noted earlier, students with a disability, especially learning students with a disability, are more likely to enter into the workforce from high school into the employment arena (Madaus, 2006), rather than attend college. As more and more disabled young adults enter into higher education, they may experience fewer opportunities for "self-exploration" because they may lack the ability to fully engage or participate in varied experiences on and off campus. Accessibility to accommodations in the college setting is a recurrent theme in disability

54

research and presents challenges for disabled college students (National Council on Disability, 2003).

One aspect of Arnett's theory may be a benefit for students with a disability. According to Arnett, today's emerging adults are taking time to move into fixed roles of adulthood (marriage, employment) as they explore different options. The delay in role development may parallel students with a new onset disability due to the changing nature of identity secondary to illness. These students may need much more time to "discover themselves" as they adapt to the challenges that chronic illness impose. The theory of emerging adulthood is intriguing and important for this study because it recognizes the changes that take place in individuals that are in transition.

**College Student Development Theories**

This section begins with a discussion one of the earlier and more widely known theories of college student development (Chickering, 1969) and covers some of the current literature and newer theories that examine student development theories in diverse populations. The newer theories embrace the concept of multiple, fluid identities. The literature and theories presented here form the foundation a discussion of identity development in disabled college students.

Chickering's Theory of Identity Development (1969): College student development is a complex process that has received wide consideration in higher education literature in the past thirty or more years. The increase in theory development in the field of higher education has paralleled the increase in access of diverse students in the later half of the 20th century. Development in college students is conceptualized as a growth process that students experience in the course a four-year degree (Chickering,

1969). The process includes experiences that enrich or impede a student's self-growth and social growth (Evans, et al., 1998).

The models of student development are generally grouped into three categories including psychosocial and identity theories, cognitive-structural theories, typology theories, and person-environment theories (Evans, et al., 1998). As discussed, psychosocial and identity theories in college student development are heavily influenced by the earlier works of developmental psychologist Eric Erikson (1959, 1980) in his classic eight stage theory on identity formation. Fundamental to the theory is the idea that an individual will journey through stages of identity formation throughout the lifespan. Each individual must master the critical developmental tasks germane to the period or the individual will risk a delay in development or "identity crisis" (Erikson, 1959, 1908). How an individual progresses through the stages is heavily dependent on coping skills and environmental support. The critical developmental stages that Erickson argues are essential for growth and healthy psychosocial development is pertinent for the healthy development of college students. Indeed, many of the college student development theorists have created models that are interested in identity formation.

One of the most "highly regarded college student development theorists to date" is Arthur Chickering (Evans, et. al., 1998, p.52). His theory of identity development (Chickering, 1969) examines the developmental concerns of college students and the environmental conditions that influence student development. Integral to the theory are the "seven vectors" that serve as a "map" for a college student's intellectual, physical and social growth and describe: "major highways for the journeying toward individuation- the

discovery and refinement of one's unique way of being- and also toward communion with other individuals and groups including the national and global society" (p.35).

The seven vectors conceptualized by Chickering (1969) and later revised by Chickering and Reisser (1993) include: developing competence and self-awareness, learning control and flexibility by managing emotions, establishing identity, balancing intimacy with autonomy, moving through finding one's voice or vocation and developing purpose, refining beliefs, and making commitments and social responsibility that develops integrity (Chickering, 1969, p.35). Chickering (1969) proposes that the vector "map" is somewhat sequential, and early vector development provides the foundation for development of the later vectors (Foubert, Nixon, Shamim & Barnes, 2005). An important element of Chickering's theory is how the college environment influences student development (Evans, et al., 1998). Of essence to the theory, the educational environment should facilitate student development through the "integration of work and learning, recognition and respect for individual differences, and acknowledgement of the cyclical nature of learning and development" (Hamrick et. al., 2002, p.37).

Chickering's theory is one of the most recognized college student development theories in higher education, but it has several limitations for a college student with an acquired hidden disability. Chickering (1969), like Erikson (1959) conceptualizes the theory in a linear, sequential fashion. A student with a new-onset disability may experience the vectors involving competence, learning control, autonomy, and vocational exploration much differently. Students with relapsing symptoms may also have difficulty with establishing consistency in the educational environment.

57

Foubert, et al. (2005) examined the sequential nature of Chickering and Reisser's vectors in a longitudinal study of 247 racially diverse college students. Results demonstrate that in the sample, the sequential nature of the vectors as conceptualized by Chickering and Reisser (1993) was only partially supported; the vector of developing purpose did not necessarily occur at the end of the vector sequence (Foubert et al., 2005). In addition, reported as consistent with previous research, Foubert et. al., (2005) found sex differences in the vector of intimacy or developing mature interpersonal relationships. The females in the study experienced mature, intimate relationships sooner than males. From their research, they conclude, "development is not so much a series of steps or building block, but rather could be conceptualized differently, like horizontal" (Foubert et al., p.470).

Yet, another limitation in Chickering's theory for the disabled individual is the concept that student development is dependent on physical "growth." Indeed, the vector "map" suggests college students' growth includes intellectual, "physical," and social growth (Chickering, 1969). Like Erikson's theory (1959), this concept is problematic for a disabled person because it links physical bodily function to psychosocial-cognitive-identity development (Weeber, 2006).

Even though Chickering's theory of college student development has limitations for the student with a disability, including the chronological nature of vector attainment and the reference to physical function, the theory has other aspects that are applicable to students with a disability. From a sociocultural perspective, Chickering and Reisser (1993) note that one component of developing autonomy is the ability to be less influenced by others' opinions. Considering that the identity in an individual with a

disability is so convoluted by the negative social perceptions of disability, this concept is important. The discussion of disability identity formation in its entirety will be addressed in the next section.

Students with a disability may also benefit from Chickering's emphasis on environmental influences that allow for growth in college students (Chickering & Reisser, 1993). A college environment that supports a student with a disability is one element that helps the transition from high school (Hadley, 2007). In a recent qualitative study of ten, traditional-age, first year college students with learning disabilities, Hadley (2007) found that the students were not satisfied with the level of college support services, especially when compared to their high school accommodations. Also, the students reported that their "dream" college environment would include a learning center or a "single place where they could go to take an exam when they needed extra time and/or privacy, individual help from tutors or to collect notes for their classes" (Hadley, 2007, p.12).

In summary, one of the most compelling reasons to use Chickering's theory for students with a disability in this study is the link between college environmental factors and student engagement. Evans et al. (1998) explains that supportive conditions in the college environment significantly affect development, and "these include concepts of challenge and support, involvement, marginality and mattering, and validation" (p.25).

### *Diversity and College Student Development Theories*

The early theorists in college student development are credited for paving the way to a broad understanding of the forces that shape the college student. However, later theorists recognized that the early theories were built on a homogenous student

population. Authur Chickering's (1969) theory of college student development was based on a sample of primarily White, middle class students from a small private college in Vermont. William Perry, noted for a cognitive-structural theory of student development, based his research for the theory on White males from Harvard (Evans, et al., 1998).

With the changing demographics of the college student population, it became clear to student developmental theorists that new student development theories would require a diverse perspective (Chickering & Reisser, 1993). Recent research in the psychosocial development of college students has expanded to include theories that are more closely aligned with marginalized groups. The increase in diversity throughout college campuses led to the development of theories of identity formation in women (e.g., Josselson's Theory of Identity Development in Women, 1987) and in different racial and ethnic groups (e.g., Cross's Model of Psychological Nigrescence, 1991; Helms' Model of White Identity, 1993; Phinney's Model of Ethnic Identity Development, 1990). The advancement of inclusive models of identity development is the basis for a flood of recent research (Ashmore, Kay & McLaughlin-Volpe, 2004; Cross, 1991, Phinney, 1992; Syed & Azmitia, 2008).

More recently, the traditional models of college student identity development have been scrutinized as one-dimensional in scope (Umana-Tayor, 2008). The shift to complex, holistic models of student development represent a changing paradigm in higher education circles, and Umana-Taylor (2008) provides a glance of newly emerging models and conceptualizations of student development that encompass sociological perspectives and self-authorship as a way to define identity. Social environments assign roles for marginalized groups, including the disabled. The newly emerging models of

student development promote self-authorship (Baxter-Magolda, 2004), and challenge the social structures that define a person's identity (Umana-Taylor, 2008). With the prevailing worldview, the dominant culture primarily dictates identity development in oppressed individuals. New models of identity development for oppressed groups, including the disabled, will allow for a "redefinition" of a new identity independent of the dominant group worldview (Hardiman & Jackson, 1997). Jones and McEwen (2000) proposed one of the first student development models that addressed the concept of "multiple identities." The researchers base their model on the premise that an individual may have several identity orientations (e.g., race, sexual orientation, sex, disability, social class, and religion, professional) that contribute to a "core" sense of self (p.405). The Conceptual Model of Multiple Dimensions of Identity (2000) was developed from qualitative, grounded theory research with 10 undergraduate women from diverse, ethnic backgrounds. The model acknowledges "multiple identity dimensions" that contribute to identity development that is inclusive of race, sexuality, class, religion, and culture.

Jones and McEwen (2000) schematically conceptualize multiple identity dimensions as having a center nucleus called a personal or core identity. The core includes personal attributes, characteristics. Intersecting the core identity and thought to interact with each other are multiple identity spheres that include culture, race, religion, class, sex, and sexual orientation. The last construct includes contextual influences such as family background, sociocultural condition, and current experiences (p.410). The contextual influences are both internally experienced and externally defined (for a complete description of the model, please refer to Jones & McEwen, 2000).

In general, the model presented by Jones and McEwen (2000) is limited in applicability due to the small sample size, but its significance for a student with a disability is noteworthy. This model captures the social stigmatization that may contribute to identity development in the disabled "culture." As will be discussed, a disabled individual may be influenced by the contextual influences in which others perceive the disability.

**Identity Development in the Students**

Conceptualized in this study as a key component to student engagement, the disability identity is now discussed. The focus on identity will "set the stage" for interviews with students about engagement behaviors because the researcher believes that environmental factors in the college setting (social-interpersonal-physical structure) contribute to identity or "sense of self" and subsequently influence behavior. Thus far, the discussion of identity development in college students has focused on well known developmental theories such as Erikson's (1959, 1980), Arnett's (2000), Chickering's (1969), and a less known multiple identity developmental theory (Jones & McEwen, 2000).

The aforementioned theories have expanded the knowledge base for higher education officials and have illuminated the developmental needs of students as they journey through college. As shown, these theories, taken collectively, have pros and cons for the student with a disability. Unfortunately, even though students with a disability, especially those with hidden disabilities are attending college in greater numbers, an understanding of identity and college student development specific to disabled individuals is in its infancy.

One of the more pertinent articles reviewed by this researcher is presented by Mpofu and Harley (2006). The authors discuss racial and disability identities as separate yet distinct contributors to career counseling outcomes in persons of color who have disabilities. Importantly, the authors note that the construct of a disability identity or theoretical model for disability has "lagged behind" other inclusive theories of identity such as race and sex (p.16). Mpofu and Harely (2006) contend that the lack of specific disability identity theories is due in part to the fact that people with disabilities are not viewed as a minority group.

### *Historical Development*

The very nature of an "identity" experienced by a disabled individual cannot be understood without a conversation that addresses the representations of the disabled prevalent in society that influence the disabled "sense of self." A view through this lens may allow officials in higher education to begin to unravel the social stigmatization that exists for the disabled, and perhaps assist in understanding the need to design a college environment that is "enabling" in terms of student engagement.

Most disability scholars would agree that a disabled person's identity today is influenced by past cultural attitudes, values and beliefs about disabled individuals (Gill, 1997; Longmore, 2003; Patston, 2007; Weeber, 2004). Throughout history disabled individuals have been traditionally characterized as having a shameful condition, a sickness, a defect, or an abnormality that should be fixed or rehabilitated (Brandt, & Pope, 1997, Stearns, 1994). Much less prevalent today, the belief that individuals with disabilities are morally damaged had its early roots in religious thought and viewed disability as the result of sin. The "moral model" is found in many cultures that view

disabled persons with fear, ostracism, and disgrace (Stearns, 1994). Examples of discrimination toward the disabled are abundant since the beginning of time; "asylums" for the mentally ill, leper colonies, and segregation of the deaf and blind are a few examples.

Stereotypes of disabled persons in the literature are common, and generally portray the disabled in a negative, even monstrous light (Dahl, 1993; Mitchell & Snyder 2001). In a discussion of the negative imagery of disability representation in literature and film, disability scholars Mitchell and Snyder (2001) see a "restrictive pattern of characterization that usually sacrificed the humanity of protagonists and villains alike" (p.196). Some of the most influential American and European characters in literary works unconsciously imprint negative depictions of the disabled in the non-disabled psyche:

> The crippled Greek god, Hephaistos; Montaigne's sexually potent limping women, Shakespeare's murderous hunchback king, Richard III; Frankenstein's deformed monster; Bronte's madwoman in the attic; Melville's one-legged monomaniacal Captain Ahab; Nietzsche's philosophical grotesques; Hemingway's wounded war veterans; Morrison's truncated and scarred ex-slaves; Borges's blind librarians; Oe's brain-damaged son; and Dickens's sentimental hobbling urchin, Tiny Tim" serve as vivid imagery in their "perverse representational distortions of the disabled body" and a "catalogue of warped humanity. (Mitchell & Snyder, 2001, p.196)

The stereotypical descriptions of the disabled in literature went unchallenged for years but the climate began to change somewhat for disabled individuals when the social reform movement swept the country in the early part of the 20th century (Stearns, 1994).

Even though the reform created an increase in disability awareness, there was still a considerable amount of prejudice against the disabled and mentally ill. One of the founders of the mental health movement was Clifford Beers, a Yale graduate, who wrote an autobiography about his life of depression and subsequent institutionalization for three years in a mental asylum (Beers, 1910). In his book, *A Mind That Found Itself,* Beers (1910) describes the substandard conditions he endured while institutionalized, which led the way for greater understanding of the plight of the mentally ill.

Also with roots in the first half of the 20th century, the eugenics movement is one of the more disturbing examples of prejudice against the disabled. Eugenic supporters believe in the creation of a "master race," with a goal to "cleanse" America of defective "genes" (Black, 2003). In his account of the eugenics movement, Black (2003) asserts that the twisted ideology of eugenics was actually a chilling American predecessor to the atrocities committed by Adolph Hitler and Nazi Germany against the Jews. This movement led to involuntary institutionalization and sterilization of many disabled individuals, and created widespread human rights abuse against the mentally ill, disabled, people of color and immigrants. Unfortunately, remnants of this negative view of disabled can still be seen today.

A symbolic representation of disability as an imperfection helped to reinforce the philosophy of the medical model of disability. Pastson (2007) challenges the medical and social models of disability that equate human function with value. Instead, he presents a new paradigm named "constructive functional diversity" which describes "atypical" function. Similarly, Brisenden, (1998) suggests that when a disabled individual is understood only in terms of what he or she cannot do, this thought ignores the social

65

aspects of the disability. The social climate historically reinforces bias against the disabled. As an example, Edwards (2004), in his paper regarding the issue of prenatal screening for medical conditions that result in disability, explored the negative attitudes by society toward the disabled. He contends that the prenatal screen sends a negative message to people with disabilities because it equates disability to illness. Further, the author argues that a self-identity that views disability as a medical "flaw" is morally unacceptable. Closely aligned to the medical model is the rehabilitation model, which regards disability as a limitation that requires rehabilitation services.

### *Healthy Disability Identity*

The disability model is considered the healthiest in term of identity development for disabled individuals. This model has helped to change the historical paradigms that have led to discrimination, exclusion, and stigmatism against the disabled. Instead of viewing the disabled person as the "problem," the disability model attacks social discrimination, negative attitudes, environmental and systems barriers that exist.

There are two noted disability researchers that have addressed the problem of identity development in disabled individuals, although no specific theory has yet been defined: Gill (1997; Weeber (2004), and Weeber (2004), for example, examined disability identity development in her detailed dissertation research using qualitative semi-structured interviews with 18 leaders of the disability community. She reports that her research on identity development in the disabled is part of a larger, grant funded project from the National Institute for Disability and Rehabilitation Research. Her findings demonstrate that disability identity evolves over time and is seen as a dual-dimensional process. From her findings, she identified eight factors that contribute to the

development of disability identity; a) values, beliefs and assumptions of cultural context, b) education, c) age at disability onset, d) sex identity/sexual orientation, e) personality traits, f) new paradigm of disability, g) disability community and, h) role models, disabled or nondisabled.

Several of Weeber's (2004) findings are important to this study. Of note, fifteen of the eighteen participants had degrees in higher education, and eleven of the participants had two or more degrees. Consistent with disability research, education was an important factor to the study participants; however, "getting a good education was one fraught with many obstacles and barriers" (p.254). The participants wholeheartedly agreed that education is an "important element in identity development" because it allows the disabled "take on adult roles and activities in society" (p.275). The educational system is viewed by the participants as being based on the medical model or "sick" model of disability, described as "locating the problem within the disabled individual rather than educational systems that are ill prepared to support all kinds of learners" (p.275). This finding speaks to the educational environment, which is intricately linked to student engagement.

From the study (Weeber, 2004), the age of disability onset was also important to the development of the disability identity, which resonates with this study. Acquiring a disability later in life was interestingly associated with the ability to reject the negative views of the disabled by society sooner than individuals with disabilities from birth. The researcher explains that the findings may be due to the fact that the six college-age participants in the study with an acquired disability had already developed a self-identity as a non-disabled person, and may have not "internalized those negative messages since

childhood" (Weeber, 2004, p.255). Given this finding, students with new-onset disabilities may be more likely to experience positive engagement behaviors on campus.

Weeber (2004) also found that the "disability culture" was a factor that helped the participants develop "collective pride" (p.250) with other disabled individuals who accept and honor them. One of the student engagement behaviors or college activities that is related to success is the peer-student interaction (Kuh, et al., 2006a). Socialization with the peer group is thought to be one of the most important influences of college student development (Astin, 1993; Kuh, et al., 2006a; Pascarella & Terenzini, 2005).

An aspect of the peer interaction found to have a salutary effect on student engagement is the student experience with diverse others (Kuh, et al., 2006a). Diversity on college campuses is known to "benefit all students" (p.72) and includes an appreciation of others who may be different in terms of religion, personal values, race, ethnicity, or different backgrounds (Kuh, et. al., 2006a). Inclusion of students with a disability on college campuses allows for exposure of the non-disabled to the richness that the disability culture brings. A diverse campus setting with a well established "disability culture" might be important for engagement in disabled individuals.

Weeber's in-depth glimpse at identity development in disabled individuals is promising for disability scholars, because it may lay the foundation for future student development theories. Likewise the findings from Weeber (2004) support the integration of identity development within the construct of student engagement for this study.

Other scholars have examined identity in disabled individuals, and more recently, Schaller (2008) looked at the label of "disability" in relationship to the construction of identity, with implications for the faith community. She explores "multiple, fluid, and

narrative concepts of identities" in interviews with three disabled woman and challenges the concept of "unitary self" (p.89). According to Schaller (2008), unitary self refers to the construction of self that is based on the narrow belief that disability is the primary characteristic that defines identity (p.90). In her findings, two of the women had unitary concepts of identity that were characterized by a medical and social identity. She explains that the medical identity is the label that a disabled person associates with that overshadows any other defining characteristic of the person (e.g., dyslexia, vision-impaired). The disability "label" constructed by society is seen as "narrow and negative" (p.91), and this concept is tightly woven into a disabled person's sense of self. The social construction of a disability is viewed as a limitation, a deficit, or a problem.

Although her research is based on a small sample (Schaller, 2008), it provides a first account glimpse into some of the social and psychological underpinnings that shape a disabled individual sense of self. The negative "dominant discourse" (p.92) of the disability experience captured by the women's stories could be similar to a disabled college student experience. For instance, one participant in the study described a negative early experience with her parochial grade school teacher who "taught that dis/ability is a test from God." Further, the participant "disagreed with the teacher dispensing this theory, stating that a virus caused her polio–she was suspended from school for three days...she learned to keep silent about her beliefs until she was in a safer environment" (p.91-92).

In an article that also challenges the cultural beliefs about a uni-dimensional concept of identity in individuals with disabilities, Rhodes (2008) argues identity formation in people with epilepsy is not exclusively a product of physical or social

factors, but a complex interaction of "biology, environmental, social, psychological, cultural and political factors–which will interact and be experienced differently by different people ant different times and in different situations" (p.385). Importantly, for this study, Rhodes examines the contextual influence of the environment on identity formation, which is an implicit component of student engagement.

From the disability research reviewed, this researcher supports the notion that development of identity in disabled persons is strongly influenced by the dominant culture views or socially constructed views of illness as a limitation. Although somewhat contrary to what disability scholars have found, several researchers have found distinct yet similar patterns of identity development in disabled and non-disabled college age students, suggesting that the "label of disability" may not be entirely problematic. In her dissertation research of a sample of 127 college students with visible disabilities, Buggie-Hunt (2008) looked at the relationships between disability and psychosocial development and identity development. The students completed a developmental task lifestyle assessment scale (SDTLA) and a scale that measured disability identity attitudes (DIAS), where she found no differences in identity and psychosocial development between students with visible disabilities and a normative sample of college students without disabilities.

This preliminary investigation by Buggie-Hint (2008) requests further research on the problem due to several study design limitations. Aside from the small sample size, another limitation cited by the author is the scale used to measure the construct of disability identity attitudes. The author is correct in that several important points need to be considered when discussing scale use with complex constructs, e.g., attitudes. Many

surveys used to measure psychological constructs are developed with item responses that are ambiguous, unreliable, and are based on researcher restrictions or bias imposed by the scales' responses (Bond & Fox, 2008). In other words, the instrument may not accurately reflect the construct; thus, the reliability is questionable. Given that, the findings may not be accurate. Regardless, the findings from Buggie-Hint (2008) are not completely applicable to this study because the researcher used a sample of students with visible disabilities.

In another study of late stage adolescents (18-24 years) born with the physical disability of spina bifida, Kinavey (2006) found differences in the way the study participants viewed their identity. Based on analysis of the narrative interviews, three categories of self-understanding emerged, including identity as overcoming disability, identity as objectifying disability, and identity as integrating disability.

Three of the study participants were noted to claim identity as overcoming disability. This stance is characterized by "an identity, or self-understanding, as one who overcomes; specifically, overcoming the culture's understanding of them as weak, fragile, needy, and incompetent" (Kinavey, 2006, p.1096). The author explains that the need to "overcome" disability is born out an "attempt to disprove the cultural stereotype" of disability (p.1103). This pattern usually results in "gaps" in identity formation and a less "integrated sense of self" (p.1103). Further, Kinavey (2006) contends that because the disabled individual is constantly trying to overcome the disability, they "risk exhaustion."

Based on the above findings, although the participants have a congenital, physical disability, it is reasonable to assume that a college student with a new-onset disability

may adopt a similar identity. Because of the change in health status, they may be more familiar with the dominant culture's view of disability, and seek to change this perception.

The identity claim of objectifying disability was found in three participants and is described as the individual who experiences disability externally, or distinct from "core" self. This stance was seen in the participants who had experienced "significant emotional trauma in relationship to their disability" (Kinavey, 2006, p.1098); thus, the individuals became isolated and withdrawn from social experiences. In relationship to this study, the "trauma" endured by the students as a result of their new-onset disability of an orthostatic intolerance syndrome, may, among other things, limit "engagement" or participation.

The final disability identity stance uncovered by Kinavey (2006) was found in five, or the majority, of the study participants. Identity as integrating disability is conceptualized as one who takes up the disability into his or her "core" identity or sense of self. The participants who exhibited this stance "consciously acknowledged the stigma surrounding disability while actively working towards self-acceptance" (p.1101). Given as an example of this identity stance, the participant described attended a large public university, which required her to "confront her disability, its opportunities, and its challenges more directly" (Kinavey, 2006, p.1101). One of the campus challenges as noted by this participant included the physical surroundings: "her first personal crisis involves her ability to traverse the large, hilly university campus and surrounding neighborhoods with her usual assistive devices, long leg braces, and forearm crutches. She finds it physically exhaustive and enormously inefficient" (p.1101). Other campus challenges named in this example by Kinavey (2006) include fighting social

72

stigmatization, and the peer relationships–the participant "acknowledges being lonely and depressed." (p.1101).

In terms of college student engagement, the richness of narrative description from the participants provides a piece of supporting data for this study. As well, the author notes that the three primary ways of self-understanding disability in this sample is similar to the identity development in the dominant youth culture.

### *Hidden Disability Identity Development*

To this point, the literature primarily has addressed identity development in individuals with visible disabilities, or has not differentiated between hidden and visible disabilities. Although not delineated in the research, there has been a considerable amount of discussion that speaks to the "diminishment of identity" or the poor self-concept of persons with hidden disabilities (Taylor & Epstein, 1999). On the contrary, a study by Gans, Kenny and Ghany (2003) found that the global self-concept of middle school children (n= 50) with learning disabilities (LD) was no different from students without LD.

Similarly, in another study by Cosden and McNamara (1997), the researchers looked at self-concept in fifty college students with and without learning disorders (LD). Even though LD students who scored lower on tests had lower grades and lower perceptions of academic abilities than students without LD, there were no differences on global self-concept. Surprisingly, the researchers note that the college students with LD reported higher levels of perceived social support or social acceptance from peers than the students without LD. One explanation given by the researchers was that LD students might rely on peer support as a basis for selecting one university over another (Cosden &

McNamara, 1997). Not unexpectedly, both groups of students reported that campus organizations and support from instructors contributed to self-concept. For the LD students however, the most important organization was a student with a disability support program (Cosden & McNamara, 1997). This is one example from the literature where the peripheral constructs of self-concept and identity contribute to the foundation of participation or engagement.

Research on "new" identity formation in individuals with traumatic brain injuries (TBI) has been recently addressed in the research (Klinger, 2005; Nochi, 2000; Petrella McColl, Krupa & Johnson, 2005). Considered a new-onset or acquired, hidden disability, individuals with traumatic brain injury may have subtle or non-existent physical changes in appearance (hidden), yet cognitively they suffer (Klinger, 2005). In a qualitative study of six adults with TBI by Klinger (2005), one of the five themes described by the participants was the need to change self-identity after the illness. The exploration of a new identity by the participants was viewed as integral for adaptation to the injury and for occupational success. Although this study had only five participants and all were adults, individuals with traumatic brain injuries may be compared to individuals with the acquired illnesses associated with orthostatic intolerance. The change in identity or re-invention of "self" is a primary task that may be difficult for a college student.

It is apparent from the review of the literature on identity development that the person with a disability is distinctly different from the mainstream dominant culture of the nondisabled. Historically, the label of "disability" makes this cohort unique. Given this, it is reasonable to argue that college student development in students with a disability may be influenced by a negative disability identity. The development of

identity by disabled individuals based on a narrow view of physical-self and social-self has implications for college students, especially if we agree that the foundation of identity formation occurs at this time.

### *Importance of Disability Identity for Engagement*

For the purpose of this study, an awareness of the way a student with a disability defines "self" is important, because this understanding may be linked to how this student participates or engages in the college setting (Astin, 1993). If, for example, a college student views his or her identity only in terms of physical limitations and negative perceptions of the disability by society, he or she may be at risk to develop a negative identity. The college student may not have the resiliency to withstand the negative environment that may shape his or her world. As a result, the college student may resort to nonparticipation in activities, and perhaps limited social and academic engagement.

A glance again at Chickering's Theory of Identity Development (1969) uncovers another vector closely related to identity development–namely, the development of autonomy or self-sufficiency. Self-advocacy is a skill that has been associated with positive adjustment in disabled high school students (Phillips, 1990) and disabled college students (Hadley, 2006; Graham-Smith & Lafayette, 2004; Lock & Layton, 2001). In a survey of college service disability coordinators at 74 colleges, Janiga and Costenbader (2002) asked the participants to list how secondary schools could improve transition services for students with learning disabilities (LD) who attend postsecondary schools (p.468). The majority of the respondents (66.7%) suggested the need to improve LD student self-advocacy skills, followed by a need to increase student understanding of their disability (38.9%). In another study that investigated compensation skills used by twelve

female college students with learning disabilities, Reis and colleagues (2000) found that self-advocacy was one of the skills necessary for college success.

Given the paucity of research on a true theory of disability identity, it is no surprise that identity formation in students with hidden disabilities is not singled out as a distinct group. That said, in agreement with Mpofu and Harley (2006), the authors believes that a healthy disability identity, including hidden disability identity, could be protective and contribute to student growth, similar to a healthy racial identity (p.17).

The student with orthostatic intolerance may be more apt to have difficulty with identity formation because of the acquired nature of the syndromes. The "newness" of the disability label could contribute to non-participation or poor engagement by these students. In the study previously mentioned by Schaller (2008) that looked at identity development, one woman with an acquired disability suffered a "profound disruption in sense of self" (Schaller, 2008, p.96). Students who acquire syndromes associated with orthostatic intolerance suffer from a dramatic life change in a very short period of time. Thus, instead of a gradual transition into a disability identity, like an individual with a congenital disability, the person is thrown into the depths of a "marginalized" group quickly. A poor sense of identity may cause significant adjustment difficulties, especially in college.

### Engagement in the Dominant Culture/Diverse Groups

As reported earlier, college students who have orthostatic intolerance syndromes experience daily functional difficulties, and their ability to expend additional energy is limited. Dressing, bathing, eating, studying, and many activities of daily living consume a tremendous amount of time and energy. A busy college environment may overwhelm

these students. As such, one particular area that may be adversely affected is student engagement. Astin (1984) describes student involvement as physical and academic energy expenditure. Based on decades of student involvement research by Astin (1984) and others (Pascarella & Terenzini, 2005; Kuh et. al., 2006a), it is well known that students who are actively engaged in their learning environment have higher rates of persistence and are more likely to graduate.

Academic achievement in college students has been associated with high levels of student engagement (Carini, Kuh & Klein, 2006; Kuh, 2001; Umbach & Wawrzynski, 2005; Ullah & Wilson, 2007). Carini et al (2006) surveyed a large sample of college students (n=1058) at 14 different 4-year colleges universities using several instruments. Although the relationship between academic performance (critical thinking and grades) and student engagement was weak, the results suggested that the lowest ability students benefit more from engagement than classmates with higher ability.

Umbach and Wawrzynski (2005) examined the relationship between student engagement and faculty practices. The sample was obtained from two large national data sets including students who completed the National Survey of Student Engagement (NSSE) (n= 42,259) and faculty who completed a survey that measured faculty expectations for engagement (n=14,336). The findings suggest that faculty members that use teaching and learning strategies to increase active and collaborative learning, interact more with students, engage students in experiences, and use academically challenging pedagogies; tend to value educationally enriching experiences in their classrooms and are associated with students who report higher levels of engagement and learning.

Engagement patterns of diverse groups of students have been reported in the educational literature (DeSousa & Kuh, 1996). Kuh (2001) argues, "Institutions would be wise to discover how various groups of students are performing and target those that need special attention" (p.16). Further, he explains, "with many more historically under-represented students matriculating, it's important to examine engagement patterns of these groups" (Kuh, 2001, p.2). Much of the research on student engagement in diverse, underrepresented groups demonstrates that these students have different engagement patterns than the dominant culture. These groups benefit when we try to understand the factors that increase student engagement.

Lundberg, Schreiner, Hovaguimian, and Miller (2007) looked at predictors of student learning and involvement in first generation college students and students from diverse racial/ethnic groups. The researchers used a large, stratified, random sample of 4,501 undergraduate students divided into seven racial/ethnic strata that included 643 students in each stratum. The end point variables included gains in academic learning and gains in personal learning. Thirteen independent variables were used to predict gains in academic and personal learning and included the frequency of involvement in activities such as the library, computer use and information technology, campus facilitates (e.g., student union, recreation center), course learning, writing, interaction with faculty, clubs and organizations, interactions with peers and acquaintances, discussion of topics and integration of ideas, and activities related to arts and sciences (p.65).

Findings from the large-scale study by Lundberg et al. (2007) indicate that first generation status had a negative effect on involvement or engagement in course learning, attending fine arts events, involvement in scientific experiments, and interactions with

student acquaintances. In terms of involvement, most of the ethnic groups (except multi-ethnicity) had significant, positive effects on involvement. Thus, in general, the findings demonstrate that involvement or engagement "functions differently for students based on race/ethnicity and first-generation status" (p.77-78).

Student engagement literature demonstrates that minority students, especially African Americans and Hispanics, report higher engagement than White students in spite of the fact that they perform consistently lower in academic performance (Green, Marti, & McClenney, 2008; Hu & Kuh, 2003). It may be possible that students with a disability, who are also considered a marginalized group, may function differently in terms of engagement and benefit from engagement.

Another conclusion by the researchers was a needed effort to increase "interactional diversity among first-generation students" (Lundberg, 2007, p.77). This could be accomplished through support programs and workshops, because "campus-wide programming that fosters engagement with others who are different from oneself will benefit the campus population in general, but first-generation students in particular" (p.77). In terms of a student with a disability, the research echoes the importance of a supportive, engaging campus climate to enhance student success. A supportive campus environment for the disabled is well documented in disability research. To better help diverse students, clearly, "the responsibility for creating campus climates that are engaging for all students rests squarely on the institution" (Lundberg, 2007, p.77).

In another study that demonstrates the benefits of engagement in minority populations, Fischer (2007) examined background characteristics and institutional characteristics that affect college involvement and outcomes in Black and Hispanic

students. Specifically, the study collected data from the National Longitudinal Survey of Freshman (28 institutions of higher education; n= 3,924). She reported that the background variables of first generation college students and low socioeconomic status, and institutional factors (minority student in a White campus) negatively influenced success in these areas. Her findings demonstrate that the predictors of college grades vary among ethnic groups, but in terms of engagement, "what happens once in school is also important for grades" (Fischer, 2007, p.144).

Minority students in the study by Fischer (2007) demonstrated a positive relationship between student involvement in social activities and academic success; thus, the author contends, "students who become more involved in various aspects of campus life are not only more likely to stay in college, but may perform better academically" (Fischer, 2007, p.130). Her belief is that most models of student involvement and student attrition are based primarily on the dominant culture (white, middle to upper class students), yet "there is much research to suggest that this process of college adjustment may not go as smoothly for other groups of students" (p.130).

Reporting on a study that explored first generation and low-income students, Filkins and Doyle (2002) compared these students to second generation and low-income students on levels of student engagement using the National Survey of Student Engagement (NSSE). A large study, the dataset consisted of six urban institutions, resulting in 1,910 participants. Regression analysis found that for both groups, student engagement in active and collaborative learning activities and interacting with the faculty was positively related to student cognitive and affective growth during college.

Consistent with other research, low income, first generation students tend to benefit more than the second generation, non low-income students in effective educational practices that stress engagement. One such effective practice is a supportive relationship with faculty members (Filkins & Doyle, 2002). These researchers conclude that the study findings "provide further evidence of the influence that active student involvement with faculty can have on different facets of students' personal growth" (p.14). Not only was faculty important to the students, but also the greatest influence on student outcomes (student learning and personal growth) was the perception that the campus environment was supportive.

Pike and Kuh (2005) compared engagement patterns in first-and second-generation college students (n=1,127) and found that first generation college students reported less success in learning and educational intellectual development, view the academic environment as less supportive, and were unable to successfully integrate diverse college experiences when compared to second-generation students (p.289). Contrary to previous studies that attribute poor academic, social, and intellectual engagement to the pre-college characteristic of first-generation status, Pike and Kuh (2005) found that engagement was instead related to living on campus and high educational aspirations. In other words, the first-generation college student may benefit more from what he or she participates in during college; his or her successful engagement is not necessarily related to the status of being a first generation student.

Living on campus, as the researchers note, has a positive effect on academic outcomes and is thought to be due to the close living arrangements and frequent interactions and discussions among students who may have different values (Pike & Kuh,

2005). Of interest to the disabled population, it is known and reported previously in this dissertation that students with a disability take twice as long to earn a college degree than non-disabled college students. This is thought to be secondary to a number of factors including the need to enroll in part-time classes or a reduced course load for disability-related reasons (National Council on Disability, 2003). Many part-time, students with a disability are less likely to live on campus, and perhaps their engagement patterns may reflect this. As Pike and Kuh (2005) would suggest from their findings, the disability "status" may have less to do with academic success; rather, how the student with a disability engages in college is important.

Harper, Carini, Bridges and Hayek (2004) studied sex and race using the National Survey of Student Engagement (NSSE) in research of student engagement in African American undergraduate students (n=1,167) at twelve, 4-year, historically Black colleges and universities (HBCUs). Interestingly, and contradictory to previous research, the researchers report no sex differences in engagement experiences between African American males and females. The authors of the study, like other student development researchers interested in engagement, assert that the study was designed to "monitor engagement trends to determine who is involved in what and explore variances that exist among various student subgroups at different institutions" (p.271).

Kinzie, Thomas, Palmer, Umbach, and Kuh (2007) explored sex and engagement in a study that compared engagement experiences in women at two different institutions including co-educational and all women's colleges. The sample for this large-scale study consisted of three years of NSSE data from over 42,000 female freshman and senior college students. The women in all women's colleges reported greater engagement in

educational practices, higher support, and more success in college then the women in the co-educational colleges.

From the findings by Kinzie et al. (2007), women at women's colleges report greater frequency of engagement behaviors, which translate into the fact that "these colleges appear to create a climate where women are encouraged to realize their potential and become involved in various facets of campus life, inside and outside the classroom" (p.159). Although it is known that students with a disability report the importance of disability support services, little is known if the perception of a supportive campus environment contributes to engagement in this group.

Wasley (2006) addresses the gains in student academic performance in diverse ethnic groups when they are active and involved in the campus setting. In an article from *The Chronicle of Higher Education*, Wasley (2006) summarized the most salient findings from the National Survey of Student Engagement (NSSE) in the year 2006. From the NSSE data, the author reported that underserved and minority populations benefit the most from institutions where engagement is a high priority. Underserved minority students who participate actively in the campus environment were found to have better grades and had higher attrition rates to the second year of college. As reported, the pre-college educational disadvantages among minority students seemed to be ameliorated by high levels of engagement that included collaboration with peers inside and outside the classroom (Wasley, 2006).

As shown, the plethora of research on student engagement in historically marginalized groups is promising; Hispanic, African American, first- generation, women, and low-income students are welcome recipients of an explosion of knowledge in student

engagement. This knowledge is critical for higher education practice and policy. The relationship between student engagement in effective educational processes including a supportive campus environment and successful college outcomes has yet to be explored through the disability lens, but unmistakably the data support its success with diverse students.

### *Engagement in Disabled College Students*

As shown in the abundance of student development research, there are a variety of factors that contribute to the success of college students. The construct of student engagement has emerged as a way for students to participate in activities that help "level the playing field" especially for those from low-income family backgrounds and others who have been historically underserved (Kuh, et al., 2006a). Although a large body of research exists which demonstrates the positive effects of student engagement in the dominant culture and some diverse groups, surprisingly no research exists on engagement in students with disabilities. This is unfortunate, because as noted previously, students with a disability have lower persistence and graduation rates than their non-disabled counterparts (National Council on Disability, 2003). The crux of student involvement research postulates that students are more likely to persist to graduation when they are involved in the learning process (Kuh, 2001; Kuh, et al., 2006a).

### *Framework of Student Engagement in Students with Disabilities*

Why student involvement or engagement is a critical concept for students with a disability is important for several reasons, some of which have been delineated thus far. To recap, aside from low participation, persistence, and graduation rates among the disabled, there are several concepts related to student engagement behavior that can be

coupled to research on students with a disability. To explore this issue, I will present one of the most comprehensive documents that address college student engagement by George Kuh and colleagues (2006a) entitled *What Matters to Student Success: A Review of the Literature.*

Central to the detailed report is the construct of student engagement and a theoretical framework that describes factors related to student success and engagement (Kuh, et al., 2006a). In its entirety (156 pages), the document summarized a collection of research studies on student engagement, with special emphasis on benefits to students from diverse groups. Although an exhaustive summary, it mentioned no research studies that address the student with a disability. One reference to students with "physical or visual limitations" was in a section on the physical structure of the campus (p.71), which is addressed in the next section.

Nonetheless, several student engagement concepts emerge from this report on student engagement by Kuh and researchers (2006a) that are pertinent to the student with a disability. To start, the discussion will briefly describe the following constructs; a) institutional attributes of student living arrangements and student centered campus cultures, b) student success initiatives, c) pre-college characteristic of educational aspirations, d) faculty-student contact, e) peer interactions, f) experiences with diversity, g) co-curricular activities, and h) student satisfaction. Collectively, these constructs from student engagement will be coupled with disability issues.

Student Living Arrangements and Student Centered Campus Cultures: Where students live when they attend college and the physical structure of their surroundings is known to influence engagement. Students with full-time status and students who live on

campus have higher levels of engagement behaviors than part-time students and those who live off campus (Pike & Kuh, 2005, Kuh, et al., 2006a). Living on campus affords the student greater opportunity to interact with faculty and other students, which translates into an increase in college persistence and academic success (Astin, 1993; Pascarella & Terenzini, 2005). Students with a disability are more likely to attend college part-time (National Council on Disability, 2000), and live off campus.

Close proximity with peers and faculty is beneficial in terms of engagement; additionally, it is reported that a well-physically designed campus can also play a significant role in learning and engagement (Kuh, et al., 2006a). Student centered campuses are created when the educational environment fosters growth and student learning is enhanced. Kuh et al (2006a) reports that these environments are "intentionally designed" and "do not happen by accident" (p.71). The architectural design of the campus and proximity of buildings may contribute or impede the interaction between students of different academic majors, and between faculty and students. For students with visual and physical disabilities, "the natural and built physical environments of the campus shape behavior by permitting certain kinds of activities while limiting or making impossible other kinds" (p.71).

Architectural barriers continue to be a significant problem for disabled college students (Madaus, 2008; National Council on Disability, 2003; 2008; National Center for Postsecondary Supports, 2000). Even years after the passage of the American with Disabilities Act (1990), and Section 504 of the Rehabilitation Act (1973), the problem of architectural barriers for the disabled on college campuses continues. This is more recently highlighted by investigations from the Department of Justice (DOJ) into the

architectural-physical accessibility of colleges and universities, which resulted in a widely publicized lawsuit by the DOJ against the University of Chicago (National Council on Disability, 2008):

The settlement covers such areas as accessible paths of travel, accessible university housing, and emergency evacuation plans. Interestingly, the agreement calls for information on travel route accessibility to be posted on the university's Web site, but it appears to make no provision, nor evince any concern, for whether those Web sites are accessible. (p.76)

The campus physical environment was explored in this study, because even though it is well recognized that physical barriers exist for the student with a disability on campus, little is known about how this environment shapes engagement.

Student Success Initiatives: A second construct from the student engagement framework presented by Kuh et al. (2006a) are programs designed by college and universities aimed at improving persistence, retention and graduation rates. Campus support services that assist students in their academic pursuits are known to positively affect educational outcomes (Kuh, et al., 2006a). Courses designed to help students with writing skills, time management, academic advising, career placement, note-taking, goal setting, and test taking strategies have been found to aid them in their academic success (Kuh, et al., 2006). In terms of diverse groups, "student success courses also support underrepresented students adjustment to college" (p.63). One of the findings related to student use of the support services provided on campus is the fact that the locations of the centers influence use of services. Logically, services located in residence halls and close proximity to student housing increase utilization for students.

As demonstrated with underrepresented groups, student success courses are also relevant to students with a disability, who are at high risk for academic difficulties (National Council of Disability, 2003). The Department of Justice effort to heighten awareness for administrators in higher education to improve accessibility in the physical environment for the disabled is a step in the right direction. Yet the same cannot be said for program development, academic accommodations, and campus computer and information technology accessibility (National Council on Disability, 2008).

The importance of program development for student with a disability success is addressed in disability literature. The document, *College Survival Skills: Tips for Students with Disabilities to Increase College Success*, sponsored by the National Science Foundation and the Department of Education (University of Washington, 2000), provides guidelines for college students to enhance learning. Study skills, time management, and other tips used by students with a disability for academic success are detailed.

Success programs designed specifically for students with disabilities are strategies that have been addressed in high school transition programs for adolescents with disabilities into employment and postsecondary education arenas. Wolf-Branigin, Schuyler, and White (2007) reported that disabled adolescents have great difficulty with transition into "complex systems that include employment and housing domains" (p.324). Also included in the "complex systems" by the authors is the postsecondary educational system. In their two-year study, 64 adolescents with disabilities participated in an intervention program designed to increase the likelihood that the adolescents would transition from high school into employment (Wolf-Branigin, et al., 2007). The sample included students with mental retardation (44%); medical disabilities including asthma,

arthritis, obesity, diabetes, and seizure disorder (34%); attention deficit and learning disabilities (18%); and cerebral palsy (4%). Endpoints measured were physical and psychosocial health functioning (emotional, social, school), and employment readiness in a pre-post test design. Of the participants, 10-20% planned to attend college, and these students were selected for the "College Bound" track of the intervention (p.325). The track included focus on transition to career and postsecondary education, the development of self-advocacy skills, and exploration of student choices.

Findings at baseline of quality of life for all students were below norm-referenced peers, which will be discussed in detail. After two years in the program, the adolescents improved in all aspects of functioning including health, physical, emotional, social, and school. Also, and important for this study, is even though the adolescents in this sample improved their score from baseline, they continued to score significantly lower than non-referenced peers in emotional, social, and school function (Wolf-Branigin, et al., 2007).

Several points can be made from this study (Wolf-Branigin, et al., 2007) that are important for the disabled college student, and for student success initiatives as envisioned by student engagement researchers. The most disturbing finding is that even with a well-designed intervention program, students with a disability still have a way to go to "catch up" to their non-disabled peers in all areas of functioning measured, including the cohort of students from the study who participated in the college bound segment. Although the students in this study were in high school, this study is just one example of the barriers that students with a disability must overcome, and the need to design college student success courses and environments to aid this group.

How campus support services are used in students with disabilities is important, and the location may be of even greater importance for the student with a disability. As discussed, a major theme for students with a disability is the physical proximity of services, access to buildings, rooms, and parking.

Educational Aspirations: A third category from the student engagement framework includes student desire to attend college. Educational aspirations have also been known to influence engagement in college students (Pike & Kuh, 2005; Kuh, et al., 2006a). Yet, disability research suggests that educational aspirations are much lower for disabled high school students, even to the extent that "rarely do parents and children think that postsecondary education is an alternative" (National Council on Disability, 2000).

Faculty Interactions: The fourth category in the framework is the student interaction with faculty members. By and large these interactions are significant contributors to student engagement. The interactions include campus formal and informal contacts (Kuh, et al., 2006). Academic in-class and out-of-class experiences with faculty members is reported to contribute to positive student perceptions of the campus environment. Given that belongingness or inclusion is an essential theme associated with student involvement (Astin, 1984; Fischer, 2008), it is self-evident that this concept is applicable to the student with a disability.

Much of the research on student with a disability-faculty interaction is presented in the semblance of faculty attitudes toward the student with a disability, which is next addressed. This research perhaps stems from the culturally embedded labels attached to disabled individuals who are described as "dependent," "marginal," "freaks"

"nonhuman" or "even dangerous" (Albrecht, et al., 2001). The underlying message suggests that the attitude of faculty members needs to be somehow "adjusted." Antonak & Livneh (2000) suggest "negative attitudes toward persons with disabilities create real obstacles to the fulfillment of their roles and attainment of their life goals" (p.211). These authors present a paper on a review of studies that looked at attitudes toward the disabled and describe the methods used to assist with measurement of this construct.

There seems to be conflicting outcome of results in higher education studies of faculty attitudes toward students with a disability. In a review of the literature on this topic, Rao (2004) summarized the research findings on seven variables that have been found to have an effect on faculty member attitudes. The variables include a) age, b) sex, c) previous experience with disabled individuals (personal contact or professional), d) faculty academic rank, e) faculty discipline, f) knowledge of disability law, and g) disability type (Rao, 2004).

For the variable of sex influence, Rao (2004) notes that despite the fact that several studies report female faculty members have statistically significant positive attitudes toward students with a disability when compared to male faculty attitudes toward the disabled; an almost equal number of studies did not support this finding. Even though age was a variable examined in the research, it did not play a significant role in the influence of faculty attitudes. Rao (2004) also reported that the majority of studies found that faculty members with the greatest disability experience had significantly more positive attitudes toward the student with a disability when compared to less experience faculty. The majority of studies reviewed by Rao (2004) did not confirm faculty rank as significant influence of faculty attitudes. In the many studies noted by Rao (2004),

department affiliation influenced attitudes. The majority of studies confirmed that in general, faculty from the hard sciences had significantly less positive attitudes of the disabled college student than faculty in the soft sciences. Of the two studies reviewed by Rao (2004), the results were split in terms of disability knowledge influence on disability attitudes.

In an earlier mixed methods study of 420 faculty members at a large Midwestern university by Leyser, Vogel, Wyland, and Brulle (1998), the researchers examined faculty knowledge, attitudes, and practices towards students with disabilities. Even though the majority of higher education faculty in the study had limited experience and contact with students with a disability, especially students with chronic illness, the majority of the faculties were willing to provide necessary accommodations. A more recent study of 188 postsecondary faculties in 7 universities in Israel found that the majority of faculty surveyed conveyed a supportive attitude toward students with a disability, and a willingness to provide appropriate accommodations to students (Leyser & Greenberger, 2008). The researchers found that the variables of faculty experience (contact, professional training), academic department, and faculty rank were associated with attitudes and practices.

Negative faculty attitudes toward the disabled were discovered in a study by Cook (2001) that looked at teacher's attitudes toward students with mild and severe disabilities. As reported previously in this dissertation, Cook (2001) surveyed 70 elementary school special education teachers, or teachers who had significant experience with students with a disability. Of the elementary school teachers reporting, 97.1% (n=68) had previous inclusive teaching experience with an average of 8.7 years of previous inclusive teaching

experience. The study design included a survey that asked the teachers to nominate students in their class to one of four attitude categories. The categories included attachment, concern, indifference, and rejection. The nomination rejection prompt consists of the following question; "If your class was to be reduced by one child, whom would you be relieved to have removed?" (Cook, (2001) p.208). Important for this study, students with mild hidden disabilities were significantly overrepresented among special education teachers' nomination in the rejection category.

On the flip side, the disability higher education literature reports that student perceptions of higher education faculty are not always positive (NCSPES, 2000). Malakpa (1997), in an article entitled "The Problems in the Admission and Retention of Students with Disabilities in Higher Education," reports that negative attitudes by faculty members is one of the top three problems encountered by students with a disability, preceded by lack of accommodations and poor student support services. Faculty attitudes are reported as negative, reluctant, and indifferent when asked to provide accommodations for students with a disability.

A closer look at how faculty attitudes toward the student with a disability contribute to behavior or interaction with the student may provide some additional insight into the ambiguity of student and faculty perceptions. Bento (1996) reports findings of a mixed-method study of university faculty that described the barriers encountered by faculty when asked to supply accommodations for students with a disability. Data from interviews of thirty-five faculty members found two main barriers that affected the faculty decision-making process: a limited understanding of the nature of various disabilities and limited understanding of disability legislation. The rich data from the

faculty interviews uncovered the following concerns encountered by faculty members: embarrassment about asking disability-related questions concerning the student, lack of disability knowledge, doubt and confusion as to whether a hidden disability actually existed and if accommodations were warranted, and the frustration over lack of advance notice for the requests for accommodations from the student with a disability.

Conversely, in the same study (Bento, 1996) and in interviews with 18 students with a disability who received accommodations for disability at the postsecondary level in the same institution, results reveal a different perspective. The students expressed frustration of the need to repeatedly explain their disability to faculty members for accommodation requests. From the study, the author explains,

Not only was this emotionally exhausting, but it also made students feel as if they were being perceived as "a disability, not a person." Students often took offense at some faculty members' thinly disguised suspicions about their "taking advantage" of the disability. And they felt humiliated when treated as if they were "begging for special favors

"I'll never forget that teacher who said: 'I'll do it only this time!' What does she think? Can I stop being disabled when I want to?" (p.494)

Similarly, the position paper "People with Disabilities and Postsecondary Education" by the National Council on Disability (2003) agrees that postsecondary faculties and other higher education officials lack training, and have limited knowledge of disability needs and supports. That said, in the same paper, the findings suggest that "students with disabilities are unaware of the availability of services, and do not access

94

them" (p.16). As noted previously, self-advocacy is a skill frequently cited by faculty as a critical component for student with a disability success.

It appears as though a combination of factors contribute to student-faculty interaction in students with a disability; whether it is faculty unfamiliarity with disability issues, faculty attitudes of ambivalence toward the student with a disability (Bento, 1996), or lack of student self-advocacy, the responsibility ultimately rests in the arms of higher education. Students with a disability have a number of strikes against them as they access higher education, and the college environment should encourage participation and belongingness. Institutional shortcomings in accommodations and faculty awareness and support translate into "risk for failure" and "negative self-esteem" for post secondary students with disabilities (National Council on Disability, 2003, p.17).

Student-Peer Interaction: Like student-faculty interaction, the student-peer interaction is a critical component of involvement (Astin, 1993) and engagement (Kuh, 2001). There are a number of student engagement behaviors found to enhance academic growth (Kuh, et al., 2006a, p.42). The peer-student interactions generally revolve around socialization with other students to discuss classes, diversity issues, and collaboration on projects. Social isolation, resulting from negative disability attitudes, is a significant problem for students with disabilities and is considered even harder to abolish than accommodation barriers (Malakpa, 1997).

Experiences with Diversity: This category of the framework is closely related to student-peer interactions. The ability for students to interact with diverse others enriches the college experience. All students, including diverse students benefit from the interaction with diverse others (Kuh et al., 2006a; Umbach & Kuh, 2006).

Participation in Co-Curricular Activities: This category of the framework includes the participation in activities on campus such as club sports, fraternities, or sororities. Students who join social groups increase engagement, and this is related to student persistence (Kuh, et al., 2006a). For the student with a disability, these kinds of participation could present physical and social challenges.

Social isolation among students with disabilities is a common theme in disability research (Fichte, 1988), and several studies suggest that students with a disability desire an increase in social interaction, especially with peers. In an exploratory study that demonstrates the social isolation of physically challenged college students, Coston and Bing (2004) queried seventy-six college students on how they would improve the quality of their academic experience. Not surprisingly, several of their responses were closely related to being engaged in the campus environment. Forty percent of the sample suggested workshops and outreach programs, and other comments included the desire to join fraternities and sororities and the desire to participate in meals and other social events with the nondisabled.

Sixteen undergraduate students with physical disabilities participated in a study by Hodges & Keller (1999) that identified factors associated with social involvement on the college campus. From the interview data, the researchers found that for students with a disability, perceived acceptance by the peer group was an important influence on participation in extracurricular activities.

New college student adjustment: The next category of student engagement encompasses programs designed to increase student persistence to second year. Orientation programs, first year seminars and other programs designed to ease student

entry are included in the *Framework for Student Success* (Kuh et al., 2006a). College student adjustment and transition into college for the student with a disability is a construct in the disability literature that may be even more salient than non-students with a disability because of change in identity and adjustment to an illness.

The transition from high school to college is a time of tremendous stress and adjustment for students, and even non-students with a disability report adjustment difficulty. Many students are living on their own for the first time in their lives, and they may lack self-regulation, communication skills, self-advocacy skills, and the ability the to problem solve. College students must adapt to institutional, academic, personal-emotional, and social changes and stressors that can tax the even the most resilient student.

Friedlander, Reid, Shupak, and Cribbie, 2007 report on a study of 115 freshman undergraduate students surveyed both first and second semesters of the first year of college. Multiple regression analysis revealed that in the first semester, increased social support from friends (not family) predicted improved adjustment to college. Decreased stress predicted overall adjustment (academic, social, personal-emotional). Another finding noted that increased self-esteem (global, academic, and social) predicted decreased depression and increased academic and social adjustment.

Unfortunately, faculty and administrators in higher education are well aware of the outcomes of poor adjustment to college, including alarming rates of college student alcohol use (Hingson et al, 2005), substance use and depression (The National Center on Addiction and Substance Abuse (CASA) at Columbia University, 2003), mediocre retention rates, and persistence to degree completion. Indeed, only one in four freshman

students persist to sophomore year, and one-half of college students who start a four-year degree persist to completion (Hersh & Merrow, 2005).

Little research exists on adjustment to college in students with a disability. However, student transition and adjustment to college from high school has been described in non-disabled, under-represented groups including minority students (Anglin & Wade, 2007; Fischer, 2007; Hurtao, Sainz, Espinosa, Cabrera & Cerna, 2007; Santos, Ortiz, Morales & Rosales 2007) and international students (Ramsay, Jones & Barker, 2007). It is known that the student with a disability experiences a greater degree of adjustment difficulty than the non-student with a disability during the transition from high school to college (Maduas, 2006; Schutz, 2002). It likely that students with a disability may be at risk for poor adjustment to college, not only for the reasons that most non-students with a disability fail, but also because of the added burden of adapting to a chronic or debilitating illness.

Bishop (2005) presents a framework for assessing a person's response to chronic illness and disability (CID). He based his model on constructs from quality of life, rehabilitation psychology, and rehabilitative counseling literature. Analysis of the framework collected survey data from 72 disabled college students and found a significant, positive relationship between quality of life (QoL) and adaptation to CID. Thus, the research by Bishop suggests that these college students reported higher quality of life associated with positive adjustment to their disability. Perhaps college students with an acquired illness like orthostatic intolerance may have difficulty with quality of life or satisfaction in college especially when they have the added burden of adjusting to a new disability coupled with adjusting to the college environment.

College students with the disability of orthostatic intolerance may find that adjustment to college is overwhelmingly difficult; however, there is no research to support this assumption. One area of research that has received considerable attention in higher education recently has been in learning students with a disability. Students with orthostatic intolerance may be likened to those with learning disabilities (LD) in that they are both hidden disabilities. Learning-students with a disability have unique difficulties in reading, writing, mathematical analysis and disorders of attention, which ultimately infringe on academic, social and emotional areas (Heiman, 2006).

There have been a handful of studies that address college student adjustment in students with a disability with learning disabilities (Heiman, 2006; Saghatoleslami, 2005). College students with and without LD were surveyed for their perceived social support, stress, sense of coherence, and on their academic success compared to their self-rating of their struggles and failures. Findings from the study by Heiman (2006) indicate that students with learning disabilities (n=190) experience higher academic stress than students without learning disabilities (n=191). The LD students were likely to attribute their academic success or lack of success due to external factors, where those without LD attributed their academic success or lack of success to study skills and academic characteristics (internal factors). In addition, the students with LD in this study were found to perceive themselves as having less social support than their peers without LD. In a study of first year community college students diagnosed with learning disability, Saghatoleslami (2005) found that students with LD are more likely to experience adjustment difficulties compared to those without LD.

Based on the limited findings presented here, the research on students with learning (hidden) disabilities suggests that academic and social adjustment for these students is problematic. These findings support the need to look at new college student adjustment in other students with hidden disabilities.

For this study, the researcher believes that institutions can foster a successful transition for students with a disability into the college environment, just as engagement literature suggests. Early recognition of concerns combined with a proactive approach and awareness of the needs of students with hidden disabilities may help adjustment, engagement, and ultimately persistence.

Student satisfaction: The last construct addressed in the *Framework for Student Success* is student satisfaction, which is highly correlated with engagement (Kuh, et al., 2006a). Satisfaction with the institution "is an important but sometimes overlooked variable in determining the quality of the undergraduate experience" (p.44). Barriers for students with a disability interfere with satisfaction of the college experience and perceived quality of life. Satisfaction per se is not addressed in disability literature, but quality of life in individuals with disabilities is a construct that has received attention.

In the last several decades, the proliferation of health-related quality of life (HRQOL) research in the biological and social sciences has been largely generated in an effort to enhance outcomes for groups of individuals with specific health-related conditions, and to measure the efficacy of health-related interventions. HRQOL is used to guide political and social policy program planning in public health, nursing, medicine, education, business, and economics.

Disability researchers are quite interested in how people perceive their life, health, and well-being. Quality of life or satisfaction with daily functioning and college activities takes on special meaning for disabled individuals. Peter (1997), in his writings on individuals with disabilities and their personal accounts of their lives, defines quality of life as "those aspects of one's life or lifestyle that contribute to, or the absence of those things that diminish, one's well-being" (p.27).

Conceptualization of quality of life (QoL) may be different for people with disabilities because they may see their quality of life as positive, despite obvious functional limitations (Brown, 1997). Thus, many disability researchers believe that the current QoL models may not accurately reflect the level of a disabled person's self-perceived quality of life (Brown, 1997; Cummins, 1997; Schwartz, Anderson, Nosek & Krahn 2007). Most QoL models measure individual function as a primary construct, and equate functional status with health. Because of this, people with disabilities may score low on quality of life as reflected by their functional impairment (Schwartz, 2007). In agreement with this thought, students with functional impairment may score low on a college student engagement measure like the National Survey of Student Engagement (NSSE) if based on physical activities.

However, it is not necessarily true that the physical/emotional constraints imposed on disabled persons lead to a poor quality of life (Cummins, 1997). As well, Cummins (1997) argues that the current quality of life (QoL) models are overly restrictive, and focus primarily on disease and injury. That said, the construct of quality of life for people with disabilities must be holistic and consider a person's development across the life span, adaptation, and environmental factors in order to "understand the way an individual

perceives their life circumstances" (Peter, 1997, p.28). Because of the difficulty with quantitative measurement of quality of life, Peter (1997) advocates a qualitative research approach to quality of life issues for disabled individuals.

In her article describing the measurement of quality of life in people with disabilities, Schwartz (2007) argues one must "consider how adaptive their environment is in enabling them to participate and experience good health" (p.530). Similarly, Velde (1997) agrees that participation in purposeful and meaningful activities enhance quality of life for disabled persons. Participation in meaningful activities is important for student engagement, and one may come to the conclusion that lack of participation may have consequences on quality of life and satisfaction with experiences.

Studies have shown that individuals with the hidden disability associated with syndromes of orthostatic intolerance experiences difficulty with quality of life (Baron-Esquivias et al, 2003; Giada et al, 2005; Santhouse et al. 2007; Van Dijk et al, 2006). Grubb (2006), in an eloquent editorial describing quality of life research in individuals with orthostatic disorders, reports that not only is one's sense of well-being reduced while experiencing symptoms, but also day-to-day functioning. Orthostatic intolerance syndromes may cause a high degree of daily functional impairment, similar to chronic heart failure, epilepsy and chronic obstructive pulmonary disease (Baron-Esquivias et al, 2003; Benrund-Larson, Dewar, Sandroni, Rummans, Haythornthwaite & Low, 2002; Santhouse et al., 2007).

College students with orthostatic intolerance are particularly vulnerable to a negative quality of life. The college environment is much less sheltered for students with a disability, and the support they may have received at the secondary level is usually

lacking at the postsecondary level (National Council on Disability, 2003; Schutz, 2002). Well outlined in this dissertation previously, lack of disability awareness in higher education officials, lack of disability support services, accommodation difficulties, financial support problems, social isolation, and other health-related difficulties all create barriers for the student and as such may negatively affect satisfaction with the college experience.

Whether quality of life or satisfaction with the college experience contributes to engagement in students with disabilities is yet to be studied. For this study, a qualitative approach is warranted. This approach will enable the researcher to view quality of life in students with orthostatic intolerance from a panoramic lens, including one that encompasses identity development, college student development, adjustment, self-advocacy and adaptive skills, and an environment that fosters participation or student engagement.

**Hidden Disabilities and Self-Disclosure**

A common problem with a "hidden" disability is that often individuals are reluctant to disclose their disability; thus, they struggle alone (Adreon & Durocher, 2007; APONTE 2004; Lynch & Gussel 1996). This, in turn, may affect their ability to become involved in the educational process; hence, learning may be compromised. In a review of college students with learning disabilities and emotional-behavioral disorders, Gobbo and Shmulsky (2007) report that these students typically don't disclose their disability, and privacy laws also contribute to the problem.

Self-disclosure is a skill that is vital for students with disabilities (Graham-Smith & Lafayette, 2004). The majority of college students with orthostatic disorders do not

exhibit obvious physical impairment; in turn, they may also avoid disclosure. Because they fear disclosure, these students may not participate in meaningful activities with faculty and peers, which limits engagement.

**Summary**

The value of a postsecondary education in our society cannot be disputed. Baccalaureate degree attainment for disabled college students lags behind those students without disabilities (National Council of Disability, 2008). Students with the hidden disability of orthostatic intolerance may be at risk for poor outcomes, in part due to the obscurity of the disease. Engagement research in students with hidden disabilities is non-existent, and this study is the first research reported that explores the topic in a group of college students with a hidden disability, notably, orthostatic intolerance.

No research exists that examines perceived academic, institutional, physical, and social factors encountered by these students as they traverse through college. As well, little is known if barriers influence patterns of student engagement. A student with a disability that experiences belongingness and inclusion in the college setting may develop a positive self-identity, a healthy adjustment to college life and a positive perception of quality of life. This student then is more apt to actively engage in the academic environment, which in turn may ultimately affect student success in the college setting.

**Chapter III**

**Methodology**

**Introduction**

This study introduces the reader to five college students who have a hidden disability of orthostatic intolerance. Orthostatic intolerance is similar to many other health-related disabilities that are not obvious to other individuals. The students in this study told their stories about their personal engagement experiences on their college campus. They described physical campus engagement, institutional engagement, academic engagement, and social engagement.

This qualitative study used a collective case study to present each student experience in the natural setting of their campus (a bounded system). The data collection method consisted of two in-depth interviews, participant observation, and a one to three day visit to each instructional site. The narrative interview approach was an important aspect of this study because it provided a broad understanding from the student perspective. The interviews were combined with the data collection method of participant observation. This method allows the researcher "to understand the meanings that everyday activities hold for people" (Marshall & Rossman, 2006, p.102). The participant observation of the student in the college setting added depth to understanding experiences that may not have been recounted during the interview. Participant observation took place between the two interviews, and this sequence helped to add to the meaning of the campus observation.

For the document analysis, the students shared documents from their respective colleges such as disability or accessibility manuals, course schedules, and grades. For

several students the documents included a personal reflection of their college experience. These documents, especially the manuals from each college disability office, were starting points for discussion. The integration of the document analysis data with interviews and participant observation allowed a broader perspective of their engagement experience.

This chapter begins with a general discussion of qualitative research methodology, followed by a discussion of the theoretical constructs used to support the qualitative methodology. The research design is presented. Included in this discussion is a description of the collective case study, and the setting and population (sampling method, selection criteria, adult consent). Data collection methods are then described in depth, including the interviews, participant observation, and document analysis. Next, data management and analysis is presented. Literature support for the research design is then addressed, followed by a discussion of the researcher role in case study design. The chapter concludes with subjectivity and ethical concerns, followed by the trustworthiness of the research study.

**Qualitative Research Methodology**

The literature demonstrates that the journey through college for many students with a disability is hindered with obstacles. However, because little is known about the engagement behaviors of students with orthostatic intolerance in college, trying to capture the essence of their engagement experiences was grounded in qualitative inquiry. Student engagement is a complex, multifaceted behavior and well suited for qualitative research. Leedy & Ormrod (2005) noted that qualitative research doesn't skim the

surface. Indeed, this type of methodology aims to "dig deep" into the understanding of the multidimensional aspect of social phenomena and human problems (p.133).

In contrast, quantitative research is interested in hypothesis testing, objectivity, and the ability to generalize findings to other persons. Unlike quantitative research, qualitative research does not necessarily begin with a hypothesis, but is open to the participants' point of view. Qualitative research investigates "multiple perspectives" of the participants (Glesne, 2006, p.5). The qualitative research process detailed in this study was exploratory, open, semi-structured, and flexible (Marshall & Rossman, 2006). Ergo, the research questions were somewhat loosely formulated and based on previous research of variables associated with college student success and on college students with disabilities.

The qualitative methodology is appropriate and arguably preferred for individuals with disabilities. In his work with quality of life in people with disabilities, Brown (1997) observes that in order to understand people with disabilities, a qualitative approach using a descriptive lens may better capture their everyday lives. Further, he advocates for research on quality of life for individuals with disabilities that is "concerned with people's perception of well-being, social connectedness, opportunities to fulfill potentials and with the discrepancy between what is desirable and what exists" (Brown, 1997, p.77). The student college stories in this study follow from Brown's premise.

**Theoretical Constructs for Qualitative Studies**

The qualitative methodology in this study embraced a combination of a constructivist paradigm and an advocacy worldview. The constructivist paradigm posits that the individual and his or her perception of the world are shaped not only by

experiences themselves, but also the social contexts that encompass experience (Glesne, 2006). In other words, how we make sense of our world is a reflection of our personal perspective, shaped by environmental, social, political, and cultural influences of the experience. Individuals with disabilities face a variety of obstacles in the context of a college setting; their personal perceptions interact with their social environments. How they view the environment may influence their desire to participate and may affect educational outcomes such as persistence and retention.

Constructivists maintain that perception is holistic and not easily categorized into discrete variables. Perception is not absolute, and there is no value judgment as to the legitimacy of the perception (Glesne, 2006). Further, Stake (1995) noted that constructivists believe that "knowledge is constructed rather than discovered" (p.99). Reality, then, is self-constructed rather than researcher constructed. Creswell (2007) contends that constructivists believe the goal of research is to "rely as much as possible on the participants' views of the situation" (p.20). The constructivist paradigm is quite different from logical positivism, a paradigm that values scientific objectivity and generalizability. Instead, the constructivist approach values "rapport, reflexivity, and trustworthiness" (Glesne, 2006, p.7). This study adheres to the constructivist paradigm in emphasizing descriptions of personal experiences that are unique to each case but also have similarities with other cases.

This study also maintains an advocacy worldview, which seeks to convey the student experience for the sake of assisting others with similar concerns. Creswell (2007) describes this view as an "action agenda for reform that may change the lives of the participants, the institutions in which they live and work, or even the researchers' lives"

(p.21). The focus is to bring about change in practice for marginalized groups. Thus, it is well documented that students with disabilities encounter discrimination on the college campus. Students with hidden disabilities probably encounter issues of unfairness, alienation, or discrimination similar to what other marginalized groups on the campus face, but like their disabilities, these issues are largely hidden. The findings from this research may help change practice and policy in higher education and disability services.

In addition to the constructionist and advocacy view, the research methodology was supported by several theories of identity development, college student development, which constitute the framework for student engagement. It is known that orthostatic intolerance syndromes typically strike during the vulnerable teenage and young adult years, or the emerging adult years. Student development theories ascribe to the notion that students will master developmental tasks in the college setting that help them succeed. College students in this study faced the added burden adapting to a chronic illness and college life. The theoretical foundations help us place college students with hidden disabilities into the conventional higher education system, and help illustrate the challenges they face.

**Research Design**

### Collective-Case Study

This qualitative study used multiple or collective-case study design. Case study research involves "the study of an issue explored through one or more cases within a bounded system (i.e., a setting, a context)" (Creswell, 2007, p.73). Case study research is well known in the traditional medical and health sciences, and more recently has been recognized a useful typology of qualitative researchers (Creswell, 1998; Denzin &

Lincoln, 2005). Although case study research in the traditional sciences historically uses quantitative methods for data collection, the "case" in both traditional science and qualitative research is a complex description of a phenomenon that is not well known. Another important similarity is that the case is rich in detail and does not readily lend itself to generalizability.

Case studies use in-depth data to help us learn more about situations that are poorly understood (Leady & Ormrod, 2005). Further, case studies are described as the study of a "bounded system" which is situated within a setting or context that the researcher specifies (Stake, 1997 p.2). Multicase study or collective case study is a "special effort to examine something having lots of cases, parts, or members" (Stake, 2006, p.vi.). Each case is examined separately for problems and relationships to gain a deeper understanding of a situation. One of the characteristics of qualitative cases studies is to provide a "thick description" of the participants concerns and perceptions (Stake, 1995 p.42). In this study, each individual case provided the researcher with the participants' description of their unique college experiences. These experiences are then analyzed individually, referred to as within-case analysis. Although participants in this study had their own distinct views about being a college student with a hidden disability, in order to make sense of the cases individually, the cases were then analyzed by cross-case analysis (Stake, 2006). This analysis provided for identification of common themes across cases.

In summary, the collective case study design used in this study explored the issue of college engagement behaviors from the perspective of students with a hidden disability. Each college or university setting is the "bounded system" that shapes the

110

physical, institutional, academic, and social factors that contribute to the experience. Each individual student experience or case was then compared with other student cases.

**Setting and Population**

Sampling Method: The selection of participants (cases) for this study used purposeful sampling. Creswell (2007) defines purposeful sampling as the selection of individuals for the research that can "purposefully inform an understanding of the research problem and central phenomenon in the study" (p.125). Purposeful sampling is unlike sampling measures used in quantitative research. The random sampling strategy used in quantitative research is chosen for the sake of generalizability of findings; however, it is not necessarily suitable for qualitative inquiry (Flyvbjerg, 2006). Random sampling does not provide depth or insight into given problems. As such, purposeful sampling is interested in depth of information and information-rich cases (Glesne, 2006). In his writings on case study research, Flyvberg (2006) believes that it is important to purposefully select cases to enhance study validity.

The selection of the participants for this study was based on the criteria endorsed by Stake (1995) in his book, *The Art of Case Study Research*, directing the researcher to select cases providing the greatest amount of understanding, which are readily available and which may also provide us with an alternative or unique view that is not typical (p.4). The cases were chosen to increase understanding of students with a disability' college experiences; referred to as an "instrumental case study" (Stake, 1995, p.3). In an instrumental case study, the focus is on "a specific issue, rather than on the case itself" (Stake, quoted in Creswell, 2007, p.245).

The college student participants in this research were recruited from a group of college age youth with orthostatic intolerance who participate in the Dysautonomia Youth Network of America, Inc. (DYNA). DYNA members include a potentially large group of youth from the United States who are diagnosed with dysautonomia and orthostatic intolerance. DYNA is a national, non-profit organization dedicated to serving adolescent children and young adults diagnosed with various types of dysautonomia conditions. Orthostatic intolerance is a common characteristic of dysautonomia. DYNA is designed to facilitate change, foster awareness, and encourage compassionate care for patients and families with dysautonomia and orthostatic intolerance (DYNA, Inc., 2009). Many participants of DYNA are college age.

The primary resource for DYNA members is a website, and the president of DYNA oversees the site. In order to gain access to participants, the researcher spoke to the president of DYNA verbally and emailed a formal request for permission to use the web site for recruitment of participants (Appendix A). Permission was granted from the president of DYNA via email (Appendix B), and a posting on the web site for recruitment of research participants was implemented. The web-site posting contained the following information; a) name(s) of researchers, b) call for research participants, c) purpose of the research, d) brief description of the research procedures and time frame, e) inclusion criteria, and e), contact information (Appendix C). This study used the DYNA web site to recruit participants, following procedure approved by DYNA officials and the University of Toledo Institutional Review Board.

According to Stake (1995), another criterion for selection of cases is to choose cases based on ease of access. Thus, the DYNA web site was more suitable than trying to

gain access through colleges and health-care settings, which can lead to problems with confidentiality. In addition, the college age student had the choice to participate by responding to the web posting for recruitment rather than being approached to participate. This in turn may have helped to prevent researcher bias. The students who responded to the web posting were asked to submit their name and contact information via email to the researcher if interested. They were also asked to identify demographics as follows: location, type of school (2 or 4 year); sex; age; place of residence while attending school; major; year in college. The five college students chosen for this study were selected because they were able to provide insight into the problem and because each student represented a heterogeneous geographical area.

Selection Criteria for Sample: In the early 1980s, Watters and Biernacki (1989) first describe targeted sampling as a social science research methodology for use in HIV/AIDS and substance abuse research. Epidemiologists employed this sampling method initially to monitor HIV transmission among IV drug users. Targeted sampling refers to the process whereby members of the population or individuals' familiar with the population refer others or recruit others for the sample. This method is helpful for the study of hidden populations, or those populations that are "difficult to reach due to social stigma, legal status, and consequent lack of visibility."

The inclusion criteria for selection of the sample was as follows: a) students attended and were currently enrolled in a 4 year college or university, b) students lived on campus, c) students were male or female, d) students were selected with different majors (to increase variability), e) students were not active patients of the researcher (not seen in last year), f) students were undergraduate students from different class ranks: freshman,

113

sophomores, juniors or seniors, g) all racial and ethnic groups were considered, h) all

students were between 18-25 years of age, and I) students were diagnosed with a

condition of orthostatic intolerance.

From the list of potential recruits who met the inclusion criteria, the final selection

of participants was at the discretion of the researcher. Each case chosen was based on

travel expenses, travel distance, the current health status of participant, geographical

location, and schedules of both the student and researcher.

To prevent students who were not chosen to participate in the study from feeling

excluded, the results of the research will be posted on the DYNA web site after study

completion. At this time, these students will be encouraged to share their stories of

campus engagement experiences through on-line journaling.

Consent to Participate: Once chosen, each participant was emailed a consent form

by the researcher and informed that they would also be given the same consent form prior

to the interview to sign. The Institutional Review Board (IRB) at The University of

Toledo approved this consent form. The consent form included title of research, name of

researchers, purpose of research, description of the research, permission to record,

permission to take photos and examine photos, permission to use documents of

participants from their college experience, potential risks of research, potential benefits of

research, confidentiality, voluntary participation, contact information and a signature

section.

Each participant was encouraged to voice any concerns or questions at any time

before and during the study. None of the participants had any significant questions, and

the majority of the email correspondence consisted of scheduling interviews and campus

participation observation experiences. The participants were asked to email their course schedule, and any other pertinent schedule conflicts they could foresee during the time of the college visit.

**Demographics of Sample**

A total of 19 students who responded to the call for participants recruitment letter posted on the Dysautonomia Youth Network (DYNA) website were potential participants for the study. Of this total, 5 college students were chosen to participate for the study, as described below. Participants were asked to provide information via email about age, major, class rank, location of their school, type of school, and residence. All students were diagnosed with a condition of orthostatic intolerance, either neurocardiogenic syncope (2 students) or postural tachycardia syndrome (3 students). All students had adult consent to participate and met the inclusion criteria. The participants indicated that their health was relatively stable and free of severe symptoms at the time of the interview.

Sex: Of the pool of respondents (N=19), all were female (95%) except for one male (5%). The male participant was initially chosen for the study to allow for a different sex perspective, but unfortunately he was unable to participate at the last minute due to scheduling conflicts. Thus, because travel arrangements to the university were already made, a student was recruited using the targeted sampling technique. The president of the organization contacted a student with the disorder who attended the same university. This participant contacted the researcher via email, and because she met the selection criteria, she was chosen to participate.

It is not surprising that the response to participate was primarily from females because young females with orthostatic disorders outnumber young males almost 5 to 1

(Grubb, 2008). Thus, 5 students (n=5) participated in the study, and all were female (100%).

Race: According to Nichols and Quaye (2009) Anglo-Americans account for nearly 72% of college students with disabilities. Potential participants were not asked to self-identify race/ethnicity, which in hindsight was an oversight. As it turned out, the five students chosen were White, which may be explained by the fact that the majority of individuals diagnosed with orthostatic disorders are not only women, but also White (B. P. Grubb, personal communication, March 2009). This is an interesting, but largely understudied phenomenon in the autonomic literature. In a study of 659 elderly, postural hypotension (a form of orthostatic intolerance) was twice as likely for whites than blacks (14.5% vs. 7.5%. P = .001). This study has somewhat limited applicability to the current study due to the age of the sample, because there are a number of age related autonomic/orthostatic changes in the elderly that limit generalizability (Lipsitz and Grubb 2005; Novak and Lipsitz 2004). On the other hand, Franke and colleagues (2004) found no group differences between black and white college males (N=18) in tolerance to orthostatic stress. Their study, however, used a small sample of males, and as noted, females outnumber males in orthostatic disorders at this age.

Another explanation for the racial differences in the response to the study may be due to socioeconomic factors that are well known to influence health care in the United States. The white participants may in general be more affluent, or have greater access to health care than other minority groups. Orthostatic intolerance is a largely unrecognized syndrome by the medical community, and one that may be easily misdiagnosed in patients with less economic resources. For instance, in the Autonomic Disorders Clinic at

the University of Toledo Medical Center where I am employed, 70% of the patients are from out of state and 10% out of the country. Limited resources in underserved populations such as minorities contribute to the racial disparities in health care. This likely influenced the racial make-up of the sample (B. P. Grubb, personal communication, March 2009). There are very few centers in the U. S. that specialize in disorders of the autonomic nervous system and orthostatic intolerance, most notable being The Mayo Clinic, Vanderbilt University, and The Cleveland Clinic. A medical visit to any one of the centers is likely a huge financial burden or an impossible task for someone with limited resources.

An additional explanation for the lack of racial variation within the group of participants may be related to the fact that the recruitment of students was done via email. Computer access may have been difficult. In a study of 570 African American undergraduate students at a single university, findings demonstrate that African Americans enter the university setting with less computer experience, and this difference is not ameliorated by the college experience (Hawkins & Paris, 1997).

Table 1 displays descriptive demographic data of the participants for age, sex, race, class rank, and major.

**Table I**

| | | | Description of case for age, sex, race, class rank, major | |
|---|---|---|---|---|
| Age | Sex | Race | Class Rank | Major |
| 19 | Female | White | Freshman | Journalism |
| 20 | Female | White | Sophomore | Animal Science |
| 21 | Female | White | Junior | Nursing |
| 20 | Female | White | Sophomore | Speech/Language |
| 20 | Female | White | Junior | Human Development |

University characteristics: The 5 college students were selected from universities from across the United States, spanning over 5,000 miles traveled. The broad geographical area helped to add dimension and geographic heterogeneity. The student participants attended universities from the east, south, west, and northwest regions of the U.S. The schools were a mix of public and private four-year universities with the minimum enrollment of approximately 8,600 students to a high enrollment of 36,000 students. Table 2 displays descriptive data for university location, type, and enrollment.

**Table II**

| | Description of university for location, type, size | | |
|---|---|---|---|
| Univ. | Location | Type | Size |
| 1 | East | Public | 36,000 |
| 2 | East | Public | 36,000 |
| 3 | South | Private | 8,600 |
| 4 | West | Public | 14,440 |
| 5 | Northwest | Public | 23, 320 |

**Data Collection**

The data collection took place in March 2009 and spanned two weeks. Each campus visit with the participant lasted approximately 1-3 days. The data collection included two formal interviews, participant observation, and document analysis.

One advantage of the research was the ability to engage in participant observation. I sensed that the students felt my commitment to their issues by my role as an "active participant" in the research, and many students admitted that they were surprised I would travel such a distance to interview them (I traveled over 5000 miles in two weeks). Glesne (2006) calls these "commitment acts" which demonstrate the time and energy the researcher puts into the research. Commitment, in turn, facilitates rapport between the researcher and the participants.

As mentioned, the student visit experience spanned 1 ½ to 3 days. Originally, the research observation days were to span 3 to 4 days. Because of time constraints and costs, the observation hours were extended over the course of one day and condensed into fewer days. I believe that this did not compromise the study, because even after 1 ½ days I sensed saturation of the data collection. I didn't anticipate that the participants would be so open and that the students would address the research questions easily. One particularly organized student said "I can't think of anything else that I could add," indicating that she felt content with the amount of time spent together. This student was also the same student who I spent the least amount of time with. I also sensed that the busy students were thankful that I was mindful of their time commitment. Just fresh from spring break, the students reported academic stress at the beginning of the semester during my visit, and I gathered from their hectic school schedules that the shorter commitment meant one less worry for them.

The campus visit or participant observation phase was somewhat exhilarating for me as a researcher. Indeed, I emailed my committee members after the first interviews to express my excitement with the process. It dawned on me that the years of planning the dissertation and over 150 pages of text were unfolding. More importantly, from my "debriefing" notes after the interviews I commented that "I was able to let go and allow the student ownership of the research."

The moment I began the interviews the students took over. They seemed quite eager to have their stories told. Several students had taken upon themselves to arrange well-planned campus tours. Humbleness replaced my arrogance or "expert role" as a researcher. I felt very fortunate to be a guest in their personal space, and to follow their personal campus "footprints." This was far from my preconceived notion of what a professional research role should be. At this point, I could remove myself fully from my medical role. Walking with them through their life for that brief moment illuminated how incredibly strong and resilient the students were in their ability to adapt and adjust to chronic illness and disability. This was in stark contrast to a clinical medical visit. I was able to capture a glimpse of only a very brief journey into their campus experience, and felt honored that they could share their successes, accomplishments, failures, and hardships. As their stories unraveled, the superficial or obvious concerns came easy. Yet for most, we were able to dig deeply into the layers that encompass their dreams, fears, frustrations, ambiguities and the uncertainty that their hidden disability brings. The innermost layers, once revealed, helped me to see how this experience shapes their identity, or who they are.

**Procedures**

The procedures for the interviews, participant observation, and document analysis are briefly detailed in the next section.

The participants read and signed the consent forms prior to the interview. The interview questions, based on the research questions, followed the interview protocol found in Appendix D. The face-to-face interviews took place on the participants' respective college campuses in dorm rooms, apartments, cafeterias, student lounges, eating establishments, campus malls or green spaces, and libraries. The first interview for each student was approximately 45 minutes to over one hour. The longest initial interview was almost 75 minutes long. A total of over 15 hours of interview audio recordings were obtained, or approximately three hours of audiotape for each participant.

The email correspondence as well as the first interview allowed the student time to develop rapport and trust with me, which is critical for qualitative research. Rapport allows the participants an opportunity to disclose information freely, which adds credibility to the study. After all, the essence of qualitative inquiry is about the interview data. Thus, the nature of the relationship between researcher and participant is essential for trustworthy research (Glesne, 2006). The students were aware that I am a member of the medical board of the Dysautonomia Youth Network of America (DYNA), and this was a unique position to understand the medical condition of these students. Because I was not perceived as a "foreigner," the issue of rapport was not a difficult task.

Signs of rapport include the ease of the interview, and the ability for the participant to gain something from the interview experience (Glesne, 2006). All of the students thanked me for my interest in their personal stories, my research in dysautonomia, and my pursuit to help others understand students with hidden disabilities

and orthostatic intolerance. It was apparent to me even during the first interview with students that they approached the interviews somewhat "prepared" to tell their stories, indicating that they claimed some ownership in the research process. One student provided me with an "itinerary" of her concerns and experiences as part of her document sharing. Another student revealed that she had never given thought to some of her campus engagement experiences, or at least the feelings associated with them. The frankness in their communication and the ability to articulate sensitive issues reminded me that these special students have very personal stories to share. I admired them for their openness, and continue to be amazed at their strength as they have learned to cope with a chronic, acquired-hidden disability during one of the most important times of their life.

The second interview was less structured and usually consisted of a series of interviews lasting anywhere from 5-45 minutes each that were spaced throughout the student's daily activities. This format seemed to work very well as the student and I traversed the busy campus. The total time for the second interview was anywhere from 60-90 minutes. The students were informed that when the transcriptions were complete and emailed to them for member checking, they could take this opportunity to add anything else of importance to them that might not have surfaced during the interviews (Appendix E).

Yet another form of data that enabled triangulation was the sharing of personal documents by the students. Most of the students provided me with printed information from their campus disability office. These documents were helpful during the interviews because the students could address the accommodations as we reviewed the document together. For one student who did not share printed documents, we walked the campus

path and took photos of the wheelchair access ramp, her scooter, the handicap parking

lot, and other "symbolic" icons that represent her "life" with a disability. This student

was much more visible than the others, because she frequently used an assistive

motorized scooter to help her with the long distances she had to cover. The criteria used

for document analysis can be found in (*Appendix F*.)

**Data Management**

The following documents were stored on a computer disk by the researcher

throughout the study: a) IRB protocol submission forms and IRB approval, b) letter of

approval to use website to recruit participants, c) web-posting for recruitment of subjects,

d) adult consent forms, e) general description of research questions for IRB and

participants to review, and f) the transcriptions. The interviews were recorded with a

recording software program called Digital Voice Editor that allowed the researcher to

record the interview, play the interview, and then transcribe on to a word document

simultaneously. Once transcribed, the transcripts of the interviews were stored on the

same computer disc. A binder was also used to store the hard copies of the transcriptions,

documents, and consent forms. After completion of the study, the data will be stored by

the researcher without identifying information for a period of five years and then

destroyed.

**Transcriptions**

Over 15 hours of audio-taped interviews translated into 170 pages of transcribed

interviews. The researcher transcribed the first case interviews, and a paid, private

transcriptionist transcribed the remaining four cases. The identifying information of the

students was removed prior to giving the audiotapes to the transcriptionist. Initials

identified the students, and each student was given a pseudonym (Debbie, Jessa, Kimberly, Shana, Casey).

Transcription conventions: Oliver and colleagues (2005) remind us that transcription is a "powerful act of representation"; thus, to accurately reflect the substance of the interviews, this study used a denaturalized approach (Oliver, et. al., 2005, p.1273). "Denaturalization" refers to the practice where a verbatim description of speech is attempted, but some of the "idiosyncratic elements of speech are removed" (p.1273). The substance of the interview depicts the accuracy of the interview, rather than accentuating every utterance, pause, accent, nonverbal, or involuntary vocalization. Denaturalized transcription focuses attention on the interview content rather than the technicalities of the conversational discourse (Oliver, et. al., 2005).

I reviewed each written transcription while listening to the audiotapes. At this point, the transcription conventions set forth in Appendix G were applied. Even though I carefully listened to the audiotapes, some of the audio recordings were incomprehensible, and this was noted in the original transcript. Member checking was used for the participants to check the accuracy of the transcripts; none of the participants added or changed their transcripts. To protect participant confidentiality, identifying data such as names, colleges, cities, organizations, and medical institutions was omitted; this study substituted "my college" or "my city" etc. These were not indicated, as the substitution did not alter the meaning.

**Data Analysis**

Initially, I reviewed all of the transcripts and documents in their entirety to help make general sense of the data. An important part of data analysis in qualitative case

study inquiry is to "pull apart the data" (Creswell, 2007). Thus, each case was analyzed separately (within-case analysis) and collectively (cross-case analysis). Within-case analysis is the process of becoming familiar with each case to allow emergent themes to take shape. Cross-case analysis is the process of using divergent techniques to look for patterns between the cases (Eisenhart, 1989).

The assertions from the data analysis in this study also consider the reader's interpretation. This is referred to as "naturalistic generalization" (Stake, 1995). In essence, the researcher attempts to make the case understandable and this in turn, helps the reader learn and use this knowledge for similar cases. As defined, "Naturalistic generalizations are conclusions arrived at through personal engagement in life's affairs or by vicarious experience so well constructed that the person feels as if it happened to themselves" (Stake, 1995, p.85). One outcome of this research study is to help the reader understand the experience of the college student with the hidden disability of orthostatic intolerance. The data analysis is described in the following section as a five-step process.

### The Narrative Description

To begin the process of data analysis, this study provides a narrative description of participant demographic information, pre-college themes, and the contextual setting of the interviews and university. Though the pre-college themes were not originally part of the study, it became clear from the transcripts that the pre-college themes were important elements to college engagement. In this section, the individual participants describe briefly the onset of their acquired hidden disability and their high school period. This includes a description of the student educational aspirations to attend college and the decision to attend their current college. It was important to examine the background of

125

students and the challenges they faced in high school, because this may contribute to college engagement experiences.

The content from the transcripts in this section and a cross-case analysis revealed several common themes. The themes include: a) unpredictability and uncertainty associated with the disorder of orthostatic intolerance, b) the unanticipated change in college plans, c) parental support balanced by the student need to establish independence and control and d) competent students with low expectations (Table 3). The campus contextual theme revealed that the majority of the students felt a need for organization within their environment. The demographic and pre-college theme contextual narratives provide rich background information to help "set the stage" for case analysis and subsequent cross case analysis of the engagement categories.

**Table III.**

| Pre-college themes and literature source | | |
|---|---|---|
| Pre-College Themes | | Literature Source |
| 1. | Unpredictability disorder | Orthostatic intolerance |
| 2. | Educational aspirations: change in plans | Identity Theory |
| 3. | Parental support/ establish independence | Identity Theory |
| 4. | Academically competent/low expectations | Disability Literature |

*Categories of Student Engagement Delineated*

In step two of data analysis, the data from each case is organized into six categories that are representative of the research questions. This organization was intended to facilitate professionals' being able to relate the cases to existing concepts they recognize as relevant to their work. These categories were created from the Model of Student Engagement, College Student Development Theory, disability literature, and

126

disability identity development. The processes of categorization or cataloging data are referred to as "emic" (Schwandt, 2007). Each category was labeled with a code and sections of text were then identified on the hard copy using the codes. This helped to pull out chunks of etic data for analysis. "Etic data analysis" refers to a data analysis method that is created by the observations of the researcher or within the study, or the process of explanation by the researcher (Schwandt, 2007). The six categories, text notations or codes, and literature source can be found in Table 4.

**Table IV**

| | Description of categories for cases and literature source | | |
|---|---|---|---|
| | Category | Text Notation Code | Literature |
| 1. | Academic Engagement | AE | Student Engagement |
| | a. Faculty | | |
| | b. Learning Activities | | |
| 2. | Social Engagement | SE | Student Engagement |
| | a. Friends | | |
| | b. Campus Groups | | |
| 3. | Campus Physical Engagement | CPE | Student Engagement College Student Development |
| | a. Living Arrangements | | |
| | b. Campus Setting | | |
| | c. Transition to College | | |
| 4. | Institutional Engagement | IE | Student Engagement Disability Literature |
| | a. Disability Support Services | | |
| | b. Accommodations | | |
| | c. Residence Life | | |
| | d. Campus Policies | | |
| | e. Financial Support | | |
| | f. Other Services | | |
| 5. | Self-Disclosure/Self-Advocacy | SD/SA | Disability Literature |
| 6. | Identity | I | College Student Development Disability Literature |

**Identification of Themes**

In the third step of data analysis, a total list of themes was generated which emerged from the five cases. The initial theme list was a compilation of 53 themes from all cases, and can be found in Appendix H. After pulling apart the themes, each individual theme was then put back into the six categories in Appendix I. This organization helped to view the cases holistically, to see the emergent emic themes that the students actually experienced, felt, and described independent of the researchers' categories.

*Within-Case Thematic Analysis*

In the fourth step of data analysis for each case, the six categories were separated and the associated themes are described in narrative. This section constitutes the bulk of Chapter Four, and includes researcher interpretation of stories, and verbatim quotes from the participants.

*Cross-Case Thematic Analysis*

The last step in data analysis was an evaluation of the themes in each of the six categories viewed through multiple lenses, or a cross-case comparison, noting commonalities and differences. In this section, the combination of within-case and cross-case strategies helped describe engagement patterns for college students with orthostatic intolerance beyond the preliminary impressions found in the individual cases.

**Literature Support for Case Study Design**

The rationale to use case study design in this study was based somewhat on the writings of Flyvberg (2006). In his discussion of the importance of case study use in human learning, he states,

> It is only because of experience with cases that one can move from being a beginner to expert. If people were exclusively trained in context-independent knowledge and rules, that is, the kind that forms the basis of textbooks and computers, they would remain at the beginner's level in the learning process. (p.222)

Case study research and its attention to detail are essential methods that help us learn about phenomena. Flyvberg (2006) believes that the case study research approach is instrumental to assist researchers to become experts. Concrete experiences, close proximity, and feedback from individuals or phenomena under study provide a rich learning environment for the researcher. Stake (2006) sums up case study research as follows: "it is designed to study the experiences of real cases operating in real situations" (p.3)

Qualitative case study research design has increasingly become the goal of researchers who study students with a disability, especially students with learning disabilities (Gersten & Smith-Johnson, 2000). For example, Lindstrom & Benz (2002) used a multiple case study design in a sample of six disabled high school women graduates entering the workforce. The researchers reported "these information rich cases helped provide insight" in the interaction between individual characteristics and societal barriers women entering the workforce face (p.69). Aponte (1999) studies two cases of

adults with the hidden disability of epilepsy and found a similar focus on difficulty with social and academic engagement. Similar to Lindstrom and Benz, this study examined the individual interaction with the (college) environment, which is a common theme in disability research.

In a review article of historical perspectives on case studies of individuals with dyslexia, Anderson & Meier-Hedde (2001) contend that the case study is a valid research method used historically and in current times. Further, they state, "Case methods provide the unique opportunity to learn something of value from an individual experience" (p.18). These researchers sum up case study methodology nicely: "case studies remind us that reading problems are more than statistics; they are personal struggles to overcome what at times appear to be insurmountable odds" (p.19). Case studies are prevalent throughout the current disability rehabilitation literature including disabilities resulting from stroke (Ownsworth, Merrill, Brooke & Fleming, 2008), traumatic brain injury (Polczynska-Fiszer & Mazaux, 2008), and a variety of other disorders.

### Researcher Support for Case Study Design

The choice of a collective case study approach for this study is supported by my personal experience providing health care to patients diagnosed with orthostatic intolerance. Based on years of interactions with these patients, a common problem that surfaced in my interviews with many college age students was adjustment to college life. Instead of a supportive, nurturing environment, the students perceived the college environment as unsupportive and sometimes hostile. Many of them shared with me stories of discrimination by the administrators, faculties, and students within the universities. The "hidden disability" and lack of understanding of their disease

contributed to their difficulties. Their dreams of having a "normal college experience" were shattered by not only adapting to a chronic illness, but also managing their disability in the context of the college experience. They described their experiences as fighting an "uphill battle."

Over time, it became apparent that the stories collectively shared a common thread. Based on my hundreds of interactions with these college students, I discovered that this issue was problematic. In essence, the experiences I have had as a clinician with college age patients diagnosed with orthostatic intolerance can be viewed as preliminary fieldwork. The opportunity allowed me to gather a tremendous amount of preliminary data about their issues and concerns. Much of this information was documented on the medical record and college disability forms. Although the student stories were familiar to me, college personnel or medical providers know little in general about their collective struggle. I sought to better understand their experiences and engage in a deeper analysis of the problem. The study helped me to learn more about the problem using descriptive analysis, so educators and clinicians may better address the complex needs of students with hidden disabilities.

### Researcher's Role in Case Study Research

The role of the case study researcher has been nicely described by Stake (1995, p.91-105). The first role described is the case study researcher as a teacher. As a case study researcher, the findings from this study will be used with the goal to teach or inform the reader about the experiences of college students with the hidden disability of orthostatic intolerance. The preliminary findings from this research have been presented to the Dysautonomia Youth Network (DYNA) and are currently being incorporated into

college brochures. In addition, the findings from this study have been shared with families and students with orthostatic intolerance in clinical practice. The researcher will write articles for journals to inform educators and clinicians about the topic.

The second role of a researcher that Stake (1995) describes is the case researcher as an advocate. He believes that "phenomena need accurate description, but even observational interpretation of those phenomena will be shaped by researcher mood, experience and the intention of the researcher" (p.32). Further, he believes that the researcher should refrain from encouraging advocacy or a reflection of personal values, but rather the researcher should report findings that are "expected to carry the message" (p.93). Stake (1995) sums it up nicely; the advocacy role in case study research is to "discover the best arguments against your assertions and provide data to counter them" (p.105). This strategy was employed in the study, and the research findings presented try to reflect valid, accurate descriptions, rather than students who felt pressured to conform to the researcher agenda.

Another role of a case study researcher is the role of an interpreter. As Stake (1995) notes, the constructionist view usually serves to guide the interpretation in qualitative case study design. In addition, principles of college student development theory, the theory of student engagement, and the quality of life theory will influence the interpretation of the descriptive data for disabled individuals. Interpretations of findings are based on the concept of relativism. Relativism refers to an interpretive perspective in which multiple realities are considered rather that a single reality (Stake, 1995, p.48). This perspective is ideally promoted by a multiple case study design.

**Subjectivity and Ethical Concerns**

Qualitative research is subjective by nature, because interpretation is subjective. Clearly, my subjectivity as a researcher allowed me to identify, conduct, and effectively communicate the research. However, subjectivity cannot go unchecked and remain research. To address this, the study used triangulation of data. In triangulation, the researchers gather different sources of data, methods, and theories to substantiate or clarify interpretations (Creswell, 2007; Stake, 1995). One form of triangulation used was interviews, participant observation, and document analysis. Triangulation of data sources helped to clarify issues, shape themes, and increase validity of this study. In addition, to increase validity, the study provides rich "thick description" from the transcribed interviews. Member checking allows the participants to check for accuracy, and thus increases validity (Creswell, 2007). This study was designed to use immersion in the campus environment through participant observation to increase credibility and validity.

Related to subjectivity are ethical concerns. The first ethical issue to be explored in this section is researcher bias. As stated, this researcher has been involved professionally with college age students who have the hidden disability of orthostatic intolerance. This close association could have led to researcher bias, but precautions were taken to avoid focusing on preconceived ideas. For instance, the researcher kept a journal for the interview to reflect data collected.

Stake (1995) believes that one of the characteristics of good qualitative research is to "resist exploitation of the specialist's platform" (p.48). As such, the researcher role of clinician specialist in orthostatic intolerance could have interfered with the ability to gather accurate interview data. Fortunately, the participants did not question the

researcher about medical therapy or advice, and respected the role of educational

researcher. No medical conflicts arose during the study, and the information obtained

from the interviews and close contact suggested that none of the participants needed

physical or emotional intervention. Rather, as will be seen, my background helped

students bond.

**Trustworthiness**

Credibility, reliability, rigor, trustworthiness are terms used somewhat

synonymously qualitative research (Rolfe, 2004). Glesne (2006) defines trustworthiness

as research validity. Creswell (2007) delineates nine characteristics of a sound qualitative

research study. For this research study, the characteristics are adhered to: a) rigorous data

collection procedures: This study used data triangulation including two interviews,

participant observation, and document analysis, b) participant observation helped to

develop trust with the participants, and descriptive and interpretive validity will be

enhanced by the use of interview-participant observation as described earlier. The second

interview timed after the participant observation helped to clarify the factual accuracy of

the student perceptions. Interpretive validity was also enhanced by low inference

descriptors, or descriptions closely related verbatim accounts and field notes, c)

collective-case study design is the only method used for this study. The research began

with a single focus, which is the engagement pattern in the participants, d) the study

followed the research questions; e) the research used a rigorous approach to data

methods, analysis, and report writing. This study relied heavily on the theoretical

perspectives of student identity, college student development, disability literature, and

student engagement, f) the study engages the reader with accurate, descriptive accounts

of the participants' stories, g) The study reflects the researcher's personal views as an advocate for the disabled college student, but the findings are critically analyzed for alternative views, and h) the research is ethical.

**Summary**

The use of qualitative methodology in this study allowed the topic to be explored in great detail by the researcher. The research became the voice of the students affected with the hidden health-related disability of orthostatic intolerance, and their collective stories helped to gain a greater perspective of the problem. Data collection methods allowed for triangulation of data to increase validity of the findings. The results of the investigation follow in Chapter Four.

<center>**Chapter IV**</center>

<center>**Results**</center>

<center>**Introduction**</center>

The purpose of this study was to explore how college students with the hidden disability of orthostatic intolerance engage in college. The five case studies of college students revealed that both pre-college experiences and college experiences illuminated numerous challenges to engagement for these students. Understanding what challenges these students face can provide information that student affairs personnel, administrators and faculties in higher education can use to help students with a disability transition from high school to college and to enjoy a successful college experience. Here, we will look at each unique student experience gathered from interviews, participant observation, and document analysis. The collection of data for each case allows us to elucidate the common themes, and then fuse them into a discussion of how the themes are shared among the cases.

This chapter is organized as follows. First, the study results are divided into the following seven categories: a) the demographic narrative and identified pre-college themes, b) campus physical engagement, c) institutional engagement, d) academic engagement, e) social engagement, f) self-disclosure and self-advocacy and g) identity. Next, for each category, the five cases are discussed separately; Debbie, Jessa, Kimberly, Shana, and Casey. Each of the five cases includes a case-by-case description of the participant experience, coupled with a within-case analysis of the themes. Finally, for each of the seven categories, a summary or cross-case analysis of themes is discussed.

**Demographic Narratives and Pre-College Themes**

<center>137</center>

Pre-college experiences and student background experiences influence college success. It is known from student engagement literature that several pre-college factors predict post secondary educational success, including enrollment choices, academic preparation, college readiness, family and peer support, demographics (race, sex, SES) and motivation to learn (Kuh et al., 2006). That said, little is known about how background characteristics and pre-college experiences affect the student with a disability in college. An understanding of who these students are and the challenges they faced in high school helps explain their college engagement experiences.

In this section, case demographics, pre-college themes, and the contextual settings are described in a narrative account. Several themes emerged from this section that highlights the need for our intervention. First, the students detailed how the debilitating sudden onset of the disorder struck and affected them during their high school years. The theme of the unpredictability and uncertainty associated with the disorder surfaced. Most of the students described a relatively healthy, "normal" life that suddenly and dramatically changed. Despite seemingly overwhelming odds, the majority of the students articulated strong aspirations to attend college even though many were unprepared for the change in college planning. Most of the students reported a supportive, protective parental unit, and also the need to gain independence from the family structure. Most students shared that it was important for them to establish autonomy and manage their own lives, which included living away from home on the college campus. Although the students were for the most part academically strong, many were surprised that they were even accepted into college.

*Debbie*

When I interviewed her near the end of spring break, Debbie identified herself as a 19-year-old, White female. She attended a large public university in the eastern United States and is a first-semester college freshman pursuing a major in Journalism. Debbie was healthy until age nine when she acquired and was diagnosed with a condition of orthostatic intolerance referred to as postural tachycardia syndrome (POTS). She reported having difficulty with recall of the earlier years, and attributed this to memory loss. She also reported initial symptoms of dizzy spells, convulsive episodes, and fainting or syncope. Incredulously, she told me it had been nine years since the initial diagnosis. Indeed, she said, "It has been a really long road" that "I can't even begin to describe." Homebound the majority of time, she was home-schooled for a large portion of her high school years.

Debbie told me that she chose her college "for lots of reasons. First, I'm a big fan of the athletic teams, but they also have an incredible journalism program, it was close to home, and I was familiar with the campus because my brother graduated from the same school." She was motivated to attend college away from home, as opposed to living at home, and explained that it is "very liberating to finally be on your own. To be taking care of your self, and I don't know, I guess I am a very independent person."

The first interview took place in my hotel room on the campus, because the dorms were not reopened from spring break until the next day. Debbie lived 40 minutes or so from the campus, and her mother and brother drove her to my hotel room. Extremely close to her family, she told me she talks to her mother almost daily. Debbie was very articulate and seems much wiser than her age. Although she described herself as somewhat "introverted," she is introspective and quite easy to engage in conversation.

The second interview was really a series of interviews that began in her dorm room and continued at several different locations on campus. She explained that she lives with a roommate whom she "tries to avoid" and apologized that her dorm room is a "cluttered mess," one of many reasons why she "doesn't get along with her roommate." She described herself as being "very organized" and has difficulty with the chaotic living arrangements.

Debbie was the "consummate host" and was very sensitive to my schedule, providing me with a "full campus experience." She was extremely attentive to my needs and frequently asked me if I would like to see any other part of the campus, if I have any further questions, and if she could help in any way.

We spent over 2½ days together, and she was able to answer questions with ease. She reported, "I am so happy that someone would tell our story." I met her between classes at her dormitory room and she explained that during breaks in her schedule she typically uses this time to "rest and regroup" because the days can be physically taxing for her. The dormitory room she shared with a roommate was very cramped and cluttered, but Debbie's belongings were more neatly organized. For the second time, she apologized for the mess and blamed her roommate. She also stated she was glad her roommate wasn't in the room, she had not seen her, and didn't know where she was for the last several days.

We left the dormitory and walked a short distance to the student union. The campus is full of energetic college students, and the student union reminded me of a shopping mall during the holidays. I was overwhelmed by the activity, yet Debbie, in her matter-of-fact demeanor did not complain. Although it was a busy campus, I sensed that

Debbie is somewhat socially isolated, as her only conversation with friends was a phone call from a college student friend who has the disorder of orthostatic intolerance and attends different college.

*Jessa*

When I visited her campus, a large, public university in the eastern United States, Jessa identified herself as a 20-year-old second-semester college sophomore. She stressed that her class ranking was "credit wise" and not "time wise." A White female, Jessa planned to major in the Animal Science or Pre-Vet Program and minor in German.

Jessa reported that she was healthy until the age of 17. During her junior year in high school, she began to experience "blackouts" described by her as the loss of vision whenever she stood upright. She reported the sensation of lightheadedness, and near fainting that required her to hold on to things for support while standing. The episodes increased in intensity and frequency to the point where she began to "walk into people" and would have to "stop her conversation" while upright. Concerned that the episodes were obviously not "normal" and interfering with everyday life, she sought medical attention and was told to "drink more water," and then "sent home."

Because of a "family situation" her medical condition "fell through the wayside," and she did not get an official diagnosis until almost 8 months later. A second medical provider sent her to a specialist who determined she was suffering from a condition of orthostatic intolerance referred to as postural tachycardia syndrome (POTS). Although she was able to remain in high school, she reported that it was a struggle especially considering her family issues. She was able to receive accommodations for high school classes with the help of her parents. In spite of this, she reported, during her senior year

141

her "energy level, motivation and self esteem were so low" that she was overwhelmed. The sudden-onset of disabling symptoms had her quite perplexed: she stated, "I really didn't understand why and what was going on. I really didn't comprehend the illness to that extent." The syndrome wreaked havoc on her world, as she told me, "Unfortunately I went to a very competitive high school, almost cutthroat, and just seeing myself fall was hard."

When I asked Jessa about how she decided to attend college, she told me "It's a long story. Surprisingly it is not at all where I wanted to go. I sort of wish I wasn't here still." Because of such low energy both physically and mentally her senior year, she explained, "I applied sort of half-heartedly for two colleges, and two is not enough for the competition that is out there these days." Her grades had fallen her junior year while ill, which contributed to why she wasn't accepted at the two colleges to which she applied.

At that time, her father stepped in and called the current college on her behalf to inquire about admission. She reported at that time college was far from her radar screen: "I didn't really want to deal with it, you know, I just wanted to take the year off, I was just too overwhelmed." Bewildered by the uncertainty of the illness and the disruption in her life, Jessa related,

> When all around me my friends were applying to ten colleges, and getting into eight of those, and exuberant about life, and I was just, you know, I never had any energy, and what happened to my motivation? Anyway, my dad called on my behalf and it was way past the deadline and they said they would take rolling admission only if there were no openings, but made no promises.

Jessa was accepted in a special program for students who were not accepted in the first go-round only, she said, "by some miracle."

Just fresh from spring break, Jessa met me for the first interview Sunday night on campus. We initially met in front of her dorm but because she lived with several roommates, she led me to a quite, private room in the library. Initially somewhat reserved, her responses to my questions were extremely reflective. As the interview unfolded, she revealed a part of herself she had never examined, stating, and "I guess I really never thought of that before." In subsequent interviews, she told me the experience had been somewhat uplifting for her. When I reflected back upon the all of students I encountered, she reported much more difficulty with engagement in the campus setting.

*Kimberly*

Kimberly identified herself as a 21-year-old college student, a second- semester junior, with a major in Nursing. She is a White female and attends a private university in the southern United States that she described as "kind of like the rich white kids' school…there's not a lot of diversity, but they are working on that."

Like the other students diagnosed with orthostatic intolerance Kimberly told me, "I was perfectly healthy until I was sixteen years of age." She then began to experience severe gastrointestinal symptoms of nausea and vomiting that ultimately led to the removal of her gallbladder. When her symptoms persisted, she underwent a series of multiple medical evaluations that resulted in a hospital stay for almost her entire junior and senior years in high school. "I was in the hospital over two-hundred days that year trying to figure out what was wrong." Understandably, she said, "It was a disaster." Plagued with severe headaches and abdominal pain, she ended up undergoing several

surgical procedures, one of which led to chronic intravenous therapy using a permanent IV access port and a cerebral shunt, which relieved spinal fluid pressure on the brain. Thus, she was homebound much of her junior and senior year of high school.

As far as college aspirations, Kimberly told me that because of her deteriorating health, "at first we didn't even know if I was going to graduate from high school." Describing herself as "stubborn and determined," she explained her decision:

I was just in the hospital one day and I was like what am I going to do? I knew I wanted to be a nurse. I was up at about 3am and I thought this is ridiculous, and I know that it sounds bad but I am not going to a community college. I had aspirations to go to U Penn or Georgetown; those were the schools I was looking at before I got sick.

Having to shift gears educationally, she started looking at schools closer to home. She chose her college because the college "has one of the few bachelors programs and also gives you the college experience and I didn't want to be just living at home if at all possible."

Because it was a last minute decision – "literally one week before the applications were due" – she worried about acceptance to the college. Kimberly reported that for her college, the admission policy was excellent: "They have a place on the application that you can explain what is going on, like why I didn't have a traditional transcript and I had been in AP classes, why I dropped all of those." As well, she was able to submit a personal essay, which was returned to her with positive comments from the admission committee. She reported they noted that they "thoroughly enjoyed reading my essay and it showed how strong of a person I was. It was kind of cool to see that they appreciated that."

Even though academically strong, she seemed surprised that she would be accepted to the college:

> By some crazy miracle I was accepted, and it was the only college that I applied to so if I didn't get in here I really don't know what I would have done. I didn't think about it at the time.

I first met Kimberly at her apartment, which was literally across the street from the campus health sciences building, which she told me is an ideal location. She lived alone, and her apartment was beautifully decorated, tidy, and bursting with photos of her family and friends. We sat at her kitchen table and she radiated confidence with her extremely organized and business-like manner. She was very prepared for the interview and provided me with multiple documents to review including disability forms, transcripts, course schedules, and applications. She shared the documents with pride, especially the disability brochures from the college that she helped to create. Indeed, I will demonstrate how these documents add to the richness of her story later in this chapter.

*Shana*

Shana identified herself as a 20-year-old sophomore with a major in speech and language pathology. A White female attending a mid-size public university in the western United States, Shana told me she was first diagnosed at age 10 with a disorder of orthostatic intolerance referred to as neurocardiogenic syncope (NCS) after "I passed out in a tree and broke may arm." After starting medication to control the disorder, she was very functional: "I always did everything I wanted to do, it didn't affect me, and although I was dizzy and would have tremors, nothing really noticeable until I got appendicitis in

high school." This was the summer before her junior year and unfortunately the symptoms progressed to the point where "I just never really got better. I started passing out a couple of times a week and I couldn't stand for very long at all so I was in bed a lot of the time so tutors would come in."

Although physically struggling with a sudden onset illness, she proudly reported that she was able to attend a program at a technical college for high school students and obtain a medical assisting certificate:

I would go there for three hours a day and I would come home and sleep the rest of the day. I would pass out sometimes and they were all medically trained so they loved it. I would work on homework when ever I was awake.

Shana reported clear educational aspirations:

I was always sure I would go to college." She had a strong desire to "get out on her own" and as a consequence, it caused some anxiety in her parents. "My parents wanted me to stay home because they were worried. I don't get around very well on my own." Shana chose to attend a college that was two hours from her home, and although they were "very supportive" her parents were also "upset that I was determined to go so far away.

But Shana felt a strong need to be independent and break away from a supportive home environment, explaining,

I think I really wanted that independence because I didn't have that at home. I did nothing on my own and everything was taken care of for me. I wanted to make sure that I was still able to be an adult and do everything that everyone else did so I wanted to come here.

146

I first met Shana at her apartment, a street, or two from campus, where she lived on the second floor with four other roommates. We decided to conduct the first interview on campus, and Shana told me she was unable to walk the short distance to campus. She reported that she rarely walked to campus because she feared fainting. Thus, we drove to the campus in a handicap-equipped van with an automatic wheelchair ramp access.

Shana was different from the other students whom I interviewed who were much less visible with their disability. Thus, Shana provided an interesting perspective, because she used the assistive devices when feeling the need. We were able to park in handicap accessible parking, which she noted was centrally located; she used her walker for the entire campus tour. She explained,

> I almost always take my walker. I think sometimes it is just a comfort for me, because I pass out so often, I mean, it's like I'm use to having it here with me even if I don't need it, just in case, it may help me to get to my car.

The handles of the walker are decorated with colorful, metallic bicycle streamers, and the handlebar has a few little stuffed animals hanging from it. Unlike Kimberly, who works hard at trying to overcome a "disability label," Shana's walker would suggest differently.

*Casey*

Casey self-identified as a 20-year-old, junior status, and White female, with a major in Human Growth and Development at a large public institution in the Pacific Northwest. Casey explained that before her symptoms began, she enjoyed a relatively healthy childhood and was "very, very active: I did basketball, I did tennis, and I was everywhere all the time." At age 12 she reported difficulty with exercise tolerance while

147

running track, noting "I had a lot of trouble breathing, I felt out of breath, this went on for a while, for about 10 or 15 minutes and then I would pass out." Although the symptoms continued, she did not receive a diagnosis for almost 3 ½ years.

Casey was able to function fairly well in middle school, and ran track her freshman and sophomore years of high school. She explained, "I was doing pretty well, training with my dog, that was one of the higher points, and then, you want to know what happened? Come junior year it was very bad in the mornings." She was so debilitated that she only attended school for 1½ hours a day. She noted that it was challenging for her socially. Academically she suffered as well:

> In school I was always the good student, A's, B's, my junior year I started having
>
> a lot of trouble, which was very, very frustrating for me. I'm kind of a
>
> perfectionist so for me not to be able to do that was really, really frustrating.

Casey had educational aspirations to go to college: "I knew I wanted to go, I knew I was going to definitely try it, and I think my mom was one of the biggest – she didn't want to let me go. She was definitely very attached, and I was, too."

Although her mother wanted her to attend a local college and commute, Casey decided to attend a school 45 minutes away. She explained:

> I did that purposely, for myself because I knew I needed it. I needed to be on my
>
> own because it was very frustrating for me to have to watch my friends, you
>
> know, they can go out and get a job, they can kind of do more to support
>
> themselves, and I know I am very lucky my parents are great but I wanted to take
>
> a little bit more control of my life.

I met Casey on campus, outside the football stadium, and we walked across campus to a centrally located green space framed by the colorful blooming trees of spring. We positioned ourselves on a concrete ledge close to the steps, and agreed that because of the beautiful day, we would start the interview outside. Sitting poised in the warm sun, Casey adjusted the large sunglasses that framed her small face. She appeared cheerful and relaxed, unaffected by the bustling students who crossed the busy college mall. Like the other students, she had a tale to tell and in a soft voice began to detail her college experience.

After over an hour, the fading late afternoon sun reminded us that spring had not fully arrived so we walked indoors to the library to warm up a bit. We concluded the interview, and we walked the campus. While we walked, Casey showed me the short cuts she used to conserve energy. Although I am over twice her age, she rested frequently and avoided the stairs.

The next day, we had a second interview in her apartment just a stone's throw from campus, where she lived alone on the second floor, due to roommate "horrors" in the past. Her apartment was simple and clean. I inquired about the many photographs that decorated the living room, and she explained they are high school friends, her boyfriend, parents, and her sister. She had prepared documents to share, primarily of the disability services, and we spent over an hour with the second interview.

Summary

This section introduced the five cases by providing information about the pre-college experiences and the contextual setting of the interviews in order to provide a bit of historical background that helps to explain the engagement experience. Although not

149

initially part of the research questions, the salient pre-college themes that emerged are important for educators. We have learned that for each case, the acquired disorder of orthostatic intolerance created a disruption during the high school period that corresponded with college planning. A haphazard application process to college was also identified. The stories revealed that the students were academically strong with high educational aspirations to attend college, yet paradoxically surprised they were accepted to college. The students all expressed need to develop autonomy and to live independently away from home despite the wishes of their parents to stay close to home. Another theme included social isolation in high school that continued into college. Many of the students reported need for organization and cleanliness, especially in their living environment. This need for organization was somewhat at odds with the typical college setting.

**College Experience and Engagement**

In the previous section we provide a sense of background information for the students; now we introduce the heart of the story. Specifically, how does their disability affect different aspects of engagement of the college experience? It is important to look at this because ultimately, engagement influences success. In the following sections, you will see that all categories of engagement were affected, and were related to the disability. Some of the challenges to engagement were similar among the cases; thus, the themes to engagement for each category are highlighted.

**Campus Physical Engagement**

This category includes living arrangements, the campus setting and student behaviors or activities that rely on structural or architectural accessibility on campus. We

look at the location of the dormitories and structure of housing, parking access, classroom locations, food service location, and ease of use, the location of student lounges, student union, and other structural accommodation issues. Also included is a discussion about roommates, because the disability affected these relationships. Several of the students presented a longitudinal perspective, meaning they detailed their living experiences over several years while in college (i.e. freshman, sophomore, junior, senior). This perspective illuminated how they adapted over time and learned from previous experiences as to what worked for them and what didn't. One student reported on her commuting experience prior to living on campus. This perspective suggested that commuting provided limited ability to engage and was physically exhausting for a student with a disability.

As will be seen in the students' stories, the common themes that emerged from this section underscore the physical barriers that students with disabilities face when they attend college. First, the students all reported that the disability required a physical adjustment to campus. The limited physical stamina from the disability reportedly required many to prioritize daily activities based on energy. The physical structure and accessibility of the campus often prevented these students from fully participating. Many students did not anticipate the physical challenges the campus presented, and over time they discovered what worked best for them in terms of day-to-day issues and roommates.

Another common theme was the lack of individualization for room assignments. The process did not consider their individual needs, and as a result many encountered accessibility barriers and problems with roommates. Now we look at individual cases and a detailed description of experiences with the physical environment and how this influenced engagement.

*Debbie*

No doubt for most freshmen the act of physically sharing living space with individuals whom they must engage can be challenging. Debbie's case well illustrates that having a disability can be even more problematic.

Debbie reported that her roommate experience has been somewhat of an adjustment:

> Getting used to dorm life, having a roommate was a big thing. I have actually had two roommates since I have been here. My first roommate was wonderful: she went to bed as the same time as me, she had early classes so obviously she had to go to bed earlier, so that was fine, and that really helped me to having to adjust to sleeping in a new environment and everything. Then she moved out, and got into a better living situation, and I had the room to myself for quite a while, for several months, and that was even nicer.

Debbie told me that for physical health reasons, "I just need my sleep so much," because lack of sleep makes her condition worse. Unfortunately, the new roommate who eventually moved in took some getting used to:

> My new roommate doesn't like going to bed at a decent time, and she doesn't like getting up in the morning. For the first few weeks we had a major problem with her alarm clock: it would go off and she wouldn't turn it off, so I would have to because I would have to sleep. So we have fought about the alarm clock quite a bit. She does get it now finally, but that was a really hard issue initially. For me, waking up calmly in the morning rather than being aggravated by, "oh my

roommate's alarm is going off" right away is a stress and annoyance that you just don't need.

Debbie liked both the solitude of living alone, and being on her own schedule. She noted, "I like my own space and privacy." She described herself as an "introvert" and she explained,

Even being around my roommate that was social interaction for me, and that was physically kind of taxing just having someone else in my space. Even the first night she moved in she had tons of friends to help her to move in and it was just very overwhelming. I was surprised how overwhelmed I was to see so many people just invading my space. It was physically hard.

On several occasions when Debbie took me to her room, she indicated that she "hoped my roommate won't be there," and expressed how annoyed she was by her roommate's lack of respect for her needs.

Physical adjustment to the campus for Debbie was a common thread throughout the interview, and was highlighted during our tour of the campus:

I think studying and everything was easier because I was homebound most of my illness; so I am use to studying and everything on my own. So I think that was towards my advantage. But physically the adjustment was much harder because of my illness because everything is so much harder to adjust to when you have physical limitations. You have to take your health into consideration.

Academically she felt competent, but physically, she felt challenged.

The location of classrooms and student services helped Debbie participate in daily campus activities:

Getting use to walking the campus was really big because I never used to really exercise that much. It is a really big campus and you have to walk to get to all of your classes. You have to walk to talk to all of your professors and their offices, you have to walk to get food, you have to walk to get to the disabilities office in order to get all your forms, and it's up this giant hill, and you have to walk all the way up there.

Although the closest dining hall is a three-minute "short walk" from Debbie's dormitory she noted "But still it's a walk." If she has a cold or illness, she "can't make it that far." Even though the student union is closer, Debbie couldn't use her meal card to purchase the food because it is not dormitory food.

To conserve energy on the large campus, Debbie adjusted her academic schedule around the location of the classes. "Luckily when you schedule they do tell you the location so you can take that into account." Thus, aside from her need for sleep, privacy, and physical energy conversation, she was happy with her room location: "It is located really nicely on campus and it had air conditioning, not all the dorms have air conditioning and that was very important-from my illness standpoint–to have air-conditioning." Debbie had a wheelchair accessible room because her roommate used a wheelchair.

This room also had a private bathroom, which was important for Debbie:

I am prone to a lot of infections with this illness and they clean the other bathrooms every day, but in the morning and after all day with everyone using them–coughing and sneezing–it has been helpful.

*Jessa*

154

As mentioned, Jessa lived at home her first semester as a freshman, and she was

admitted to a non-traditional type-program because she applied late to college due to the

illness. The program consisted of night classes, and she reported trouble with engagement

or feeling connected to the campus:

> There was no way to get involved on campus because all of the campus activities
>
> occur while you are in class at night. So I mean, the program made no effort to
>
> connect you to each other or anything. I lived at home with my parents, and my
>
> sister and friend were away at school. I virtually knew no one. I really did need
>
> some connection.

The disability onset in high school affected college enrollment choice, which

affected her not only socially, but academically. She reported difficulty:

> The program offered very limited classes; only core classes. So I couldn't
>
> continue my German studies and actually I couldn't take any Animal Science
>
> classes, which are only offered in the fall. So I was a year behind when I started."

Jessa was the only student in the study who commuted. She explained her reason

to commute:

> I guess I wasn't confident about living on campus, but really, outside of actual
>
> medical reasons it was really because of me. Being at home is a supportive
>
> environment.

Although the home environment was supportive, the commute to campus

presented a number of obstacles for Jessa:

> I was commuting and I had 12 credits. I was commuting about 4 days a week. It
>
> was a 45-minute drive with traffic, and sometimes it took 1 ½ hours if there was a

155

bad accident. This was awful stress at the time. I had to leave extra early to make

sure I was never late. By the third semester of college the commute was definitely

a fatigue factor and just getting trapped in traffic a lot of the times. The parking

also was terrible: it's at the edge of campus and I had to walk a really long time. I

would come to class always like in euphoria, so they say. I was always out of

breath, and it took about ten minutes to get settled down. I was very red in the

face and just like I'd come in to class huffing and puffing. Almost like, what have

you been doing? Jogging for the past hour?

Finally, after all of the trouble commuting, Jessa decided to live on campus. Not

only was the commute hard physically, Jessa explained that she decided to live on

campus to take full-time credits to "catch up" because she was behind academically.

Social engagement was not a reason Jessa chose to live on campus. She related:

I actually didn't consider it because of college activities or anything. I'm really not

interested in any of that and really don't have the energy for it. I am not very into

it. To be full-time (living on campus) is extremely convenient obviously. The

language house is very centrally located, and the center of campus.

Thus, the language house was appealing to Jessa because of the central location of

the living arrangements and the ability to share a dorm with "similar, like-minded"

students. These students helped her academically because she could practice German

speaking and "gain fluency in the language." Jessa cited lack of energy for involvement

and reiterated her decision to live on campus:

I am not happy living on campus. This is going to sound very contradictory, but, I

am happy with my decision, because I think in the long run, it's really going to

help me get all the credits I need and hopefully graduate in five years. That's my goal. But I am really not happy on campus. It's not for me. I don't have the energy or really have the want to involve myself. I think that would be very draining. I am also really not into the college scene, like any of the sororities and drinking. I really look down on that. I don't mean to judge other people, but…

Jessa took me to the language house apartment on the 5th floor with no elevator access. She explained that each floor consisted of a different language group and unfortunately the "German cluster" was on the top floor.

As we climbed the narrow staircase, I asked her if the stairs posed any difficulties. Jessa explained:

I did not have a choice in rooms because I could not stay in the language house if I wanted a more physically accessible room. Sometimes it is hard, and I am out of breath. But this semester I am doing better physically.

The dormitory apartment was arranged with a common kitchen area and several large bedrooms each with three to four sets of bunk beds. No roommates were in her room at the time. I asked her about the living arrangement and her relationship with roommates. Jessa explained that she is required to participate in activities that involve the language house because she is in a "language immersion program." I assumed Jessa would be somewhat connected socially to them, but on the contrary, Jessa reported:

We don't really talk. I have a friend that goes to Hopkins and she's talking about how she and her roommates are always going out to dinner, or if they are not in the dorm together, they will plan to meet up, or study together. I really wish I could have that; like some cohesiveness with the people you live with. Everyone

157

eats at different times. I never cross paths, not frequently anyway, in the kitchen. I

don't think anyone goes to the dining hall, because the dining hall apparently has

awful food. It is lonesome, quite lonesome here on campus. But, in a way it's

good, because I told you my energy depletes so fast. So it's good for me not to

have so much interaction.

Even in the language house Jessa seemed socially isolated. She attributed the

social disconnect partially to the disability. She also hinted at the lack of connection to

peers on campus who drank alcohol.

*Kimberly*

The theme of roommate difficulties due to different values and the disability is

demonstrated in Kimberly's stories. Kimberly, a junior, provided a glimpse of her past

experiences living on the campus with a disability:

My freshman year was my biggest issue with the roommate situation. It affected

my grades. My first roommate basically went crazy when she got here with

alcohol and partying. She would come back at 2:00 in the morning and make

herself throw up. I really don't understand because of my disorder I threw up so

much from being sick. It was like; I don't have sympathy for you when you're

making yourself throw up.

Unfortunately, two weeks after the above roommate experience, Kimberly was

hospitalized. When she returned from the hospitalization the roommate moved out and

Kimberly had the room to herself the rest of the semester, but this was short-lived:

According to campus policy, all freshmen are required to have a roommate for the campus experience. It's part of adjusting to college life. I got a new roommate. But for me, the college experience needs to be prioritized below my health.

After the hospitalization, Kimberly had a visible tube-feeding pump in her abdomen.

She discussed her health issues with the new roommate. Kimberly reported, My roommate initially seemed supportive. But she emailed me a week later and she said she thought about it and said, "I can't handle it." I respected her for saying that but it was hard to hear. My roommate said "college was going to be too stressful for me." Like you don't think it's going to be for me, too? Yeah, it was rough. That was the first time I had ever really been discriminated against because you could say, because being sick.

Kimberly was happy to have a single room for a short period of time between the two roommate disasters. Nonetheless the experience was extremely stressful for her: "It exaggerated everything, and it just exacerbated the POTS and it was bad." Kimberly then requested a new room and a suite bathroom arrangement for physical health reasons. Although the room was physically accessible, she reported that the room was not as socially accessible: "My dorm was mostly sophomores, so I did miss out on that too. I wasn't with anybody that I was in class with, which was tough, but I had to prioritize what was more important."

Currently, Kimberly lived in an apartment by herself across the street from the building where she had the majority of her nursing classes. She told me the apartment

was in a very convenient location, but she believed it was much more expensive than the campus housing.

The decision to live in this apartment was based on the proximity of the nursing classes. She explained,

My apartment is in an ideal location because I don't have to walk far for class. But living in campus housing my freshman year was a huge adjustment because I never really used a wheelchair. I did as much walking as possible. I had to schedule breaks when I needed them. I was very careful.

*Shana*

Many college student experience difficulty finding housing that is convenient and affordable. Shana's story, like the previous stories, shed insight into how important adequate housing is for students with disabilities:

There is not much housing around here that's accessible. They say; you can build a ramp here if you want. But there's even places on campus that don't build ramps and it's not easy for people to get to, so I've ended up crawling up my stairs a lot. Some of the dorms have elevator access. You have to share a bathroom and they look like jail cells. I talked to the disabilities resource person and they hadn't been able to lead me anywhere accessible unless you want to spend a lot of money and even then it is not always as accessible.

Currently she had her own bedroom and bath, and shared an apartment with three roommates. Unfortunately, this was still up two flights of stairs.

Shana noted:

Housing definitely could be better. I spent a long time this last semester trying to find new housing that was more affordable. There is nothing that is handicapped accessible. It's difficult to find a place where I can charge the power chair. You can't get it upstairs and there are no ramps and you can't get it into the house. So, I've made it so I can charge it through my car. But I had to get permission so I can plug it into the outlet outside the building. But because there are a lot of housing complexes I was told they don't want somebody to trip on the cord so you can't plug it in here.

College students would all agree that a big campus can be challenging to navigate because of the distance individuals have to travel to-and-from classes, activities, and campus services. Many students with disabilities have difficulty navigating large campuses. But smaller campuses can pose difficulties for students with disabilities as well. Shana explained:

Because the campus is so small I could walk it. I wanted to be able to walk it. But my first year it was awful, my classes would be at one end of the campus to the other end, I would have a ten minute break between the two so I could never get there on time.

The location of classes and campus services is important for students with a disability. The food service process for on campus dining can create socialization barriers for students with a disability. Meals are an important time for all students to engage and socialize.

Shana reported that dining halls were problematic and she often dined alone:

I decided to have a kitchen in my apartment because the lines are long for on-campus dining. I don't have the physical energy or stamina to stand in line. But

sometimes I don't have the energy to even cook at my apartment. What I started

doing is having this basket under my bed with foods like granola bars or

something in a bag and I can just lean over and grab a granola bar and some water

or applesauce. I have a whole storage bin that's under my bed full of food.

Similar to previous cases, the disability of orthostatic intolerance affected

engagement with roommates. Shana, however, described a somewhat different view:

She was up all night all of the time. It made it hard to sleep but the fact that I was

so tired helps. She was just so messy and I didn't have the energy to pick up after

her and me, but other than that we were great friends. She was very accepting,

very helpful: when I would pass out in the grocery store she would help me up,

like go grab the cart that went flying. She was very, very kind about that; she was

just hard to live with.

Despite the differences in sleep schedules and tidiness, Shana suggests the

friendship was worth it.

*Casey*

Many students who attend college for the first time have to learn to manage the

tasks of everyday living and learn self-regulation. This takes on new meaning for students

with health-related disabilities because day-to-day activities require energy. Casey

described the physical adjustment to living away on campus that required planning and

prioritization in everyday activities. Previously, her mother attended to all of Casey's

needs:

She did all of the laundry, all of the dishes; she did all of the stuff that I suddenly

had to do. This took up more of my time and energy. I'd get up in the morning

and start thinking like; when am I going to be able to do this, or if I was going to

be able to do this. I have to think about a second option because there has to be

two options in everything in my day. If I can't go to class, I would try to be

productive in some other way. Of course, there were a lot of times when I was

sleeping in my dorm, so it was frustrating.

In terms of daily physical functioning, Casey had to make adjustments, but she

also struggled emotionally somewhat from not being able to participate fully in campus

life: "I think it was most frustrating for me to watch other people like to see what I would

have been like if I wasn't sick." She reported the need to balance immersion in college

with her health: "It's kind of bittersweet to have a lot of fun but then I also kind of open

my eyes to know my limits."

Casey lived in the dorm the freshman year, a house with roommates the

sophomore year, and now lived alone in an apartment a block from campus.

Casey described a positive roommate experience her freshman year:

My freshman year was definitely a very, very fun year. I had one roommate I

knew from high school and I really felt more comfortable living with someone.

She wasn't really into too much of the partying either.

As a sophomore, Casey lived with five roommates in a house, and, "I seemed to

have a lot of trouble." She reported the inequity she felt in trying to maintain some

semblance of order, "I am a very, very neat person and I tried to keep everything neat and

clean, and they were not that way whatsoever." Thus, this was also taxing physically for

her, and for this reason and others, she moved out.

Although day-to-day campus life and roommates required some physical adjustment, Casey reported that the dorms and campus were "pretty much accessible." The central locations of the dorms were convenient in terms of energy expenditure. Currently Casey lived alone in a very neat and tidy second floor apartment a block from the campus. She reported she prefers the "privacy" of living alone.

### *Cross Case Analysis of Campus Physical Engagement*

As illustrated in the individual cases, the most salient themes of campus physical engagement revolved around the disability status. Many of the students were overwhelmed and unprepared to deal with the physical challenges that living away from home with a disability presented. One student reported the engagement difficulties and exhaustion she experienced commuting. This was the same student who didn't plan well for college in high school due to the illness onset.

The students learned to adjust physically to the campus by prioritizing their health. The campuses barriers included inaccessible housing, difficult food service processes, and lack of individual housing assignments for students with health-related disabilities. These barriers affected engagement experiences including mealtime socialization and social experiences with roommates. Over time, many of the students found it was easier if they lived alone, but this was associated with social isolation.

All of the students in this study addressed the issue of the physical adjustment to living on campus. Several had physical accessibility issues on the campus, and their ability to navigate through the campus was especially hard in terms of energy conservation. Many of the students ended up "learning the hard way," and were assigned living arrangements on the campus without consideration for their unique health

164

circumstances. The dorm assignments and choice of living environment was largely out of their hands. Even so, the majority of the students were still happy with the fact that their rooms were centrally located on campus, and given the limitations they seemed to adjust. Three of the students chose to live in non-campus housing because of the accessibility issues with the campus housing, or because of previous negative experiences on campus with roommates. Several students reported non-campus housing was expensive.

Because of the difficulty with campus physical engagement, this seemed to directly impact social engagement. Many did not view their campus living in terms of social engagement, as one would believe; instead, they seemed to view it from an energy standpoint. For most of the students in this study, the roommate experience required them to "learn to find out what worked for them" and stimulated self-regulation. At the same time, the energy expended to adjust to the campus and living arrangements was overwhelmingly difficult.

All but one student reported difficulty with roommates, and as such, most found that living alone ultimately helped them conserve their energy. One student liked the security of living with roommates her freshman year, especially because they were aware of her illness. The students had interactions with roommates that were generally not affirmative in terms of how the interaction affected their physical and mental health. Indeed, one student felt discriminated by a roommate due to her disorder. One student had a positive overall social experience with her roommate, despite the fact that the living arrangement was hard for her.

Many of the students reported social isolation in interactions with roommates due to different value systems, which seemed to revolve around sleep schedules, drinking and partying. As well, several of the students expressed disconnect from the typical college party atmosphere. The students understood that this atmosphere could have detrimental effects on their personal health. The issue of alcohol and partying is explored at length in the category of social engagement in the forthcoming section.

**Institutional Engagement**

In the previous section several campus physical accessibility issues were presented that were related to the policies set forth by the institutions. We were able to see how some of the policies for housing and physical living arrangements affected engagement. The institutional policies on parking, building locations, classroom locations, and dining services had an effect on the students in their daily activities and the physical navigation through campus.

Although intricately related to physical structural issues, institutional engagement in this study examined the policies and processes related to course orientation, registration, testing procedures, grading policies, and add-drop procedures. Institutional engagement activities included contact with university personnel and policies in student services, disability services, and student health services. Institutional engagement covered financial aid factors that contributed to student involvement that included grants, scholarships, tuition-costs, and penalties for early withdrawal. Institutional engagement also looked at the relationships between students and administrative staff. Much of the discussion in this section addresses accommodations.

As we will see, there were a number of institutional barriers encountered by these students with hidden disabilities. A prominent theme looked the perceived lack of understanding of the hidden disability among university administrators and staff. This lack of understanding seemed to promote a one-size-fits-all approach for institutional policies and a philosophy that didn't fit the student with a disability. Many students conformed or adopted an acquiescent attitude to deal with the lack of student centeredness. In other words, they learned to give the institution what it needed so they could succeed, despite the fact that some students didn't agree with the policies or philosophies. Many students learned self-advocacy skills, but as we will see, at times they were selective in whom they self-disclosed their disorder to. Some students reported discrimination, fragmented communication between services, curriculum pressure, financial penalties, and academic penalties that were related to their disabled status.

*Debbie*

Good communication between campus services help all institutions run efficiently and contribute to student engagement, which ultimately affects student satisfaction with the college experience. Understandably, students with hidden disabilities require adequate communication between services to help implement accommodations. Debbie registered with disability services her freshman year. She requested a single room through residence life (RL) but was denied one because "only students in wheelchairs get single rooms." She obtained a centrally located room on campus with air conditioning.

Debbie described the communication with both residential life (RL) and disability services (DS):

167

Communication with RL wasn't problematic; I could just email or call. Although

RL was easy to access, they weren't as easy necessarily to work with. I think

disability offices are required to work with you. But res life doesn't seem to have

as many obligations to work with you if you have a medical condition. They (RL)

didn't seem very willing to work with us. They did so begrudgingly, especially

with a housing crisis on campus. In the ideal situation they would be working

together.

Thus, Debbie was frustrated over the lack of communication between the two

entities.

Debbie reported a positive interpersonal experience with a DS staff member: "The

woman who worked with us gave us very good advice; she said ask for every

accommodation you would need on your very worst day and then you would have it."

Debbie received academic accommodations through DS such as test taking

services, note taking, recording lectures, audiotape, and excused absences without

difficulty. But, paradoxically, she added:

I don't think the disability office understands that all the energy I devote to

getting them to give me what I need is in energy I could be spending so that I

might not necessarily need as many accommodations as I am asking for! It's

really a big catch-22 and I don't know if they consider it or if it ever dawns on

them really.

So despite the fact that the contact was favorable, she reported an overwhelming

amount of energy needed to complete documentation for her disability. Debbie was

surprised that the processes through disability services (DS) required such a large amount

of paperwork. The process seemed unnecessarily cumbersome: "we have to reapply every semester to give paperwork to professors and go in yearly to document." Although she reportedly understood that this policy was important for students with short-term illnesses, she believed it was not a good policy for students with chronic disabilities. She believed that the process was fueled by the lack of understanding of her disorder: "I don't think they understand. But they work with so many people with different kinds of illness." She believed the invisibility of the illness was partially to blame, and she compared herself to others with visible disabilities:

> My roommate was in a wheelchair for a while and one time I took her to the
>
> disability office and they seemed much more willing to work with her. You could
>
> plainly see that you know there is something medically wrong with her. It seemed
>
> a lot easier for her.
>
> The disability service location and policies presented barriers for Debbie:
>
> The disabilities center is up a big hill. Access is down in the basement. Ironically
>
> it is can be kind of hot and stuffy for test taking. It closes at 4pm. In order to
>
> schedule a make-up exam before closing I have to either rush between classes or
>
> schedule before closing which is a burden with day-time classes.

Debbie reported that the student health center was easy to access and had convenient hours. In addition, the process for scheduling clinic visits was easy: "You could fill out forms on-line." However, Debbie said the health care providers at the clinic: "Did not understand the condition at all. I had to explain it to them. I had to tell them if they were going to prescribe any meds or anything what may or may not interact with my condition."

I asked Debbie if the lens for student support service, academic services, and institutional services was broad enough for her as a student with a hidden disability and she replied:

> I think they are designed for cookie cutters and you know you are not going to fit in the cookie cutter all the time. You know; spread out the dough, and you take the cutter and you make a perfect little cookie. We're not perfect little cookies, we may have ragged edges and stuff, but you know, we still taste just as good. I think they are designed for people who will fit into their molds perfectly and anyone who doesn't necessarily fit is going to have to work hard to make sure they get what they need.

Debbie echoed the theme of deficiencies in student centeredness when she discussed the summer orientation process:

> They expect you to do a lot physically over orientation. You have to stay in a hot dorm room, register for classes, meet departmental heads, and take a campus tour. You know they want to show you the entire campus, and you know it is a big campus.

Debbie was familiar with the campus prior to the orientation so skipped the tour of campus. She believed it would be beneficial for others to take a tour of the campus before the orientation or eliminate it all together. Thus, despite the physical challenges to orientation, Debbie said, "I think with the orientation they have that really well." Debbie explained that she took an on-line placement test prior to orientation, and was given the results that day; this allowed her to accomplish her goals at class registration.

Many students, both disabled and non-disabled have experienced difficulties with registration for college classes. Students with health-related disabilities may have frequent absences due to illness and may have difficulty with a full-time schedule. The registration process for Debbie was reportedly marred with poor advising she believed fueled by a lack of understanding of how the disorder affects her academically. Unfortunately, this set the stage for a number of difficulties for Debbie later in the semester that included withdrawal from classes, financial penalties associated with the withdrawals, and struggles with faculty over absences. In essence, Debbie learned the hard way:

> The main problem that I encountered is that they encourage you to register for a large amount of credits. Sixteen credit hours, whew. I knew I couldn't do that. I registered for 12 credits, and had to drop one class to 9 credit hours. I'm in an intense journalism program, with two alternative curriculums. One is the regular track (16 hours), and one is the fast track. The fast track is if you want to kick even more ass! If they would have given me the option of suggested courses for taking a little more time that might have been helpful. I wish I had stuck to my guns.

Thus the academic advisors and even the disabilities office personnel were unprepared to assist Debbie in academic planning, "every time I have gone to them or someone in the college they say, are you sure you don't want to take more credits? Like I am positive I don't want to take more credits!"

Debbie detailed the consequences for students with disabilities that take a reduced academic load:

The condition affects the amount of credits you take. The amount of credits you

take affects your health insurance and it can really affect the scholarships you can

get. They also want you to be involved in things on campus; they want students

who are showing a level of involvement.

You know when you have a medical condition a lot of money is already going to

health care bills, and stuff like that, and the extra time for classes for college tuition. You

know scholarships could really help, but they are really hard to get when you don't

necessarily have the capabilities to be as involved as other students. They expect so

much, and for you to be like a perfect student and you can't do that when you have a

medical condition interfering.

Finally, she echoed her previous analogy of the cookie cutter student, "You have

to have sprinkles and icing and everything…you got to have it all."

*Jessa*

Campus disability services are important resources for students with disabilities.

These services can help students succeed academically by providing necessary

accommodations. As reported, the literature suggests some students with a disability

aren't even aware of this service on campus.

Initially Jessa did not register with disability services, and explained her rationale:

During the time of my difficulties, I could care less if I was withdrawing. I mean,

I was miserable; I really was. You know, medically and then emotionally. It was

awful and I had not the energy, nor the motivation, nor the knowledge of how to

go about proper registering with the DDS (disability student services). I didn't

know who they were--let alone to contact them or even have the energy to bother.

I was giving up. The DDS was not involved. You know, I will just withdrawal and get the pain off. You know, get the relief.

In addition, Jessa related that she didn't approach disability services because she believed hidden disabilities would not be accepted. Jessa told me that she worried about being met with disbelief even to the DDS:

I was actually worried that they wouldn't believe me because I am constantly aware that these symptoms I am experiencing are internal, like losing my sight, or getting dizzy, or sometimes I did pass out but anyone could fake that, I guess. You know, anyone could fall over (laughs).

I thought you really did have to be in a wheelchair, for them to say we will give you accommodations. So I think in a weird way that's what the disability support services, like that's the reputation. I think from a general perspective for a person to have a disability you have to like see it or something.

This "disaster," as Jessa described it, had several unfortunate consequences. She accrued financial penalties from the withdrawal, and was unaware that the withdrawal would affect her grade point average, "I'm talking about applying for veterinary school, and you can't mess around with withdrawals on your report card." Hoping to "W" for medical reasons she says that after she registered the next fall with DDS, she inquired about getting not only her money back but erasing the "Ws" for medical reasons: "They said no…because I was not registered with the DDS at the time."

Once connected with the DDS, Jessa was overwhelmingly pleased and surprised that her worries were unfounded: "When I went there as far as my experiences, it was

actually great. There is this one woman I talked to there and she was just so nice and so understanding. Just very helpful, it was great."

This staff member went out of her way to provide accommodations for Jessa. More importantly, Jessa said she felt validated and believed. Ironically, in the same DDS office, Jessa reported "a bad experience" with a disability staff member that revolved around personal privacy issues:

> I was like in the main office and there are people coming there. It was really small and she was asking me like personal questions. I thought that was inappropriate to be asking me those questions, you know, that we weren't in a room by ourselves.

Jessa told me that the DDS is accessible in terms of hours, communication, and location; "I get emails from them all the time about opportunities, job opportunities for DDS students, internships, I think they have some meetings sometimes on different topics, so, yeah, they're good.

Jessa reported the pressure she felt to succeed in the traditional mindset of academics:

> I mean personally I feel quite discouraged about it quite often. I am always feeling like going to vet school is a far off dream, like why do I even bother? I think they are looking for kids who can do it in four years, I mean I guess four years is normal, but if you take five–like what is wrong with you!

Jessa described another incident where she felt academic pressure from staff. She interviewed for a position that would allow her continue in the language house the next semester. Essentially, Jessa reported that she was questioned about why her total credits didn't match the fact that she had been in school for four semesters:

She (the director) said, 'What took you so long?' I explained to her that I was

part-time for a few semesters. She said, 'Why would you do that?' She was so

critical; I felt like, you know, none of your business. I couldn't believe it, I mean,

she was so shocked. The average language house student is probably on target,

unlike me, but I mean to be so rude about it.

Jessa reported she did not disclose her disability to this individual. She reported

that she was afraid she would be discriminated against, because the disability could have

impacted the decision to allow her into the language program.

*Kimberly*

As reported in this dissertation, self-advocacy is a skill associated with student

with a disability success on campus. Kimberly described a glowing experience with

disability (accessibility) services; "They have been phenomenal." She reportedly worked

hard to register for the services: "I had to fill out these like crazy forms." She rationalized

that this is to "Make sure I was legit, and because it is necessary due to nationwide

problems of students requesting accommodations as a way of cheating." Kimberly was

involved in accessibility services from freshman year. In fact, she was a member of the

accessibility services committee that helped to assist other students with disabilities on

the campus.

Kimberly told me her biggest hurdle was helping others understand her medical

condition, "That I had a relapsing medical condition." Thus, her ability to self-advocate

helped immensely. However, although she was her own advocate, she disclosed her

disability selectively to individuals on campus. She reported that she screened the college

disability application because she believed it could have implications for her academic career:

> I don't pass out anymore. I didn't include that I had seizures or fainting in the past (on my application). Especially with nursing, when I know going to clinical it (fainting) could be a liability. Suddenly you are too much of a liability.

Kimberly received housing and other technical/academic accommodations without difficulty. However, she reported on the communication disconnect between residence life (RL) and disability (accessibility) services, "The accessibility services director alerts housing that there is a disability issue, but housing entirely and independently decides where they can put you." RL also managed the meal plans. Kimberly described a battle over a meal charge of $800 for meals she never ate:

> Because of the pancreatitis and the POTS and I just could not eat a lot of the food. My parents and I met with a nutritionist provided by the college to help. You know, they are use to dealing with people who are vegetarian, or need kosher, allergies, gluten. I guess it's partially our fault because we didn't push for more during the year but I didn't have the energy to fight that when I was trying to do school and then not until the semester was over.

*Shana*

Self-advocacy was important for Shana so she contacted disability services at orientation, "I knew that I would need something like that. I came up the first day and that was my goal to find it up here." She met with disability services personnel, was assigned a counselor during freshman registration, and obtained accommodations and other campus services.

The process of documentation poised some challenges for Shana because was careful about the medical information she shared:

> The disabilities resource center didn't take me initially because I gave them the diagnosis of NCS (neurocardiogenic syncope, a form of orthostatic intolerance). I put down fibromyalgia because the disability brochures from the college indicated that this diagnosis would be covered. So because I have that too, for sure they're going to help me. I am going to give them that on (the application) and then I just put underneath it, NCS.

Shana perceived a lack of understanding of her condition by disability services but shared some of the responsibility; "I haven't taken the time to go explain to them. I'm sure if I went in and said, would you like to know about–I bet they would understand."

A common thread in her interaction with campus services was the lack of understanding of the illness. Evidently the campus health care service was unaware of her syndrome. Shana detailed that she broke her ribs recently due to a fall from fainting (syncope) and went to the student wellness center for treatment. The center was described by Shana as "Very accessible, free, and easy to make an appointment. It didn't cost me anything to just go in and make sure every thing is ok." But access didn't necessarily provide her with confidence in the care she received. Shana explained that the health care provider couldn't answer her questions about medication interactions, "He wasn't able to help with that at all." Shana seemed to accept this, "He just didn't understand."

In the following passage, it is not clear whether Shana is referring to the institutional climate or a specific individual within the university, but here she discusses curriculum pressure:

There's always a pressure to take more classes. Everyone had seven classes. I

want to be with everyone else and plus I am going into a graduate program. It will

take me an extra year and one half at least at the rate I'm going to graduate. I feel

so behind for my age. But no matter what, I am sure the pace I am going I will be

better for it. Even if I am behind, it's better to do it where I'm going to learn, and

not forget it. At least I feel a little healthier.

However, her decision to pace herself academically affected her ability to

participate in the nursing major:

I was going to go into the nursing program until a couple of weeks ago, but

because of the program, they don't let you take a diminished, like, a smaller load.

They make you go at a certain pace and with clinical I was afraid I wouldn't be

able to do clinical so that's what made me switch.

*Casey*

Casey received accommodations through disability services (DS) beginning her

freshman year after orientation and reported a positive experience. She received priority

registration, academic accommodations, and laboratory assistance, and she qualified for a

reduced credit load but was still considered full-time. She applied for accommodations

and did not describe the process as cumbersome or time-consuming.

Unexpected medical problems caused Casey to drop out of a term, and this

affected her scholarship, "Somehow there was some kind of misunderstanding along the

way and you know they started acting really quiet so I said o.k. Forget it. It was kind of a

little hostile for me. I am sure I can still reapply." Unfortunately, she dropped ten credit

hours and even though she was registered with the disability office, she received no

178

academic or financial credit. She reported the decision was made because she withdrew from classes after the college deadline. Casey reported that she had an affluent family, and she didn't have financial worries.

Thus, she said her parents were not affected much by the loss:

To them it (getting a refund) wasn't worth dealing with because we were already having health problems. So my parents, being kind of quiet, did not need to get our money back. I'm so thankful and I'm lucky enough I don't have to worry about money. I mean, if I did, that would be a whole different stress level that I would have a lot of trouble handling. We have good medical insurance because my parents own a company. They spend thousands and thousands on me. No, I mean, we have really, really, good medical insurance and I can't image the average person, you know, not having it or just having the bare minimum.

### *Cross-Case Analysis for Institutional Engagement*

It is apparent from the case descriptions that students with hidden disabilities in this study encountered barriers to institutional engagement. The most salient themes in this area also resonate in the preceding category of physical engagement. Specifically, we have seen that the students believed many individuals and departments within the institution don't fully understand the needs of students with hidden health-related syndromes. Students used selective self- disclosure for several reasons: they feared discrimination and feared that their disorder was not legitimate or believed. Most students were their own self- advocates, which allowed them to engage in the institutional policies and culture. They reported fragmented communication between services, curriculum pressure, and financial penalties and academic penalties from college add-drop policies.

Common to all of the interviews in some aspect of institutional engagement was the perceived lack of understanding of the hidden disability by accessibility services, residence life, academic advising services, and in two cases the student health service. The majority of the students addressed the accommodation documentation issue, and some found it unnecessarily cumbersome. Although opinions differed on the amount of hassle the process created for them, the majority of students suggested that documentation required time, planning, energy, and self-advocacy.

Despite the fact that many of the students perceived that disability services did not understand the hidden disability, the majority of the students reported positive experiences with disability services. Most campus disability offices were accessible and assisted the students with academic accommodations. This helped the students to feel welcomed on campus. Kimberly was so empowered by her experience with the disability office that she joined the accessibility services team to help assist others in disability on campus. The majority of students had positive interpersonal contact with the staff although Jessa experienced a mix of good and bad interactions. Several of the students addressed the invisible nature of the disability in their contact with disability services. Jessa feared that she would not be believed, but this fear was unfounded. Debbie felt as if the office had treated her differently than her friend with a visible disability.

Self-disclosure was related to the perception by the students that others would not understand the disorder. Three of the students gave the disability office documentation that didn't fully disclose their illness because they feared discrimination academically. Indeed, Kimberly carefully disclosed her disorder because she feared it would affect acceptance into the nursing program. Jessa worried she wouldn't be considered for the

180

language house, and Shana changed her primary diagnosis to qualify for disability services.

Another common theme was the perceived lack of communication between campus services, particularly disability services and residence life. Even when students were registered with disability services, Residence Life seemed to have the jurisdiction in room assignments. Policies for meal plans and procedures for food service were problematic for several students. Two students couldn't physically wait in long lines for food, and this affected socialization with other peers. One student didn't use her meal plan when she was ill for most of the semester and didn't receive a break in the cost.

The majority of the students with a disability expressed perceived curriculum pressure by individuals within the institution to take more classes than they could handle academically. The students who did not recognize their academic limits initially (Debbie, Jessa) suffered not only academic penalties but also financial penalties. Several students linked perceived curriculum pressure to the lack of individualized student centeredness. This was also related to lack of understanding of the disorder and student physical health limitations

Financial and academic penalties were also a prevalent theme. An unavoidable part of all of the student experiences was the need to withdrawal from class at one point during college due to medical reasons. Regardless of the fact that students had documented medical disabilities, an institutional policy was a policy. Hence, if the withdrawal occurred past the deadline, none of the students were able to change the adverse outcomes.

Three of the students addressed scholarships. Debbie eloquently described the problem associated with having a medical disability that limited engagement, impacted scholarship opportunities, and ultimately contributed to a greater financial burden on a costly chronic illness. Four out of the five students had to take a reduced course load. This part-time schedule meant longer time until degree completion and greater college costs. This finding is also well supported in the disability literature described earlier.

**Academic Engagement**

The category of academic engagement included interaction with faculty and learning activities such as internships, class projects, clinical rotations, and study abroad opportunities. Further, academic engagement included activities such as participation in classroom learning activities. In this category, the faculty student interaction is examined. Closely aligned with academic engagement was the students perceived feeling of acceptance by the faculty.

*Debbie*

Debbie reported generally favorable interactions with the faculty:

"I have found that most of the faculties are very willing to work with you. There is always going to be one professor, every semester, I have had one professor who says, oh this is just not going to fly (accommodations)."

She characterized the "great" faculties as easy going, and who expressed willingness to understand the need for accommodations without aggravation. Debbie detailed a situation where she had to drop a math class because she struggled conceptually with the topic, and the course was too difficult for her with a heavy course load:

"The professor was really willing to work with me, and she understood why I had

to withdraw. She told me that if I needed any help she still had office tutoring

hours. She said, 'I will still help you.' I could come in and she even offered that I

could come sit in her other classes in the spring semester even if I didn't take the

class. I could come and absorb some of the information. So she was very helpful."

Thus, Debbie felt validated and acceptance in this interaction with the faculty

member. She recalled an interaction with a faculty member that was not positive. Due to

an unexpected illness, Debbie missed a quiz in a class where the professor had a "strict

attendance policy." Despite the fact that Debbie had accommodations in place for

excused absences through disability services, and that both Debbie and disability services

contacted the professor the day of the illness, Debbie had to drop the grade, which

counted as a "zero." She explained:

So the quiz that I didn't even necessarily get to take was considered my lowest

grade that would have to be dropped. It wasn't necessarily fair because these are

very hard quizzes in this class, so I was kind of hoping I could save that for

maybe a quiz that I would do maybe worse on. I figured it was just better to let it

slide and let the grade be dropped and count as a zero or whatever. I figured out

the situation and figured out that wasn't necessarily something I needed to fight

for. So I just let it go.

Interestingly, Debbie reported that she had spoken to this professor at the

beginning of the semester to discuss her accommodations:

Just explaining the accommodations to her was very difficult for her because she

saw to excuse frequent absences and she said, 'Well, you know that this is going

to affect your grade. You need to be in class and you need to know what we are doing.' I said to her, look, this is not because I am lazy, or because I am a bad student. This is something I physically need. Immediately after that she kind of backed off.

Debbie tried to rationalize why the professor may have had trouble, "I think in her mind she thought, oh this is going to be a hassle for me to have to teach this student, or I might have to make a special effort." Debbie continued, "I mean, you don't want to feel like you are a hassle for somebody, and you don't want to feel like you are a burden to them or that you are making their life harder." In the professor's defense Debbie explained, "I don't even think for her it is a disability thing. I think she is just generally difficult. I think that professors that are going to be difficult about understanding a disability have just difficulty understanding anything. I think it is just their personality; they are going to be skeptical. They just assume that you are trying to make life harder for them or that you are just lazy or stupid, or something like that."

In another similar interaction with a faculty member, Debbie explained, "But then I went to the instructor and I was crying and everything and she said that you can make it up today (quiz) and she was really sweet." But the incident was not totally free of consequences; "It was more effort that I had to go through, more stress, on a day that I just did not need it. Stress just makes me more symptomatic." After all is said and done, Debbie believed that when students request accommodations from faculty, the response should be should be straightforward and without incrimination:

It does feel as if some of the professors question certain accommodations. It does feel as if they are maybe questioning you; whether or not you need it, and you

know you need it. You need to sort of defend yourself and say, I need this; this is something that is instrumental to my success in this class.

An important piece of academic engagement that Debbie addressed next is involvement in learning activities. Prioritization of activities based on energy is a common theme that has emerged from this study. Debbie recognized that being a freshman with health-related disability required her to weigh learning experiences with energy:

I am in the Journalism department and they encourage you to become involved in campus publications. That takes a lot of effort. You have to write articles and you have to interview people. I knew coming in my freshman year I wasn't going to come in and, you know, kick butt, and be editor of the paper or something. I was pretty much resigned to that fact, but I think next semester I am going to really try to do something because it is really important for my major.

Debbie believed that learning activities should be designed that consider the needs of students with a disability. She recalled one class project that required her to visit important locations on campus:

They called it a treasure hunt but it was something for me to just exhaust myself over. I had to go to all of these places on campus that I would never visit otherwise. I had to get someone to sign off on the fact that I had been there. I don't think that they took into account that they might have someone with a disability or something.

Debbie lived in a global community, and study abroad activities were encouraged although not required. Her perspective is notable: "I have enough trouble trying to get

health-care in this country. I'm not going to go to another country and mess up what I have. It is not something that I have been interested in."

*Jessa*

Academic engagement barriers were well described by Jessa, who struggled with an exacerbation of illness midway through a semester freshman year. Enrolled in four classes, she had spoken to her professors about her difficulty, "I went to all of my teachers and had a sit-down with them." Preparing for the worst, she tried to explain that she would most likely have to withdraw from two of the four classes.

Jessa tried to get a pulse on the situation. She recounted:

I was basically asking,; is there a chance I can at least get a B in the class? The funny thing is I wasn't actually failing my classes, but I started skipping them because I had no energy. I sat in the back of the class, and the mental fog was too terrible. Just sitting there feeling like a zombie. You know, I can't even comprehend it, and then it makes you think bigger things like, why am I in school? Why am I here? Why am I even in college? You know, you progress to bigger thoughts.

As troubled as she was, she decided to disclose the fact that she was ill to two of the four instructors, and made this decision based on class size. She believed it would be easier to approach the faculty in a smaller setting, "The other two classes were huge, there were like 200+ people." Jessa believed she would be less intimidated to approach the faculty in a smaller class:

I think that living on a small campus, I think the professors are much more willing to work with you. Besides, when you have 200 people or huge classes, they are

not as personable. Not to say that the professors do not understand, but there is no opportunity to talk.

Jessa based her assumption on previous experiences with her father. Jessa's father was a professor at a small university (1,500 students) and she explained, "My dad had all this great personal interaction with the students. I was there on campus a lot and I got to see him with the students all the time. We had teas at our house. It sort of fosters a sense of community." That said, unfortunately, Jessa received vastly different feedback from the two instructors of small classes she approached:

My German class was only 12-15 people; my English class was 30. I told both instructors. The English teacher was actually great. My German teacher had absolutely no sympathy, he said, my dad died my freshman year in college. It was like, whoa, jeeps.

During that same ill-fated semester, Jessa reported the physical difficulty she experienced trying to get to classes on time:

I went in to talk to my teacher, because I needed extra time in-between classes because I couldn't walk fast enough and I couldn't get there. She had a quiz immediately when class started. She had these things called clickers, which would register what you answered. That counted for your grade. I always missed it because I was coming even three minutes late to class and I would miss the quiz question.

Jessa tried to explain the tardiness to the professor:

She was quite bitter about it and she didn't believe me at first. Then she asked me my ID number and looked at my schedule and looked at the building I was

coming from and she said, 'Oh you are not lying.' I was just appalled that she

could…How could she doubt me? She has these huge classes and I guess she just

has to doubt before she believes. I don't know. She was pretty bitter about

working with me. So that is the class I withdrew from, so I didn't have to deal

with her.

Subsequent interactions with the faculty were much more favorable due to the fact

that Jessa had registered for disability services and received accommodations:

It was for more time between classes. I was allowed to come in a little late and I

was allowed to, obviously within reason, skip a class if needed and I didn't have

to give them a head's notice. Because that is the most unfortunate thing with

POTS (orthostatic intolerance) is that you don't know sometimes day-to-day. A

day might be just terrible, and you have to miss. You can't really shoot them an

email like 24 hours ahead of time.

Jessa believed both students and faculties have a role in the accommodation

process: "It is the students' responsibility to go to the professors to get the missed work,

but they (faculties) were in turn responsible, like legally bound to provide the

accommodations."

Reported earlier, Jessa was reluctant to approach disability services about her

hidden disability because she perceived not being believed.

She also reported previous unpleasant interactions with faculty. In addition, she

explained:

I was very nervous to give these accommodation sheets to the professors. You

have to give them the first week of class, and you don't even know them yet! You

haven't set up a rapport. They don't know that I really am a conscientious student, and I am not doing this because I want five extra days on my project. Like it is an excuse, you know, thinking that some students are bucking the DDS; bucking the system! I don't want them thinking that because they didn't know my character yet.

But my professors received it very well… and were very willing to work with me. Even in the science lab classes, which are extremely strict. You cannot miss the lab class. You can't make them up because of the dissections and you can't set up something like that again; experiments. She was willing to work with me so that was good.

Jessa learned a hard lesson: the importance of registration with disability services. This was especially important due to the unpredictable nature of the disorder, and to help cushion the student-faculty interaction. She explained:

Yeah, you don't know how I wished that I had signed up with them in the previous semester. So I really didn't need to use any of the services, but I was really glad to have it in case Mr. POTS decides to attack me one day. In case he decides to come back. I have blackouts and everything, it causes fatigue and bigger problems, but it leaks into life and into academics and you start to feel like you are losing control.

Even though Jessa worried about the fact that the disorder of orthostatic intolerance will strike again, she told me with pride that she will study abroad in Germany this summer and anticipated a good experience.

*Kimberly*

Kimberly reported positive interaction with the faculties, and her accommodations requests were well received, "Most of my professors have gone above and beyond." Kimberly explained she is allowed to tape record lectures, receive extra time for assignments and examinations, and was provided with a quiet area in the classroom for test taking away from auditory distractions, but where other students and proctors can be heard. She noted that the key to successful academic engagement hinged on direct communication with the faculty. Kimberly reported that it was important to talk to faculty about accommodations:

At the beginning of each semester, I meet with each one of my professors. I first talk to them, and because my conditions are all kind of random, things you haven't heard of. I end up typing this and explaining what each of them were and how it would affect me and what they could do, basically how it would impact them.

Kimberly played an important role on the accessibility services committee. She helped bridge the gap between students with disabilities and faculties on her campus. Other faculties had recognized the fact that she was successful in her personal experience with accommodations, and they looked to her for advice. Kimberly acknowledged that both the student and the faculty share responsibility in implementing accommodation requests. In all fairness, Kimberly explained that the faculty should not be given disability forms without an explanation as to why they are necessary:

The students weren't explaining things and so professors were kind of lost. Like literally, they would get: Could you sign this? I need extra time. But the professor has to comply because it's the law and so they have to follow it.

During meetings on the accessibility services committee, Kimberly listened to the faculties explain their previous experiences with accommodation requests for students with disabilities and reported: "They question like why you need this. Not questioning if they are sick or if they have an illness, but to what extent or if there is a special project, how do special accommodations come into play." Kimberly shared another tip to help students with a disability engage with the faculty, "Don't wait until testing time to make accommodations and arrangements."

Kimberly appreciated faculty who made an effort to keep her health-related disability confidential in the classroom; "One in particular was fantastic about keeping confidential about accommodations." Kimberly required extra time for tests, and she said the process didn't protect her confidentiality because the process singled out which students were receiving accommodations. In most instances, Kimberly reported, "You would just be staying later and it was kind of obvious and there were very many remarks made that I shouldn't be getting extra time."

Kimberly fought against the stigmatization that a student with a hidden disability was lazy or faking the disability: "My biggest issue freshman year was actually falling asleep in class because I was still on a lot of meds. So my biggest thing was like I'm not being lazy, I am just legitimately drugged up."

One piece that helped Kimberly engage academically was her major, "Our nursing program is phenomenal." She told me that "non-judgmental" interactions with the nursing professors helped to augment academic engagement. She found acceptance and validation in the nursing program because the faculty "realized and appreciated" that

Kimberly's medical experiences could be used to enhance learning: "My professors very much recognized, like, she really knows something. You might want to study with her."

Indeed, Kimberly reported she was sort of like "a show-and-tell" for her clinical group: "One of my lab instructors was a nurse practitioner. She accessed my port in front of everybody because nobody had seen an IV port before." For Kimberly, the health-related disability positively affected academic engagement; "I can't even put into words how much my illness has helped me in nursing school."

Kimberly experienced a supportive, close relationship with a professor, very much like the one Jessa longed for.

During a semester where she physically struggled, she reported:

I really don't know how I did it. I did have one outstanding professor who I baby sit her kids now, that I think was a huge, huge thing, like we swear we're soul mates…we're suppose to be born in the same generation, it's kind of funny. She was always there and if I had any problems with anything…just listening and that was invaluable.

*Shana*

Effective communication between faculty and college students is an important part of academic engagement. For a student with a hidden disability, the literature reports several challenges to communication. One challenge is that students with hidden disabilities are reluctant to approach the faculty. Faculties report that students with disabilities don't approach them in a timely manner.

Shana illustrates this in a discussion how she approached her professors about accommodations:

192

They (disability services) would give us a form with all the accommodations and

at first I would just bring it in and have it signed by the professor and never

explain anything. But after I started passing out in class I realized I probably

should say something. So now I take it in and try to give them a brief idea of what

may happen.

Shana reported two reasons for her reluctance to approach the faculties. She

believed that large classes are too impersonal for discussion, and she also feared that she

wouldn't be believed. Shana explained:

With certain instructors, I don't talk to them very much. The ones with huge

classes, its not a very personal setting, they're less likely to accommodate. I just

don't like the confrontation about it, I don't want to fight them, and I don't like it

when they think that I am faking it. It is a yucky feeling. You feel like a liar. But

for the most part I have good professors. Unfortunately there were some teachers

who don't see; they never really get it. With them I just avoid the subject

completely and try to do the best I can and try not to push accommodations with

them. So they are less accommodating and I do not want to get on their back side.

Shana experienced very supportive interactions with faculty. Shana described how

her first aid teacher helped her to participate or engage within the classroom setting:

She has been excellent. Every time she asks me to do something, she asks: Are

you able to do this or are you feeling good enough to do this? I think she really

recognizes that there could be a problem and if I say I'm ok, she lets me go. If I

say I'm not, she doesn't push at all. She told the group I'm working with; 'Make

sure you let Shana watch.' She makes sure I am a part of it.

Shana shared tips for other students with disabilities to help with academic

engagement:

Make sure you talk to your professors, and make sure they understand because

they are going to work with you a lot better if they know what's going on. I'd

definitely sit up front because sometimes it's hard to see, and don't be afraid to

ask people if you need help to get somewhere. That's always been scary for me if

I'm going somewhere and I pass out so it's nice to have someone to walk with

like if you're headed to the library. Make sure you touch base with disability

services, and make sure you have everything you need with you (like

medications). Ask for all accommodations you think you may need, even if you

don't anticipate using them–just as an insurance policy. Because if you don't start

out with them, I think it's definitely harder to get them later. Its like, they may

think, why would you need them now when nothing has changed?

Shana described class policies that challenged academic engagement: "My classes

would be at one end of the campus to the other end and I would have a ten-minute break

between so I could never get there on time."

Shana's tardiness was unnoticed in the larger classes, but she had one class where

participation counted until the end of class: "I had to stay to the end. This is your

participation point. You can't leave. You can't make these up. It wasn't a big deal, but it

would have been nice to be allowed more time."

*Casey*

Casey told me that daily symptoms of fatigue, weakness, and concentration

problems affected her academically: "It is quite frustrating because I can write or email

for ten or fifteen minutes, not for hours." She experienced episodes of fainting about once

a month now, which had dramatically improved over the years. Physical and cognitive

limitations dictated her choice of classes:

> Once I get the syllabus and get my first impression of the professor, then I can
>
> make a judgment on whether I can do the class or not. I avoid class assignments
>
> that involve lengthy writing assignments. A twenty page paper, that's just usually
>
> something I'm not up to. I look at attendance policies, late assignment policies,
>
> and then I always meet with the professors too. Individually I still want to talk to
>
> them. It gives me a better idea of how sympathetic they would be. Sometimes I
>
> can barely listen. Sometimes I can continue class, and a lot of times it is so not
>
> worth it for me so I will always be fighting them (professors). Not fighting with
>
> them but, you know, just frustrated if they don't understand.

Casey appreciated faculties who listened and accepted without judgment: "It just

makes me more comfortable when they ask about my medical condition, and it shows

that they're willing to try to understand it." Due to the hidden disability, Casey stated that

it was important to communicate with faculty: "The more open I am about it, the more I

am not going to pretend to have problems when I don't, and I make them (professors) see

that I am a good student."

### *Cross Case Analysis for Academic Engagement*

Students with hidden disabilities fight the stigmatization of an invisible disorder,

namely that the syndrome is not credible. All of the students in this study looked healthy.

Shana was the only one with a visible sign of disability. The most common themes in

academic engagement were associated with this phenomenon. These students expressed a

mix between frustration and hassle tempered with acceptance and belonging in interactions with the faculty. Some students reported they felt like a burden to the faculty, and some fought to dispel the myth that they were lazy, or faking illness. Common to the other categories of engagement, students perceived some faculty members didn't believe them. Self-disclosure and self-advocacy were key skills needed to implement accommodations. Students acknowledged that they shared responsibility with the faculties for the accommodation requests, and it was their responsibility to educate the faculties. Supportive non-judgmental faculties were important for academic engagement in this group of students. A second group of themes revolved around student centered, individualized learning activities.

*Student-Faculty Interactions*

Four out of the five students experienced a mix of both positive and negative student-faculty interactions. One student reported all favorable interactions with her professors. Noteworthy in this assessment is the fact that the student who worked hard to educate her professors (and was also on the accessibility services/disability services committee) reported the most success. Many of the students had positive relationships with the faculties, and described these members as being supportive, non-judgmental, and inclusive. Thus, these positive interactions helped the students to feel validated, accepted, and a sense of belonging in the academic setting. Also of interest is the fact that several of the students were less likely to withdrawal from the class with accepting faculty, or were more likely to choose a class based on this.

Negative interactions with the faculty were closely related to the fact that the students felt as if they were a burden or a hassle to the faculty when they asked for

accommodations. Common in all students was a strong emotional component of dispelling the stigmatization that, because their illness was not so visible, they were "lazy," "faking illness," "stupid," "trying to buck the system," or a "bad student." Four of the students noted that some of the battles with faculty over accommodations were not worth the effort, so they tended to avoid the confrontation associated with this.

All of the students discovered that once they were registered with disability services and were able to fully discuss their needs, the interactions with faculty members were by and large positive. In fact, many of them developed this skill or communication after initial bad experiences with the faculties. One found that her preconceived notion that the professors wouldn't believe her was unfounded.

All of the students noted that it was vital for the faculty to understand their illness, especially the invisible, relapsing nature of the condition because it directly affects their ability to engage in academics. Four of the students believed that they were more likely to disclose their illness in a more intimate class setting. Two of the students found that their condition actually helped them engage in the classroom.

*Learning Activities*

Of final interest in academic engagement were the themes associated with learning activities. Many of the students mentioned academic policies (attendance, tardiness, and assignments) that did not take into account their disability. The students described these policies as unfair, and argued that they were not student centered. Of the two students who had spoken of study abroad experiences, one looked forward to the opportunity, and the other felt worried about healthcare provisions abroad. Generally, all

students agreed that the decision to participate in experiences outside the classroom hinged on their health status at any given time.

### Social Engagement

The category of social engagements encompassed interactions with friends and participation in campus groups such as extracurricular activities, sororities, and other campus groups. Closely related to living arrangements and campus physical engagement described in the previous section, social engagement is less interested in the physical setting. Instead, social engagement looked at the student experience of interpersonal relationships, and how the interaction contributed to or prohibited engagement.

As will be seen in the following cases and discussed in greater detail in the cross-case analysis, several themes coalesced to explain student-peer interactions. The hidden, relapsing nature of the syndrome was not well understood by other peers, and the students perceived that the disorder was not credible or believed by others. This perception also influenced self-disclosure of the illness to peers and the perception of acceptance or rejection by the peer group. Many students felt disconnected from the peer group for this reason. Students also felt disconnect from the peer group because they didn't fit in with the college experience, which revolved around alcohol. The two value systems didn't mesh. This caused several students to find other groups (church) where individuals were more likely to have similar values regarding alcohol.

Another theme was that the syndrome imposed physical limitations that affected student-peer relationships and participation in extracurricular activities. The students developed an awareness of their physical limitations and withdrew from social experiences based on their energy at the time. This is well illustrated in the description of

198

dating. Some students, due to the relapsing nature of the illness went in-and-out of relationships or fluctuated based on symptoms.

*Debbie*

As shown throughout the categories of engagement, Debbie mentioned several times that physical energy conservation is vital to her physical health, as detailed here:

I guess with engagement, you know physically you devote so much of your energy just getting through the day: doing your homework, and going to classes, and everything. It gets very hard to get involved in the campus or anything. I have a lot of difficulty making friends, and I think some of that is me, you know. I am not necessarily the most social person. It has been especially hard for me to connect with other students who have the same priorities as I do. I expected to get on campus and be able to find people who didn't necessarily need to drink or anything and that was very hard. Fortunately, I found friends that are like me. They are fun and quiet and they don't need to do anything like that.

Debbie described her social life as relatively quiet, "I mean obviously I wish I had more friends. I have two friends, but that is all I really need. I mean we go and get dinner and that is basically it." Debbie preferred a low-key social life to help conserve energy for academics.

Debbie described dating relationships:

I'm not really interested at this stage. I don't have the time or the energy. It is just a hassle; it just requires so much time. I think that when you are involved in an actual boyfriend/girlfriend relationship rather than just friends there is more pressure on; you have to be very considerate of them. You have to be more

involved and you know you have to dedicate a lot of time to it. You know we

have to focus our energy on ourselves; and then to have to be concerned for

someone else.

Debbie's involvement with campus activities also hinged on her physical stamina:

I was interested in joining the photography club, but discovered that the club

outings involved a lot of walking in a big city. Walking around trying to make

friends just to take pictures wasn't going to work for me. I wanted to get involved

in the equestrian club, but I mean there is so much physical labor.

Because she loves horses, she reported that the next semester she may try to

"work something out" with the club so that she can participate without the physical

demands.

*Jessa*

Jessa described earlier in this paper her social connection to the other students in

the language house, "It has connected me certainly to people of similar interests. You

know, they like German, they are kind of quirky and they are probably introverts, like I

am, and that is good to start out with." However, she told me that she rarely socialized

with the students in the house, "I haven't done anything I guess socially, yet; I haven't

been involved." She discussed social relationships: "I really don't have any; I don't know

if that will change, it might." Jessa hinted that the social disconnect was related to her

value system, "I guess going off and getting drunk on the weekends is not the best way to

spend my life." Further, when asked about dating, she remarked, "it is just enough to find

friends on campus, just the energy and time."

Jessa reported difficulty finding a good friend that she can share her illness with. Jessa wanted a roommate that, "was around a little bit more," and wasn't "glued to her boyfriend." But more importantly, Jessa longed for a friend on campus who accepted her:

> To occasionally talk to, you know, about any of the frustrations of having this illness. I think because college students are suppose to be so young and so lively and so exuberant, and you know, full of, excuse me for the quote, the best four years of your life. Which is totally not true, but you know, that is where you are suppose to be healthiest. If you tell them you have this depressing thing like, oh, I have this medical condition and it keeps me from doing this or that they will say like, get out of here. I don't want to hear that.

Jessa also addressed the invisible nature of the disorder and the fear that other students may not believe her:

> You are with it. You are doing stuff. You are walking around, you know, what's the problem? You are not in a wheelchair. You don't have a broken arm, you know, you don't look s-i-c-k. Sadly, that's the problem with some of these disorders; you can't see them.

Jessa found social solace in high school friends and family members:

> I am very connected to my high school friends but in a way, maybe it sort of inhibits my ability to connect here. I loved the friends I had (in high school) and I really find it difficult to relate to college kids here. I don't understand the thing with drinking, and their sort of break-rules and be independent, and not call mom or dad for two weeks cuz that's the cool. I don't understand that.

Of the campus extracurricular activities, Jessa enjoyed the University chorale as her strongest campus connection:

When I lived at home there was no engagement on the college campus. To some extent it is that way now still. I am in the chorale, and the language house is sort of a connection; but, outside of that, no sororities, no parties, no clubs.

Although Jessa enjoyed the chorale, she reported she hadn't connected with anyone yet. However, Jessa was excited about the class, "We have four very major works, with full orchestra." Evidently, one of the major performances will span three 12-hour days, and she will travel by bus with the class to the city for five rehearsals. She believed that the opportunity would allow her to bond with others in the group. Looking ahead to the next semester in chorale, Jessa believed, "it will be more cohesive." When I asked her about the rigorous performance schedule, Jessa explained that fortunately her disorder was "quiet" for the time being.

During the semester she had to withdraw due to health reasons, Jessa found an opportunity for social engagement in a church she joined. She related, "They were 18-35ish, and they knew about it (the need for her withdrawal) and they weren't in college." For Jessa, because the church members were not college students, this ironically helped her to feel accepted. Jessa believed that if the tables were turned, she wouldn't have received a warm reception by her college friends. Jessa contended:

Let's say I lived on campus and I withdrew from class. I'm living with roommates full-time and they are wondering like, what? And that's a good question, and judging, and she's just basically in the room all day and not doing anything.

Fortunately, the church group was able to fill a void, "When I had that group, once a week and I tried to do as good as I could and you know they are not in college and not judgmental that way and are obviously very accepting. That was great."

*Kimberly*

When Kimberly got to campus her freshman year, she yearned for a true "college experience." Kimberly reported, "Forty per cent of students at my university are in sororities and fraternities, so I decided to rush." Kimberly recalled, "They impressed so much, get involved, get involved, so I did rush, obviously not very well." Unfortunately, her desire to become a member of a sorority took a huge toll on her physically:

> I was so sick my freshman year because it was about a hundred and seven degrees. You are outside, standing up, walking around all these different houses and looking back it was the stupidest thing I could have done. I had a shunt put in two weeks before that so basically had a quarter of my head shaved and it was a disaster. I realized that it's basically glorified parities.
>
> Kimberly told me the experience taught her a hard lesson:
>
> Sororities were not for me, especially because it was going to take away from academics. But just getting over to the Greek section, which is where all the houses are, is like crazy walking. Going over there, and having to dress up, and all these crazy rules and so I thankfully got out of that early but it did set me back dramatically. It's like the week before school starts; you're exhausted to even begin with, and with these roomy problems. It was horrible. I ended up in the hospital for a week, like the third week of school.

Kimberly said it was a struggle to find a group of friends that were likeminded, or who didn't, "want to go out and get drunk every Thursday, Friday, and Saturday night." She eventually found her closest group of friends in the nursing program, "I have a great group of friends now. We aren't into partying and stuff like that."

As described earlier in the section on campus physical engagement, Kimberly decided to live on her own, away from the "college experience" and dormitory life. Three previous roommate catastrophes left her battered: "I was really scarred by these first three people who I thought were really my friends and then totally turn their back on me so I kind of had like trust issues, very much had trust issues."

Contributing to the lack of trust in friends was the hurt she endured because she didn't feel believed and was judged harshly by other students. Kimberly reported that while she was in the hospital, she heard that, "I wasn't legitimately sick, which is hilarious to me."

She told me of other rumors floating around regarding her illness:

That I milked my illness. That was the biggest one that really hurt. I guess. I milked my illness because I wanted extra time (accommodation), that's what people said. I was like, why do they do that? They were saying that I was getting higher grades and that if they had extra time they could get higher grades too. It was horrible; it hurt me the most because I still say I don't want special treatment for being sick. But like, where is the line that you draw between special treatment and adaptation for illness? A lot of people just don't understand that, they haven't been there.

After she retreated from campus living she reported, "Moving out here was a little isolating living by yourself, but it's kind of fun because you can invite people over here and they can get away from their other stuff so actually it works out really well." One of her favorite pastimes is "Sitting around watching Grey's Anatomy" with her understanding nursing school friends. She feels accepted and trusts her best friend: "My best friend is in clinical with me and she knows everything (about illness) and she knows if something were to happen to me she would know what is going on." Thus, after a rocky start, Kimberly found fulfilling social relationships on campus.

Relationships with the opposite sex have not been a focus for Kimberly primarily because of time commitments and availability, "we have two guys in our nursing classes so all of your classes are nursing, and I am just not around at other places to meet guys." However, this isn't something that Kimberly is worried about, "I'm going to (date) eventually, but I can't even imagine having to work on a relationship at this point. There is enough going on as it is and it sounds very selfish, it was very hard for me to get to a point where I had to focus on me more than other people."

Kimberly discussed joining other clubs, and the difficulties she experienced:

Student governments, clubs, and stuff like that – but oh my goodness. Meetings–

having to get to a meeting after I get back from class. I'm like, I'm not going. I'm

not doing this. So if you don't really get involved as a freshman, you can't do that

much from then on because everybody gets their group and stuff like that. But to

do that would take so much energy and so much effort and not only to get to the

meetings, but obviously what the meetings are for because it's a big thing on

every resume.

*Shana*

Shana reported difficult interactions with friends and roommates who were not empathetic:

They see me walking around my apartment or I'll walk up and down to the mailbox without any difficulty and they'll be like, well why does she need a walker at school? So she must be faking at school to get attention because she can walk. I've seen it. They never say it directly but they'll kind of insinuate. Like, I'll get in the car and say I feel good today, let's not bring the walker and they'll say: what makes today any different, why can you walk now?

Shana found a social connection to peers in her church. Conveniently located right next door to campus, she stated, "We do a ton of stuff, I take classes, almost everyone here takes institute classes so I can go there because it is very low key and kind of like a family." Shana liked the group of students affiliated with the church because they make participation manageable for her, "they try to make it accommodating for me so instead of walking door to door to do ten food drives we'll do something else, like maybe we'll sit and type orders." She also liked that she feels taken care of, "I mean they assign girls to come visit me to make sure I'm doing well each month. We have boys who will come to our house to make sure we are doing well to see if we need anything, so its a lot of people who watch out for each other."

*Casey*

Casey described herself as extremely "social" so seeking out friends was not problematic. The freshman year she met people at the recreation center and in the dormitory. She told me she had several understanding friends:

206

"If I were having a hard time, I could always talk to them." She credited much of her success with friends on campus similar to successful interaction with faculties and staff, "I have always been very open with my illness. I think it is very important to be so open because obviously you need to go out and be social, and (have) all that you would call a normal college life."

Self-disclosure was important to Casey, although it didn't always equate to understanding:

There are definitely times when I can get very frustrated like with my friend. I have headaches, or just plain don't feel good; you know they really don't understand how bad it is. You know, they figure take a Tylenol, lay down, you'll be fine. Some people thought I was making it worse that it really was, like being tired and not getting up and not wanting to really do anything. There are definitely a few people that I know that still don't quite get it.

Casey believed the invisibility of the symptoms contribute to the lack of understanding. However, she indicated that the visible act of fainting is usually seen as legitimate. Casey told her classmates about the condition to help her if she faints: "I usually make friends pretty fast anyways so in a few classes, its not that I ever get embarrassed. I get a few looks.

Casey had a number of non-empathetic roommates; thus, she decided to move out of the dorms. She moved in an apartment with her sister, "but she was much older" so that posed some challenges. Casey's sister was in college when Casey was in high school, and now that they were reunited, Casey reported that she enjoyed having her sister "just to hang around with." Casey explained that her illness had an impact on her sister, "It

basically kind of opened her eyes a little bit." Yet for Casey, the reunion with her older sister was somewhat difficult, "I saw everything that she went through and I couldn't do some things…and it is difficult having an older sister."

Casey liked to participate in campus activities, "I am very into sports so I go to football games. I do go." However, she noted that she paid for a good time, "How I feel afterwards is a different story." Casey's physical demands from the disorder are well illustrated in the "stones" analogy that she found on a website called, "But You Don't Look Sick." Casey shared this story with me:

When I first become friends with someone I try to describe what I go through. I tell friends that my total daily energy level is like a whole bunch of stones. This is kind of like the energy you have throughout the day. Something tangible. For each little thing you do, you take away stones. You just don't get out of bed. You know, you haven't slept, you only slept three hours the night before (from illness), you are so tired and you don't want to get up but you have to and you have to make yourself breakfast. I mean these little things really make a lot of difference. Some days I have no stones to give away. There are times when you really want to do something…you're going to have to sacrifice a certain amount of energy.

For the most part, Casey normally discusses her disorder with friends. Casey described "Good time friends; I may hang out with". These friends don't know about her illness. Casey admitted, "I have acted out, you know at a fraternity, or at someone's house."

Regrettably, Casey has learned from experience to discuss health issues with friends and to avoid situations where her well-being is compromised. She stated, "It can

be a very, very scary situation to be in sometimes." Casey told me of an incident where she went with college friends to a Dave Matthews concert who, "Were all drinking and they were doing drugs." Casey became ill (she was not drinking or doing drugs) at the concert and couldn't count on her friends to assist her back to the campground. Unfortunately, Casey decided to go back alone in the dark. She trudged along, extremely ill and was terrified when she realized she didn't have her cell phone or ID. She recounted, "It's kind of my fault because I didn't exactly let them know that I needed someone. I ended up having to go lay down by myself and I'm aware the whole time. I passed out, but I can hear everything so I know what's going on around me. I can hear everyone passing by me making comments like, 'Oh, she's had too much to drink.' Making horrible comments and you know I am just laying there and can't do anything because I look like I am completely passed out."

A security guard was no help, because he thought Casey "was drunk." Even one of her friends walked by and made a comment not knowing it was Casey. After what seemed like a lifetime for Casey, a bystander finally took her to the hospital. She recalled, "I ended up spending the night in the hospital. My friends didn't even notice I was gone until the next morning." Casey learned a hard lesson that night: "I was very frustrated, disappointed more than anything. My really good friend didn't even think to come once they got back from the concert to even come check on me." In retrospect she said, "One of the things you learn; who you can count on, and who you can't."

Thus, Casey had problems with college friends who "don't know how to have fun without drinking." In fact, she added:

I mean every person I know drinks. That's why I am particularly careful in every

situation when I'm out with people. I try to have someone with me that is sober. I

have to make sure that I feel good enough where I know I will be ok and not to

put myself in situations that will trigger me passing out. I have to learn what

environment I can be in and what I can't.

Casey told me she had no trouble with relationships involving the opposite sex, "I

have a lot more male friends than female friends." As well, Casey had a boyfriend who

lives in her hometown. Casey said this pattern of male friendship started back in middle

school, when she fainted frequently. Evidently many of her girlfriends and classmates

tried to mimic her fainting, and Casey said this caused all kinds of trouble.

### *Cross-Case Analysis for Social Engagement*

Social engagement involves relationships with friends, roommates, peers, and

other group members. It includes participation in co-curricular activities such as clubs,

sororities, fraternities, committees, and recreational activities (Kuh, et al., 2006). It also

involves self-perception of others and others' perception of self that leads to the ability to

interact with others.

The salient themes in this category formed two challenging cycles that influenced

social engagement. The first experience involved the primary theme of the invisibility of

the disorder. Interwoven here were themes of relapsing nature of the disorder, perception

of judgment/fear of rejection, faking illness/ "milking" illness, disconnecting from peers,

and finding acceptance and belongingness. The second experience included themes that

originated from the physical demands of the disorder. Themes in this area included

physical function day-to-day/balancing engagement with effort, learning

limitations/learning lessons, learning self-regulation, evaluating/clarifying values, and disconnection from the "typical college experience." The following section discusses the two cycles of social engagement experiences in greater detail.

As noted, orthostatic intolerance syndromes are not well understood, even in the medical community. Symptoms are invisible, yet can be incapacitating and intermittent in presentation. All of the students perceived that their peers believed they faked their illness, pretended, or exaggerated the symptoms. Four of the five students reported that they perceived their peers as too judgmental, and thus acted on their perceptions of judgment and withdrew from the relationships. The students acknowledged that the relapsing nature of the disorder (one minute you're fine, and the next your not) and the invisibility of the disorder (but you don't look sick) probably contributed to the lack of understanding. Yet even in two students who at times had visible signs of illness (Kimberly with shaved head and IV port and Shana with walker and wheelchair), the students' still perceived that their peers questioned the disorder. Indeed, one student harshly accused Kimberly of "milking" her illness for academic gain. The perception of doubt about the disorder influenced engagement interactions. Some of the students limited engagement. Students were more likely to feel disconnected from peers when not believed. At times, this influenced subsequent self-disclosure to friends, and the ability to form relationships. The majority of students in this study ultimately found college friends who were supportive and provided a sense of belonging. Yet the road to finding friends was rocky.

Analysis of the engagement categories revealed that physical stamina is intricately linked to participation in these students. The incredible physical limitations directly

affected the students' ability to join clubs, participate in extra-curricular activities, and interact with friends. As a consequence, the students had to learn to balance everyday activities with engagement activities. This self-regulation is demonstrated throughout the cases. Analysis also discovered that students tended to display a social engagement pattern that was sporadic in nature. The students intermittently joined and dropped out of groups and relationships based on symptoms.

On-campus groups and activities such as the photography club, sororities, equestrian club, chorale, sporting events, recreation center, and the Language House connection were mentioned as sources of social engagement. One student (Jessa) participated in two clubs (Language House and University Chorale). Of interest is the fact that Jessa reported no social connection with specific group members in the language house, but saw promise in the Chorale because she enjoyed music. Another student mentioned perhaps joining the photography and equestrian club, but did not end up participating due to limited energy. Two students attended sporting events on an occasion, and one student tried to attend regularly. Casey attended the recreation center regularly, depending on her health status.

Three students cited lack of time and energy to devote to romantic relationships. Two students mentioned the need to "take care of themselves" first and foremost. One student had a boyfriend, and the relationship was perceived as manageable due to the fact that he lived off campus, almost 45 minutes away in her hometown. She reported that this was an ideal relationship because she had her own time and independence.

Indirectly, the deleterious effects of alcohol and lack of sleep on student physical health status resulted in disconnect from the typical college scene or lack of connection to

peers who were involved in drinking alcohol and "partying." All of the students

mentioned that they had difficulty understanding or connecting with other students who

made this their priority. In fact, one student (Casey) painfully found that when she

surrounded herself with peers who partied, the result was frightening and potentially

dangerous. Two of the students initially sought experiences in Greek life, yet because of

physical limitations and the association with alcohol, this group had lost its appeal.

Several students (Jessa and Shana) reported a positive experience with religious

groups. Both perceived a feeling of acceptance and non-judgment within this setting.

Indeed, one student (Shana) felt safe when students from the church came to check on her

at home. In addition, she experienced a sense of inclusion when activities were tailored to

help her engage in this environment. These groups seemed to have salutary affect on

engagement because the values were more congruent with the students.

In summary, all students in this study described barriers to social engagement.

The limited understanding of the disorder resulted in disbelief it existed. The students

perceived that their peers not only didn't understand the syndrome but also question the

legitimacy of the disorder. Student perceived peers as judgmental. These perceptions

influence their interactions, and in some instances student withdrew from social

interaction because of this. Commonly, the students engaged intermittently with peers,

dropping in-and-out of relationships. Several found friends that they perceived as

supportive and accepting. Diminished energy created barriers to social engagement.

Indeed, for these students, their "stones" are quickly depleted, leaving few left for social

engagement. Students learned to balance their campus social activities, dating

relationships and friends with their health. Students limited social interactions with

students who drank alcohol and partied, primarily because these behaviors were not congruent with their values.

### Self-Disclosure and Self-Advocacy

Self-disclosure and self-advocacy are behaviors that are combined together in one category because self-disclosure is a prerequisite behavior to self-disclosure. In this study, self-disclosure refers to the process where the student with a disability formally or informally self-identifies that they have a disability (Kravets, 1994). Self-disclosure behaviors can help students with disabilities succeed on campus, because they promote self-advocacy. Many students use these behaviors to obtain accommodations for academic and physical limitations. Self- advocacy refers the behaviors of students that are self-directed. These behaviors include acceptance of responsibility for oneself to formulate and execute plan to achieve goals (Field, Sarver & Shaw, 2003). Student with a disability success in college has also been linked to self-advocacy.

Both self-advocacy and self-disclosure are behaviors used by students to request accommodations through disability services. In addition, these behaviors are seen in student-faculty interactions, student-staff interactions, and student-peer interactions. Previously, for each category of campus physical engagement, institutional engagement, academic engagement, and social engagement these behaviors were loosely identified in each case. In this section however, the behaviors are grouped together to gain a greater appreciation of the importance they play in engagement across all categories.

*Debbie*

In terms of institutional engagement, Debbie reported that she disclosed her illness early on as a freshman. She contacted residence life and disability services with the help of her mother. Debbie explained,

> They don't seem to really like it when your mom helps you, which can be really hard sometimes as a student. You are so busy concentrating on your studies and everything and finding the time to run and jump through the hoops that they want you to jump through. So my mom tried to help me with all of that but mostly I tried to communicate with them.

Debbie reported that her request for accommodations was initially done jointly with her mother, and then she initiated subsequent contact. Debbie told me she had learned how to self advocate for accommodations: "I think you have to learn what they want from you. I don't necessarily think it is a skill. I think it is learning what they need and what they want." She reported trying to get a "jump" on accommodations early for the next academic year, and was told to "contact them later." As a result, Debbie noted, "So you have to stick to their schedule and you have to go with what they need, and I think it is just learning the disability office and the kind of paperwork they need." Although her mother was initially helpful, Debbie believed that the disability office wanted "to instill in you to advocate for yourself." She stated, "I know my mom wants to help. I always tell her no; I need to do it."

Debbie had somewhat of a different experience with self-disclosure and self-advocacy in academic engagement. She endorsed self-disclosure, and advocacy in interactions with the faculty: "I always try to make sure they are aware." Debbie believed

that faculty who understand her world added to academic engagement. She believed that communication with faculty should be implemented more efficiently. Normally, students receive forms from disability services, and the student contacts the faculty to meet and discuss the disability accommodations. This process, as described earlier in the paper by several students, requires extra time and energy trying to set up appointments. Often, it is difficult to "pin down" schedules of both student and faculty during the first week of class. Debbie believed that an alternative may be more suitable: "I think maybe it would be easier if they just designate a time during the first week of their classes that people with accommodations could come to them and have a discussion."

When I asked Debbie if she expected anyone to be more of an advocate for her on campus she noted:

Not necessarily for them to be an advocate for me, but just to be more supportive of me being my own advocate. I understand they want people with disabilities to advocate for ourselves and they don't want to do it all for us. It's just the amount of resistance I have encountered in certain areas, especially like over seemingly trivial things…you would think they would be a little bit more supportive.

When I asked Debbie what helped her most to participate on campus, her answer spoke to the ability to advocate for oneself. Debbie responded:

I think for the most part it is on you. If there is anyone that is going to help you it is going to be you. I mean the campus does set up a lot of opportunities for you to be involved, I guess you just have to find out what works for you.

Self-disclosure and self-advocacy were beneficial behaviors for Debbie on campus. She used these behaviors to help receive accommodations from disability services and implement these with faculty to increase academic success.

*Jessa*

Debbie focused on self-disclosure and self-advocacy behaviors in institutional engagement and carried this to academics. Unlike Debbie, Jessa focused these behaviors at first on academic engagement. But the academic engagement was not well planned, and only occurred because she was in crisis. Unfortunately, this sequence caused difficulty for her. She ran into difficulty when she did not self-disclose her disorder to disability services. Thus, her first semester was marred with academic and financial penalties after unplanned withdrawal from classes. When I asked Jessa why she didn't self-disclose and contact disability services, she explained, "Unfortunately my family has been like, anything that happens in the family stays in the family… not that there is anything bad going on." She agreed that this is likely because her family doesn't want to burden other people. Jessa explained,

> You don't bother people with that, its like medical things are private, and no one needs to know about that… any prescription medication is supposed to be hidden. It was never anything that they were trying to hide. It is just extremely private.

Jessa believed this value system prevented her from disclosing the disorder. She explained,

> You know, no one knew I had it…this hidden disability, people don't tend to disclose it, and I never did. No one in my apartment knows, my dorm, my suite

217

mates, no one knows…so I mean unfortunately in my family; we kept it hidden somewhat.

A very private family discouraged disclosure, and Jessa made it clear that the nature of the disorder (relapsing, invisible) also contributed to her choice:

It's hard to think about disclosing to a friend or teacher because there are times that I am good and sometimes I am not. I don't want them doubting me if they see me fine on a good day and they say, 'I don't see anything wrong.'

Blackouts…you can't see them, only I can experience them, and people are not going to believe me…they would probably think that I am making it up

For Jessa, non-acceptance, which stemmed from fear of rejection, was a contributing factor for non-disclosure. The above passage looked at academic engagement, but as shown, self-disclosure significantly overlaps with social engagement. Jessa felt uncomfortable with self-disclosure on a personal level, and this is an important skill need for institutional, academic, and social engagement.

Self-disclosure is usually necessary for advocacy, and was demonstrated when Jessa and her mother designed a plan for the sophomore year. After a disastrous experience freshmen year, Jessa contacted disability services. Hesitant to contact disability services because of fear that she wouldn't be believed, Jessa approached the office and disclosed the disability. Although she experienced some unpleasant interactions with disability staff (described earlier in this paper), she was overjoyed that she felt believed by disability services. Jessa learned that for her, it was best to disclose and be her own advocate.

As far as faculty interactions, once she had disclosed the disorder to disability services, Jessa approached her professors for accommodations, but didn't feel engaged or connected. I asked Jessa if she ever approached the faculty to discuss issues. Her answer suggested that faculty members are somewhat unapproachable:

> That's hard, I think, because that's sort of awkward, they are sort of your elder, but they are sort of in a situation like professor to student. I don't think it is very encouraged to go to your professor with anything.

The previous examples illuminate the important role that self-advocacy and self-disclosure behaviors play in institutional and academic engagement. Social engagement was more difficult, because Jessa received mixed results when she told friends about her disorder. Earlier in the paper, Jessa disclosed the disorder to her roommate that "is actually a friend from high school." Thinking disclosure was a "safe bet" in this situation, Jessa was somewhat discouraged with the results,

> I did mention it to her…she was talking about how she was struggling too with some medical issues and I told her how I could really relate. She didn't really take it, I wouldn't say that she didn't take it well or anything, but I don't think she wanted to hear about it.

Jessa hadn't discussed her disorder with other peers, which she said was somewhat isolating for her.

*Kimberly*

Kimberly's experience with self-advocacy was in contrast to Jessa's experience. Kimberly embraced self-advocacy as a freshman and benefited from this, especially in terms of institutional and academic engagement. Kimberly had no difficulty advocating

for herself, especially during poor health the freshmen year. She contacted academic services (disability services) about accommodations. When I asked Kimberly about her ability to advocate for herself on the college campus, she replied, "I was determined to, basically, do it." Her involvement on the Accessibility Services Committee was to help bridge the gap between students, faculties, and college administrators. She explained, "I'm actually on this committee for making it so students with a disability have a better college experience." The committee saw her self-advocacy and remarked, "You've shown us you're going out of your way to make it work."

Kimberly chose to disclose the illness/disorder early on because she was very sick. Self-advocacy for Kimberly took much preparation, and she spent a summer to prepare her case "because I knew it would be difficult to explain." As she progressed in health, she made sure that the accommodations reflected her current state of health. This was especially important in nursing, because certain diagnoses like seizures and syncope (fainting) are considered a "liability." In current relationships with nursing faculty, Kimberly didn't disclose with all members. She explained, "I really do my best not to– not that I don't want to tell them I'm sick, but my theory is if it is not going to affect my performance, there is not much of a reason to let them know."

The semester I saw Kimberly, she told me about her clinical faculty experience with self-disclosure,

> I actually told her, I did my little spiel, you know I had some illness and I have a shunt and I have a port, but it shouldn't cause any problems and I will let you know if I need anything because I was truly afraid that if anything happened in

clinical, they would be like, you're a liability we cant handle this, but thankfully that has not been a problem.

Kimberly suggested that she withholds information from faculty because she wants to be seen "as normal as possible." Kimberly described a recent example: "I had mentioned to one of the professors that you were coming tomorrow, and she's like, you're sick? I would have never known, and I'm like, this is the biggest compliment to me to know that somebody doesn't see that I'm sick, that's huge to me."

Kimberly used self-disclosure carefully with faculties and friends. As discussed earlier in the paper, peer self-disclosure ended up somewhat disastrous, because at least three of her roommates ultimately had trouble accepting her illness. Eventually, she found friends in the nursing program that she could trust and disclose, "My best friend is in clinic with me, and she knows everything if something were to happen she would know what was going on." Kimberly was perhaps the shining star for self-advocacy, and even though she was selective in self-disclosure, she demonstrated that even when the self-disclosure experiences were difficult, she was successful in engagement at all levels.

*Shana*

Similar to Debbie and Kimberly, Shana contacted disability services her freshman year, "I found them, then they assigned me to a counselor that day." Evidently, she met with a counselor every semester to request accommodations. Shana's approach to disclosure with the faculty hinged on her perception of acceptance (see academic engagement). She found that disclosure helped, but she still had some difficulty with implementation of accommodations. Shana worried the most about the cadaver lab. She explained:

It was standing for two hours if you really wanted to see everything, so that's hard. I try not to take my wheelchair into that room because it is too hard and I can't get past anyone to see anything anyway in my walker and I can't see up over the tables to see the bodies so I try to take my walker…and I don't want them to think that I'm passing out because I'm grossed out by the bodies.

When I asked her about explaining the situation to her instructor she noted, "I kind of talked to him about that. I talked to people who run the cadaver lab a little bit only because I passed out and they made it into a big deal, so we sat down and discussed it and I tried to explain what happened." She tried to speak to the instructor and lab staff about possible accommodations, but even Shana realized that putting bodies on the floor, "which they have done before for other people in wheelchairs" was not acceptable. She finished, "It seems like a lot of work and kind of gross." Shana realized that accommodation compliance is not always easy.

In this section, Shana discussed academic and institutional engagement, which could have been easier due the visible nature of the disability. In general, self-disclosure helped Shana advocate for herself. She took an active role in decision-making on how best to structure her learning experiences. Shana was able to brain storm with lab instructors about the problem of having cadavers on the floor. She decided to find another alternative to help her engage academically in the cadaver lab.

*Casey*

As seen, the majority of the students except Jessa used institutional self-disclosure and self-advocacy. Casey also met with disability services freshmen year to disclose the disorder and register for accommodations. She was her own self-advocate, which was not

222

too difficult for her because she had lived with her disorder for so long. Casey said, "I met with the disabilities office during freshman orientation. It was exactly what I needed to look forward. Just to visit with someone to see how much trouble I would be having. They are all wonderful people."

Thus Casey found that when she took control, most of the accommodation issues were undisputable. Having accommodations in place was a comforting feeling because if she needed to use the accommodations, they were available. Casey exhibited the self-advocacy and self-disclosure that led to successful accommodations, and she used these behaviors for social engagement.

Casey told me she spoke to her roommates about her disorder freshman year, "I told them a little more so I felt more comfortable." As discussed earlier in the paper by Casey, she has been extremely open with her illness, "I think I am able to explain enough for them to mostly understand." Casey learned that even friends who know about your illness aren't necessarily empathetic or accepting.

### *Cross-Case Analysis for Self-Disclosure and Self-Advocacy*

This section highlighted the constructs of self-disclosure and self-advocacy and how they contributed to engagement. By and large, the behaviors were fused, but self-disclosure was the catalyst for advocacy especially in terms of contact with institutional engagement. Jessa was the case that best exemplified how institutional non-disclosure was detrimental. This finding is noted in the literature (Field, Sarver & Shaw, 2003). Common themes in this category were grouped into a) behavior development /cumulative experiences, b) fear disclosure/ selective disclosure/ full disclosure and c) the need to educate others about the disorder.

A common theme centered on the development of the behaviors in the students, and this was dependent on a variety of past experience associated with trial and error. Skill development was associated with the fact that the students lived independently for the first time in their lives, and they learned how best to manage their life in college. Interesting is that Jessa lived at home her first year, and she didn't use these behaviors. The following year she was on campus and had to take control of her own life, or advocate for herself.

Self-disclosure and self-advocacy required an accumulation of experiences that shaped future experiences. Jessa's case best illustrates the maturational process of learning to self-advocate and self-disclose. Jessa still struggles with peer self-disclosure on campus, perhaps due to her family values. Jessa seemed to exhibit internalized anxiety and lack of self-acceptance that prohibited disclosure and social connections.

All students were somewhat selective in whom they told on the college campus, but all agreed that full disclosure was necessary for institutional engagement with disability services. All but one student contacted disability services freshman year, but this student did her sophomore year. Thus, the majority of students agreed that this contact was important for them to their academic success. One student mentioned that campus disability services (accessibility services) promoted student self-advocacy and downplayed parental involvement. Self-advocacy was an important piece for all of these students, because the process of applying for and implementing accommodations caused undue stress.

Self-advocacy and self-disclosure were skills important for academic engagement, because most students agreed that it was important discuss their disability with faculty to

224

receive accommodations. Although all students reported that they approached faculty for accommodation requests, they had some difficulty at one point or another. The difficulty usually centered on the perception of not being believed or being labeled a fraud. Several students were careful not to fully disclose to all members of faculty for fear of discrimination.

Social engagement appeared to be the most tenuous category for self-disclosure. Almost all students except one decided to disclose to peers, but this disclosure was not always easy. Indeed, these students described lack of empathetic friends and feeling disbelieved. The students based self-disclosure on previous experiences. Some students withdrew socially when previous self-disclosure experience was negative. In general, the students who selectively disclosed and fully disclosed demonstrated resiliency in social interactions.

An important piece of self-disclosure and self-advocacy in all categories of engagement was that the students felt it was necessary to educate others about the disorder. All told me they provided limited information about the disorder to others "so not to overwhelm them." They indicated at one point that the invisible complexity of the disorder limited understanding.

**Identity**

Your journey has molded you for your greater good, and it was exactly what it needed to be. Don't think that you lost time. It took each and every situation you have encountered to bring you to the now. And now is right on time. (Tyson, 1998)

The identity discussion in this section provides a limited amount of narrative support from each student that helps to influence their identity or self-understanding as a

college student with an acquired or hidden disability. As shown in the section on self-disclosure and self-advocacy, we will see that identity development was an evolving process that was influenced by the disability. In addition, this process is loosely associated with constructs from both Erikson's identity theory (1959; 1980) and Chickering and Reisser's (1993) College Student Identity theory. The constructs include gaining independence from the family unit and developing autonomy in decision making, achieving a balance between relationships and activities, developing competence, developing social and peer relationships, finding one's voice or vocation and developing purpose, refining beliefs, and making commitments and social responsibility that develop integrity (Chickering & Reisser 1993; Erikson 1959; 1980).

In this section, the cases are also loosely characterized by the disability identity stances described by Kinavey (2006). Kinavey's narrative study of late stage adolescents (18-24 years) with spina bifida identified three ways in which the participants claimed disability, namely integrating disability, objectifying disability, and overcoming disability.

*Debbie*

Debbie told me that her quality of life is, "pretty good, you know I am just so happy to be here (college) anyway." She reported that it is a big milestone just to have participated in college: "It is just exciting to be around people and everything." Debbie dealt with the disability for almost 10 years. She appeared to have developed self-acceptance with the disorder, but she admitted the college atmosphere has been stressful. Throughout the interviews, Debbie described adjusting to college remarkably well. She conformed to the "cookie cutter mold," and learned how to respond to the institutional

policies in a manner that worked best to help her succeed. Several times she mentioned that although she didn't always agree with policies and procedure, sometimes it was best to "give them what they want." Debbie recognized the difficulties that the campus poses for students like her, and she works to fight the stigmatization that accompanies it.

Debbie was able to gain independence from the family and developed autonomy on campus. She repeatedly reported the balance she had to achieve between activities, relationships, and physical limitations. She developed competence academically and moved in and out of developing social and peer relationships. She developed a voice and purpose by helping others on campus understand the hidden disability. She defined her values and beliefs about alcohol and friendships.

Debbie exemplified the disability stance named integrating disability (Kinavey, 2006). This stance required the individual to integrate the disability into a sense of self. In addition, "they consciously acknowledge the stigma surrounding disability while actively working toward self-acceptance" (p.1101). Debbie exhibits a self-understanding, and uses this to help mold her college experience as she fights some of the inequities she discovers along the way.

*Jessa*

As discussed in the section on self-advocacy and self-disclosure, Jessa took time to gain independence from the family, and this affected autonomy and self-determination. Her decision-making skills were less developed than Debbie and the other students. For instance, she wavered on her decision to stay on campus next year. Perception of academic competence was also somewhat lower; she mentioned how she felt so behind and would never make it to vet school. Social relationships and engagement were not

well developed. Finding her voice was difficult and influenced by the disability. She developed and refined her beliefs and values regarding alcohol and parties, and she redefined the family values of privacy and non-disclosure because these long held values inhibited engagement.

Jessa's disorder surfaced late junior and senior years in high school. Family, friends, and an internal conflict with the relapsing, invisible nature of the disorder influenced her identity. A common theme of the interviews focused on feeling unaccepted, or not believed by peers, faculty, and staff. Jessa reported the strongest interpersonal relationship with her mother, "I just always knew she believed me." She disclosed her illness to her best friend who attended another college, family, and a family friend. She kept the invisible disability of her "identity" separate. Jessa discussed the relapsing nature of the disorder, which also created sporadic social relationships:

> I think the hardest thing for me is that the POTS can really just come and go. And it is really hard to talk about identity then when you feel like your commitment to friends or other activities can change depending on how you feel. So talking about your identity then, you feel like–Am I healthy, or am I not? If you are ill, you have to be much more protective of you time and your commitment to friends has changed. Your friends say, 'well you used to be able to do this or that', and then, people that seem like you are changing, and you are not changing, you just fall back into your illness, and you have to catch up.

Jessa's identity formation was somewhat fragile and related to the unpredictability of the disorder.

An unmentioned fear that underlies Jessa's identity is the fear of the unknown and ultimately failure:

I mean I think that if I can make it thorough without crashing and burning like I did that one semester; it's almost like in the back of my mind all the time. I don't think that's going to happen next semester, but I am worried that the crashing and burning will happen again.

Jessa approached many of institutional, academic, and social commitments guardedly. Indeed, she did not commit to registration for the next semester until my interview with her. Jessa cautiously stated, "I made my commitment to stay (in college) at my interview today…but I am worried about it." The identity directly impacts her social engagement, causing her to be socially disengaged, "It is quite lonesome here on campus." Academic engagement was also influenced by her view of self, especially in the first year. When she didn't self-disclose, she experienced difficulty, and when she did, received mixed reaction among faculty.

Jessa best exemplified the disability paradigm, "objectifying disability" (Kinavey, 2006). These individuals separate the disability from their core self, and they "engage in strategies of defense designed to limit or contain the psychosocial impact of disability" (p.1098). This stance serves to protect the individual, and as seen with Jessa, she limited social engagement due to the pain she experienced when peers and professors didn't accept her.

Jessa gave the disability a name, which is an example of separation or objectifying disability:

The "P" and the "O" are real names like Phinneas and Oliver, I pick names I

didn't have good experience with, Phinneas Oliver takes away sanity, the "S" and

the "T." So Phinneas Oliver takes away my sanity sometimes, when he decides to

attack. But in the spring, he (POTS) came knocking again.

Jessa's identity formation changed slowly, and most interesting was the change

that occurred when she lived on campus and learned to self-disclose and self-advocate.

Student engagement research has found a positive association between living on campus

and college persistence and success. As seen with Jessa, living on campus increases

engagement opportunities, autonomy, and positive identity development.

*Kimberly*

Kimberly exhibited many behaviors of identity formation described by Erikson

(1959,1980) and Chickering and Reisser (1993).Autonomy development, self-

determination, separation from family, independent living, developing competence, social

and peer relationship, finding one's voice or vocation and developing purpose, refining

beliefs, making commitments, and developing a sense of social responsibility are seen in

Kimberly's stories.

As shown, her identity development contributed to and was affected by

engagement. Unlike the other students, she found the voice of advocacy for other

students with disabilities and a sense of social responsibility for the education of others.

Although all of the students felt a responsibility to educate others about the disability,

Kimberly's approach was broader in scope and more formal. She was a highly motivated

member of the Accessibility Services Team.

Kimberly worked hard at overcoming her disability. Indeed, she states, "I just don't like to use the word disability." She works very hard against this stereotypes that are common to students with hidden disabilities: lazy, stupid, faking. Reportedly:

I had to fill out all these crazy disability forms, basically making sure I was legit. Around the country people are trying to get extra time (accommodations) and it's just a way of cheating.

Kimberly stated that during freshman year when very ill: "I wanted to be defined by my illness because I wanted to know what the illness was because it took so long to figure out." In addition, she added that a severe illness diagnosis initially was somewhat comforting, "I couldn't have been more thrilled because we need a name for all these things." Now that this critical phase was over, she spent an extraordinary amount of time trying to fight the stigmatization:

I never want to be defined by my illness. I just know from nursing in my freshman year who might think of me as the sick girl, but my thoughts definitely don't…not at all. I didn't want to be treated differently

Kimberly requested her accommodations were kept confidential. Kimberly experienced emotional anguish when some peers judged her and she preferred not to be given special treatment:

The remarks were that I shouldn't be getting extra time; by friends…they're not friends anymore…that was weird because I sort of agreed with them in a way. Instructors would respect when I didn't want my accommodations. I wanted to be treated as normal as possible.

Although she has struggled with the illness, she noted: "I think that from being sick, I have a bigger perspective and I just appreciate things more. I have gained so much from being sick…I wouldn't trade that for anything."

Kimberly's identity developed in parallel with the illness. Initially, she was very sick, and now she is less troubled by symptoms. Kinavey (2006) may classify Kimberly as the stance of overcoming disability. This stance is defined as, "An identity or self-understanding, as one who overcomes; specifically, overcoming the cultures understanding of them as weak, fragile, needy and incompetent" (p.1096). Kimberly's ability to overcome the exacerbation in this disorder was central to her self-identity. Her story reflected her personal stamina, drive, and determination. In addition, because these individuals minimize the vulnerabilities associated with their syndrome, they serve "as figures of inspiration to family, friends, and co-workers" (p.1096). Indeed, in Kimberly's case, she received an accolade among Accessibility Services members. Unfortunately, Kinavey (2006) suggests that this stance is associated with the potential for exhaustion. A component of this identity stance is the internalization of the cultural stereotypes that disability is a character flaw. Kimberly refused "special accommodations" for the disability, and at times she didn't believe in them. Because her disability wasn't present at birth, Kimberly seemed able to withstand any negative identity associations with a hidden disability. She was very successful in her major and over her three years at college developed a strong identity that increased engagement in all categories.

*Shana*

Shana developed identity by independently living away from her parents, using self-advocacy and disclosure, gaining competence, developing social and peer

relationships, and developing a voice. Shana, a student with a visible disability at times, seemed to embrace the disability more so because of the physical visibility. She perceived that friends did not believe her if she didn't use her walker or wheelchair. She decorated the wheelchair as a visible extension of herself. When I asked her if she felt any different from other students on campus, she responded,

Compared to other students, I watch them and they're up at 7:00 in the morning and they don't come home until 9:00 at night. There are things I can't do. I can't go to all the activities. The cadaver lab is hard for me; I can't see the bodies. Elevators are hard, so I use the freight elevator. I think I am as capable, but in that way I don't think I'm disabled.

Shana didn't view herself as disabled, but accepting limitations was difficult: "I guess the first year was hard; I did the typical freshman thing where I wanted to stay out all night, which didn't work out at all, which I should have known better."

Shana's identity formation through college mirrors the stance of integrating disability (Kinavey, 2006). Notably, "these individuals articulate a shift in self-understanding over time." Shana expressed this shift in the following passage,

It took me over a year to figure out all my boundaries and this year it works out really well…I found out what I can and can't do and I found people who will let me do it. I think that's how I adjusted; I just I made a lot of mistakes and had to try to figure out what didn't work.

The last example demonstrates how she learned her limitations. Student with disabilities in this study noted this common theme, and it was closely tied to their identity and ability to engage.

*Casey*

Like the previous cases, Casey's identity evolved over the years in college and
she developed identity by establishing independence from parents, exhibiting self-
advocacy, and self-disclosure. She learned to balance school, relationships, and activities
in light of a chronic disease. She found her voice educating others about the disability,
and used the analogy of the "stones" as a teaching tool.

An important component of Casey's identity development through college with a
disability was her ability to accept assistance from others. She recalled,

I have finally learned to ask for help. I was always a forward type person. I will

do it. I can learn it on my own. I finally know that it is O.K. to ask for help, but I

am still the type of person I want to try as hard as possible to do it on my

own…but, if I need help I will just ask for it.

Casey said that self-acceptance helped her stop worrying about the acceptance of
others:

I am much more comfortable with myself and I am not really looking for

acceptance and I think other people can kind of see that so they don't even try to

make me do things…they just take me as who I am and that's fine with me.

Casey echoed self-acceptance as part of who she is; "it's who I am and I'm OK
with that." Casey also demonstrated integrating disability into her sense of self. Casey
has had to deal with her disability on campus and all of the challenges associated with it.
Casey has shared many stories of hardship and anguish. Integration of the disability
helped Casey, "confront her disability, its opportunities, and its challenges more directly,

sparking a myriad of new feelings and experiences, both exhilarating, and distressing, liberating and constraining" (Kinavey, 2006, p.1101)

### *Cross-Case Analysis for Identity*

All of the students exhibited some of the characteristics of the dominant identity theories (Erikson, 1959, 1980; Chickering and Reisser, 1993). The students in this study all eventually separated from the parental unit. But this sample may not be representative of most disabled college students. The majority of disabled college students do not live on campus. This has implications for identity development. As seen in the case of Jessa, she initially chose to live at home which caused a delay in this task. The delay in this aspect of identity formation influenced institutional, academic, and social engagement patterns. Students who live at home may be at risk to healthy identity development if they delay gaining independence from the parental unit and delay self-regulation. Consequently, this may inhibit engagement, and engagement in college is associated with higher self-image and positive development (Harper and Quaye, 2009).

Students varied in the development of student-peer relationships. All students developed purpose, and a component of this was education of others about the disability. This influenced academic engagement with faculty, social engagement with peers and institutional engagement. All of the students formulated and redefined values regarding friendships, alcohol, social activities, and dating. This part of identity affected social engagement. Most students developed academic competence when they received and implemented accommodations to assist them. This influenced engagement and identity.

In addition to the parallel in identity development with the dominant culture, the students were all working on aspects of the disability identity development described by

Kinavey (2006). Three of the students embraced the disability stance of integration of disability. Interestingly, these students have the longest history of the disorder with onset in the prepubescent age (Debbie age 9, Shana age 10, and Casey age 12). These students, although they discussed engagement struggles, displayed resilient identities.

The category of overcoming disability was exhibited in one student (Kimberly). She experienced a late-onset dramatic change in health status and was currently functioning at a higher level. She worked very hard at trying to overcome the disability. She expended an extraordinary amount of energy trying to reject the stigmatization of a "disability identity." Unfortunately, as mentioned, this may be associated with a risk for exhaustion. A hallmark of this stance is to "downplay physical challenges and hide vulnerabilities while serving as figures of inspiration to family friends and coworkers" (p.1096). Kimberly received numerous accolades from peers, faculty, and staff in her ability to overcome the insurmountable odds she faced.

The last category of objectifying disability was seen in one student, Jessa. Interestingly, she experienced the onset of the disorder late in high school. The newness of the syndrome haunted Jessa, and she struggled with thoughts that severe symptoms may return. This might explain why she tried to separate the disorder from her identity.

In conclusion, identity development was similar to theories in the dominant culture, but the disability weighed heavily on the behaviors that build a healthy identity (independence, autonomy, competence, peer relationships, purpose or voice, social advocacy, self-determination). The students all displayed some characteristics of the different disability stances from Kinavey. In addition, it was evident from the cases that the student's engagement patterns evolved over time in college. This is also noted in

Weeber's research on disability identity development in leaders of the disability community (2004). Engagement in the cases tended to be most difficult freshman year, which may be due to the fragile identities as a result of the acquired disability. The development of self or identity during college was challenging for these students, at times because they felt marginalized by the institutional policies, campus structures, and faculty and peer relationships. The positive identity changes that occurred seemed to parallel increase in student engagement behaviors, and engagement influenced identity development.

**Summary**

This chapter presented an analysis of each participant's interviews for themes associated with four categories of campus engagement. A pre-college category was also analyzed, and emerging themes were revealed from the transcripts. Finally, two categories linked to the disability research were analyzed including the categories of self-disclosure/self-advocacy and the category of identity.

Listening to the student stories of engagement helped identify the gaps in engagement, and the interviews provided powerful descriptions of the students first hand experiences. This study illuminated a number of problems students with the hidden disability of orthostatic intolerance face when trying to engage in the campus setting. The engagement difficulties span all of the categories of engagement, and are briefly summarized in the sections below.

**Pre-College Findings**

College planning interrupted: Even prior to college attendance, there were several unexpected findings associated with engagement. The late onset of the acquired disability

in adolescence appeared to directly impact college planning. Unfortunately, for many of the students, the worst of the disorder hit at a time when college planning is critical. Thus, these students understandably were caught off guard, with no clear plans for college. Academically all of the students were strong prior to the onset of the disorder.

The onset of the disorder affected the admission process to college. For instance, one student had to spend a tremendous amount of energy to complete the college admission forms. She had to explain in detail the reasons why her illness affected her grades in high school. Because of her efforts, she was successful. On the other hand, one student didn't actively advocate nor have the ability to successfully navigate this process. This is the student who didn't get admitted to the traditional campus setting altogether because her high school grades fell during her illness. She was also the student that was the furthest behind in terms of college planning. As a result, the student had to attend night classes. She reported that the night classes and commuting didn't provide opportunities for engagement.

Although all of the students had high educational aspirations, the application process for college was haphazard. Many students applied late or half-heartedly. As a result, the majority of the students attributed admission to their college by a "stroke of luck," indicating possibly that on the high school level, these students were perhaps not encouraged by their high schools or college admissions offices.

Development of autonomy: All of the students echoed the developmental task of the desire to gain independence from the family unit. But findings from this study suggest that the parents may have difficulty adjusting to the student need for independence, perhaps secondary to the chronic illness. Even though the parents in this study supported

college attendance, many students felt their parents may have sheltered them somewhat by not encouraging them to live on their own. This finding may even help to explain why students with disabilities are more likely to commute. It is known that the majority of students with disabilities do not live on campus, and this is noted to negatively influence engagement. One student described the limited engagement and exhaustion she experienced while commuting.

**Campus Physical Engagement Findings**

Lack of student centeredness: College residential living for the students in this study had its share of barriers that affected engagement. A common barrier was the lack of student centeredness for housing. The student stories suggested that the communication between disability services and residential life was fragmented; the disability office lacked jurisdiction over residential life housing decisions. Ironically, one university housing policy designed to help the student engage in the "full campus experience" was not helpful for a student with a hidden health-related disability. This policy required all freshmen to have a roommate, and for most of the students in this study, the roommate situation was problematic.

Roommate difficulties: Roommates were not always sensitive to the student health needs in this study, and all but one of the students had roommate problems. The difficulties cited were altered sleep schedules, roommate alcohol issues, and exhaustive interactions. Interestingly, all students in this study agreed that private rooms helped them engage because of their need for rest and physical energy conservation. Most of the students preferred their living arrangements to be centrally located on campus and provide air conditioning and private bathrooms. Centrally located rooms helped to

239

conserve physical energy, air-conditioning helped with the temperature regulation difficulties, and private bathrooms prevented exposure to infections in students with weakened immune systems.

Physical energy requirements for college setting: In this study, the campus physical setting directly impacted student engagement patterns. All students had difficulty physically on the college campus because of the limited ability to walk long distances, traverse hills and stairs, and stand in long lines. Thus, the physical location of classes, meals, housing, and campus services was important for engagement. The students all reported that they devote a tremendous amount of physical energy walking the campus for classes, meals, campus services–indeed, normal everyday tasks.

### Institutional Engagement Findings

Accommodation process: All of the students relied heavily on disability or accessibility services to assist them in college. Although a needed and helpful entity, the process for receiving accommodations was described as cumbersome and even physically exhausting. All students noted that the process should be less taxing. The disability services offices for all students were easily accessible, but one student reported she lacked awareness of the services and believed she didn't even qualify for the services.

Lack of student centeredness: As seen in the other categories, lack of student centeredness seemed to prevail, and lack of understanding of the health-related disability by the disability office. In addition, other campus services seemed to lack understanding, even the student health services.

Campus policies impact engagement: Rigid policies for class withdrawal were a common institutional barrier for these students. All of the students had to withdraw from

at least one class at some point during college due to the disorder. Most of the students were penalized financially and academically. Several of the students suggested that the "push" to register for more classes could have contributed to course withdrawal.

Academic curriculum pressure: In addition to the penalties associated with poor academic advising, academic curriculum pressure may have even contributed to poor student self-esteem. Several of the students mentioned that the attitudes of some individuals working in higher education suggested that part-time status is undesirable. One student felt tremendous inadequacy because she was behind academically in her rigorous major.

Lack of scholarship opportunities and financial penalties: Scholarships for several of the students in this study were seen as somewhat unattainable because many scholarship opportunities were based on extracurricular activities. One student believed the criterion was unfair for students with health-related disabilities. She noted that students with disabilities in general have huge medical costs; they take longer to complete college and accrue higher college expenses. However, these students are unable to consider scholarships due to lack of ability to engage physically in extracurricular activities. Several students mentioned the huge financial burden associated with their health-care costs. The stipulation by insurance companies that they be classified as "full-time students" to qualify for benefits under their parents' health insurance policy drove many to take more classes than they could handle academically.

### Academic Engagement Findings

Positive student-faculty interactions increase academic engagement: Academic engagement for the students in this study increased with positive faculty interactions. All

of the students by and large had positive interactions with the faculties. The students in this study were more likely to persist in the class or choose a class based positive experiences. The students described supportive faculty members as non-judgmental, willing to listen, accepting, and included the student in learning activities.

All students agreed that communication with faculty was vital to their academic engagement. Many of the students noted that the faculty acceptance was hit or miss, and were somewhat selective in whom they disclosed their disorder to. They agreed that it was the student's responsibility to approach the faculty and discuss how their relapsing, "hidden" disability affects their ability to learn and participate. The students reported it was important for them to educate the faculty because academic accommodations are vital to their success.

Hidden disabilities are misunderstood: In interactions with the faculty, an engagement barrier noted by several students in this study was the perception that their disorder was not viewed as legitimate. A predominant theme was that several of the students felt that their request for accommodations was perceived as a hassle for some faculty members. The students reported they did not want to be seen as a hassle or a "lazy" student. Some students reported that learning activities and assignments, class attendance policies, and tardiness policies were a problem. Lack of student centeredness and lack of understanding of the disorder surfaced again as contributing to the problem.

**Social Engagement Findings**

Lack of understanding of the disorder: Commonly seen throughout the engagement categories, this theme included the perception that the disorder was not understood or credible. Students, when not believed, were less likely to self-disclose to

242

peers, and this affected engagement. Students felt disconnect secondary to not feeling believed.

Social withdrawal: Students withdrew from peer interactions when not accepted or believed. As well, many of the students with this hidden disability agreed that their hidden disability challenged peer relationships. The students noted that lack of understanding of the relapsing nature of the hidden disability was at the root of the problem, but also a felt that the disorder was not legitimate. Many of the students fought the stigmatization that they were lazy, faking illness, or "milking" their disorder for academic gain

Different values limit engagement: The findings also demonstrated that the students had a hard time adjusting to socialization experiences that revolved around alcohol and parties. All of the students reported they didn't fit in with this group of students. Physically, students with orthostatic intolerance do not tolerate alcohol. Perhaps this finding contributes to non-involvement in the Greek system and other clubs. Two students found that religious groups offered the support they needed, and these groups were more closely aligned with their values.

Physical limitations for social engagement: In all cases, limited physical energy was a barrier to social engagement. Socialization experiences required planned events outside of student living space (dining experiences, activities etc). Many students had to prioritize their time between academics, day-to-day tasks, and socialization. The syndrome imposed physical limitations which affected student-peer relationships and participation in extracurricular activities. The students developed an awareness of their physical limitations and withdrew from social experiences based on their energy at the

time. This is well illustrated in the description of dating. Most students, due to the relapsing nature of the condition and symptom presentation, went in-and-out of social groups and relationships.

**Self-Disclosure and Self-Advocacy Findings**

Behavior development /cumulative experiences: This theme was dependent on student past experiences associated with trial and error. The skills of self-advocacy and self-disclosure developed through campus living experiences. Students appeared to develop these skills independently from the parental unit.

Non-disclosure/ selective disclosure/ full disclosure: All students vacillated between the three categories of disclosure. Non-disclosure in students did not provide any benefits in institutional engagement with disability services. Interestingly, some of the students used selective self-disclosure on an institutional level for fear of discrimination (entry into academic programs, into disability services, into housing).

Academic and social engagement benefited from both full and selective disclosure. Self-advocacy and self-disclosure were skills important for academic engagement, because most students agreed that it was important discuss their disability with faculty to receive accommodations. As far as faculty interaction, although all students reported that they approached faculty for accommodation requests, these students had some difficulty at one point or another. The difficulty usually centered on the perception of not being believed or being labeled a fraud. Several students were careful not to fully disclose to all members of faculty for fear of discrimination.

The good and bad of self-disclosure: The skills of self-disclosure and self-advocacy were important for academic success. Students needed to disclose the illness to

244

faculty members to receive accommodations. Self-disclosure was not preferred in situations where the students perceived discrimination, threats to confidentiality, hassle, doubting attitudes, and stigmatization. Self-disclosure was not used if student perceived their friends to be judgmental or non-empathetic. Some student withdrew socially when previous self-disclosure experience was negative.

Need to educate others: An important piece of self-disclosure and self-advocacy in all categories of engagement was the need to educate others about the disorder. Limited information about the disorder was provides to avoid overwhelming others with the complexity of the disorder.

**Identity Findings**

Identity is evolving process: For these students, the disability experience shaped their identity, and appeared to evolve over time. This identity finding seemed to be related to college student engagement. Many of the students learned through engagement experiences how to manage the college environment. Identity in the students followed dominant theories of identity and college student development (Erikson, 1959, 1980; Chickering & Reisser, 1993). Constructs from the theories included the development of independence, competence, autonomy, peer relationships, values, social responsibility, and development of voice. Although the identity development in this sample was similar to students without disabilities, the disability status affected these constructs directly.

Onset of acquired disorder influences identity: All students displayed aspects of three-identity stances of Kinavey (2006) described earlier, and several interesting findings emerged. The three students who experienced the onset of their disorder earlier in life demonstrated more resilient identities, or disability integration. These students

were grounded in their disability identity, and discussed the inequalities seen in students with disabilities articulately. Their engagement patterns appeared directly related to past success or failure with the disability in most categories.

One student fought stigmatization against the disability label and exhibited the stance of overcoming the disability identity. She worried that her discipline might discriminate against her if she displayed any sort of weakness, such as fainting. This high achieving student assisted others with disabilities to be successful in the college environment. She minimized the excessive time and energy needed to succeed with a disability, and that the process was difficult for students.

Objectifying disability is described as a separation of disability identity from the core self and seen in a student who experienced the acute onset of the disorder late in high school. This student was haunted and perplexed by the relapsing and remitting nature of the disorder. She separated this identity from her core by choosing not to self disclose, which seemed to affect engagement in college on all levels.

In summary, student success, persistence in college and healthy college development for this diverse group of students with hidden disabilities is only possible if institutional, academic, and social campus environments foster engagement. The next chapter takes shape from the participant stories, and noted obstacles to engagement are incorporated into plans tailored to improve student engagement.

**Chapter V**

**Discussion**

This chapter presents a discussion of the findings in Chapter Four and addresses the research questions. In order to facilitate campus engagement in students with hidden disabilities, each category of engagement (physical, institutional, academic, and social) will be addressed separately. This organization will allow individuals working in high schools, higher education, health care, and parents to target interventions for engagement in their area. The chapter begins with a discussion of the pre-college themes. The pre-college themes are important for students, parents, teachers, and guidance counselors working in high school, higher education officials, and health care providers.

The knowledge gained from this study is used to design strategies aimed at supporting engagement. These interventions may be fused into current practice and policies in higher education. This research also allows students with hidden disabilities to understand engagement barriers on the campus. They may then consider the strategies and use them to create a successful college experience.

**Pre-College Themes**

This study revealed several themes that can be used to help students with hidden disabilities enjoy a smooth transition to college. These themes were unexpected findings, and were not part of the original research questions. The themes emerged early in the interviews with the students. One theme noted was the haphazard process of application to college for several students. The unexpected nature and acquired onset of the disability left the students scrambling to get into college (Jessa and Kimberly). Understandably, the students and families were in the midst of managing a drastic illness, which probably

247

contributed to this pattern. These students were not prepared mentally, physically or even academically for the process of applying for college. Hence, the students ended up applying late or half-heartedly to college. Almost all of the students had worse symptoms junior and senior year in high school, and this time typically corresponds with college planning.

Due to the nature of the disability, the college application process seemed disorganized for the participant, and suggests that the process of applying to college for students with onset of disability in adolescence can be problematic. Many of the participants in the study, despite being academically strong in high school, were very surprised they were even accepted into college. This finding may help to explain why students with disabilities don't typically go to four-year colleges and live on campus. As reported, the majorities of college students with disabilities live at home and attend two-year colleges (National Council on Disability, 2000; Nichols & Quaye, 2009). The cohort of participants in this study represents the minority of college students with disabilities because they live on campus and attend four-year schools.

It is known that campus residence and full-time status enhances engagement for students (Pike & Kuh, 2005). Even in this study, one student reported the difficulty she had with engagement when she was off campus. Not only was the commute physically exhausting for her, she reported little opportunity for engagement in a curriculum that supported night classes.

Based on these limited findings, it appears as if the foundation for successful engagement in students with disabilities starts with integration into residence life on campus. The students in this sample chose to attend four year colleges, and this is not

typical, yet even in this group of students, they still had trouble with adjusting to campus life, and encountered barriers.

**Findings and Recommendations**

Recommendations for high school practices: Over 80% of the students with orthostatic intolerance slowly improve over 5 years, and this time frame usually corresponds with ages 20 to 25. To increase educational aspirations and college attendance in high school students with orthostatic intolerance syndromes and other similar hidden disabilities, high school teachers and guidance counselors should assist this process.

These students should be mentored and encouraged to visit colleges early, perhaps starting in 9th and 10th grade. College planning should be a priority for students with hidden disabilities, because as demonstrated in this study and based on the literature, the process for admission takes time and energy. The students should be encourage to "follow their dreams" to attend college. They should be advised that they may need to make some adjustments in their college choice, but early planning could give them several options.

High schools should make special attempts to organize college visits for students with disabilities. Guidance counselors should be especially familiar with college disability offices, college disability policies, and the admission process for students with disabilities. This sample is a highly selective group of students who represent middle to high socioeconomic status, and even their application process to college was laden with difficulties. The guidance counselors in high schools are at best the only hope for college admission for some students with a disability with limited financial resources.

In addition, many students with orthostatic intolerance have difficulty with cognitive functioning intermittently, similar to other students with hidden disabilities, and lengthy standardized tests can be extremely taxing. High school administrators should work with national testing organizations (SAT, ACT) to assist disabled high school students in obtaining accommodations for standardized testing. As discussed by several students, the high school grades were not reflective of true aptitude and were more a reflection of the illness onset. The high school counselors who are familiar with students with a disability should advocate for their success. They should help students complete admission documentation and add support for their academic records.

Recommendations for University Policies and Practices: Universities should design partnerships with high schools to reach out to students with disabilities, especially those who may be home bound for a portion of high school. These partnerships could resemble the same programs designed for minority high school students (Nichols & Quaye, 2009). Universities could develop high school programs to entice and encourage college attendance for students with a disability. College students with disabilities could facilitate sessions designed to introduce the college campus to high school students with disabilities. This type of mentorship and exposure may encourage students to ask other students with disabilities about their college experience. College student mentoring may help to create an accepting environment. A strong sense of cohesiveness among individuals with disability, or a "disability culture" has been demonstrated to help with feelings of acceptance (Weeber, 2004).

High school teachers and staff should encourage students with hidden disabilities to discuss their disorders, without fear of shame, stigmatization, or feeling ostracized.

Open forums on college planning in high school for students with disabilities and their families could increase their educational aspirations.

Based on the findings from this study, one aspect of the high school program should focus on the admission process to college. Several of the students spoke of the need for the application process to be much more individualized for students with disabilities. The students reported that the application didn't allow for an explanation of how the illness in high school may have contributed to academic troubles or inconsistencies in grades and attendance. Several students found the forms didn't take into account their unique situations. One student in particular ended up in a remedial-type nighttime program. Another spent an entire summer preparing for the admission. Fortunately, this same student enjoyed the benefit of a college admission process that was individualized, but the student had to work very hard just to be successful.

Administrators and staff in college admissions might need to redesign the application forms to allow for differences and exceptions. As such, admissions committees should also make an effort to contact the students with disabilities during high school, contact their guidance counselors and perhaps interview these students about their college aspirations. Early high school intervention programs, college visits, and college application programs designed to attract students with disabilities to colleges and universities demonstrate that these institutions are committed to their success.

Recommendation for Parents and Health Care Providers: Unfortunately, because of the economic climate, many schools have cut the staff of high school counselors, and teachers are overworked. Lack of funding for counselors and teaching staff requires much more parental assistance. This may work well for students with a disability who come

from affluent families, but students who lack resources or parental support are at risk for poor college planning. This can only be changed if colleges and universities assist high school with students at risk.

In order to increase college attendance and persistence in college for students with a disability, parents, and educators should assist students with a disability to become self-advocates. One of the difficulties assisting students with disabilities to succeed in college lie in the fact that the students typically rely on their parents to assist them throughout high school. Most students in this study supported this finding. As cited earlier in this paper, high school students with disabilities are uniformed about their high school Individualized Instructional Plans (IEP) and 504 plans, which are usually designed by the parents and administrators.

When students are not included in high school academic planning, this may inhibit self-advocacy. As a consequence, the students may have difficulty moving forward with college planning. Parents should increase self-advocacy skills in children with disabilities and include students in planning for not only high school, but also college. Health care providers are also in a unique position to help parents assist self-advocacy in their child. Health care providers normally see both the parents and students in medical visits, and the topic of college planning should be addressed. The health care provider may discuss physical limitations of the disability and skills necessary to adapt to the college setting. This support encourages self-advocacy and perhaps college attendance for students with hidden disabilities.

From the pre-college findings, another common theme discovered was the need for the all students to develop independence. Their need to develop competence and

autonomy are foundational for a solid identity formation. This finding supports Erikson's theory on identity development (1959, 1980), in which adolescents "separate" from the parental and family support. Yet, as shown, most of the students seemed to struggle somewhat with the fact that their parents wanted them to stay close by.

Taking it a step further, it is known that college students with disabilities do not typically live on campus, and this could thwart autonomy and healthy identity formation. If high schools, colleges, and parents do not encourage campus residential living for students with disabilities, the student is likely to limit engagement, and this increases risk for poor persistence.

Similarly, the findings support college student development theorists Chickering and Reisser (1993). In the theory of college student development they note that students learn to develop autonomy and competence as they transition through college. The participants demonstrated a strong desire for independence and self-sufficiency by choosing to live on campus and attend a college far from home. Even so, the students felt that their families in some way discouraged this independence. Students with a disability with parents who discourage a campus experience away from home may help to explain why students with disabilities are more likely to attend two-year schools and live at home.

In addition, the students in this study support the disability identity development described by Weeber (2004). Her findings report that education is paramount to identity development, because the experience allows an individual to assume adult roles in society. Adult roles require autonomy, self-control, and self-reliance.

Understandably, parents of students with disabilities may feel the need to protect and "hover" perhaps secondary to their child's health issues. Nonetheless, clinicians and educators in contact with the parents should make an effort to help the parents feel that the college environment is safe and secure. A living-learning community designed for students with hidden disabilities could help parents. These communities are designed primarily for first year students, and help to bridge the transition from home to college. Living learning communities and are associated with higher involvement and interaction in college (Pike, 1999). Forums for students and parents designed to connect them to college campuses that are welcoming and inclusive to the needs of students with disabilities may help parents "let go."

Another pre-college finding revealed that the students had high educational aspirations to attend college, but were surprised of their acceptance to college. The high educational aspirations are in contrast to the literature, which cite college aspirations are much lower in disabled high school students (National Council on Disability, 2002). However, this group probably represents selection bias because they all attend college. Of even greater importance from this study is the fact that all of the students didn't expect to go to college. This finding may be explained by the fact that the disorder contributed to a dramatic change in life planning. As a result, the self-concept or view of self may have changed. Indeed, this finding is partially supported by Walling (1996) when she reports on the tremendous change in self-concept in college students with acquired disabilities, and by Schaller (2008).

A sudden onset disability is a real obstacle to college attendance, but parents and health care providers should discuss student educational aspirations and work together to find an appropriate "fit" for college attendance.

**Summary**

Pre-college barriers to college admission for students in this study seemed to be related to a number of internal and external factors intricately related to the sudden onset of the illness at a critical time for college planning. As a result, the students had to "catch up" and spend much energy on this. Fortunately, this small, select group of students was able to attend a four-year college and live on campus. Of greater significance is that this sample is highly selective, which more likely does not even begin to represent most students with disabilities. As noted in the literature, most students with disabilities don't even attend college.

Barriers to college admission signal to students with disabilities and their families that the institution does not value them, and perhaps society does not value them. Institutions that create accepting, welcoming environments help to foster self-concept, and help to bring students with disabilities on campus. High schools must work together with universities to increase college attendance for students with disabilities.

A university's mission should boast inclusion for students with disabilities and specifically target high school students because this is more likely to help a student with a disability transition from high school to college (Hadley, 2007).

**Campus Physical Engagement**

Campus physical engagement is closely related to the pre-college themes and the transition students make from high school to college. The themes in this category are

255

associated with the unanticipated changes the participants had to make to live on campus, and navigate the physical campus environment. One of the overriding issues was the physical adjustment all participants had to make, and the recurrent theme of the need to balance engagement with energy conservation. Most of the students mentioned that the campus itself was physically overwhelming, and just day- to-day tasks were challenging.

Engagement or involvement refers not only to cognitive and mental processes but also physical activities. To that end, physical functioning seemed to limit campus engagement in this group of students. Engagement is associated with identity. Taking it a step further, limited engagement due to physical issues may impact identity formation. Walling's (2004) disability identity argument suggests the incongruence between physical functioning and identity development. In other words, identity should not be associated solely dependent on physical functioning. In this study, the students' physical functioning impacted engagement, and possibly their identity. Why this is important lies in the fact that the campus physical environment should address barriers that inhibit physical functioning.

One barrier the majority of the students encountered in this study was difficulty with roommates. The interactions with roommates were not always positive in terms of the students' physical and mental health. One student reported discrimination by a roommate, although another student reported a positive experience. The difficulty with roommates was attributed to a number of issues, but energy, sleep, schedules, and personal values related to drinking and partying seem to prevail. The students in this sample and those with other health-related disabilities benefit from regular schedules.

Roommate problems centered on the student physical need to protect and prioritize health.

Although the students in this study made a choice to live on campus, the findings suggest the mere act of college residential living with roommates didn't always secure engagement. This finding may be similar to other marginalized groups admitted to college campuses. Access for the students with hidden health disabilities didn't equate to active engagement. Jessa was a good example of this. Although she resided on a busy campus, she reported feeling socially isolated. Kimberly and Debbie also had their share of roommate problems and social isolation.

Another theme related to physical functioning was that the students' development over college was associated with learning to balance engagement with their physical functioning. Several students discovered that "setting limits" was ultimately beneficial for their physical and mental well-being. It is likely that many students on college campuses experience the fun and initial excitement of participation in the "college experience." Yet three students in the study found that "overdoing" it led to problems. In fact, one student suffered serious health issues (Kimberly) trying to fit in.

Recommendations for University Support Services: To help the transition to campus residence for students with hidden disabilities, specifically, those with physical, health-related challenges, individualized room assignments may be necessary for successful engagement. Students with orthostatic intolerance need balanced sleep, quiet time, and limited exposure to excessive peer interaction. The process of dormitory assignments should be coordinated by both disability services and residential life, so that each department works together to find acceptable living arrangements for these students.

If private rooms are not possible, one roommate or at least a separate bedroom may be acceptable.

Students with a disability will benefit from like-minded roommates. Residence life should pair students with disabilities to students who have similar sleep schedules, and perhaps even with students who choose to avoid alcohol. The room arrangements should not be left to chance, because as shown, this caused problems for the majority of students in this study.

During freshman orientation, residence life and disability services could facilitate group sessions for students with physical and hidden disabilities interested in living on campus. Programs should include discussions about discrimination against students with a disability, alcohol and substance use issues, living arrangements, schedules, strategies to balance energy and engagement, and assignment of student mentors or disability allies. Mature students with disabilities who are already on campus could help lead the sessions. Residence advisors or RAs and non-disabled peers with similar interests and values should attend the sessions. Based on the findings from this study, housing designed to support alcohol free living may benefit students with disabilities.

Private bathrooms and air-conditioning were also mentioned in this study as being important for students with orthostatic intolerance. Students with this disability and other health-related disabilities may need these accommodations for health reasons. Even services like assistance with laundry and grocery shopping could help students with disabilities on campus. Students who have assistance with daily activities may be more likely to have energy to academically and socially engage.

Barriers to the college physical environment are a common theme in the disability literature, and this theme was also documented in this small study. All of the students illustrated how physically overwhelmed they were just walking the campus to attend classes, meals, and campus meetings. As such, students with significant physical issues may consider a smaller campus, as suggested by one of the students. On some campuses, transportation services may be necessary, although students in this study did not report using this service. Nonetheless, a transportation service should be offered on all campuses.

As reported from the engagement literature, a well-designed campus physical environment facilitates engagement and learning (Kuh, et. al., 2006). Students with disabilities are even more apt to benefit from an architecturally designed campus that is mindful of physical limitations. Just navigating the campus for the participants was difficult in terms of energy conservation. As reported in this study, Shana had difficulty finding accessible housing with a power chair, and her description of sometimes "crawling up the stairs" of her apartment is a distressing example of this. Kimberly is an example of a student who benefited from having all of her classes across the street from her apartment. Jessa and Shana had academic engagement issues because they were late for class due to the lengthy physical walk across campus. In addition, Jessa's fifth floor room in the Language House was not physically accessible, but she had no other option for residential living in the language immersion program. Thus, the findings in this study agree with other disability literature that reports the problem of inaccessible campus and architectural barriers for students with a disability, especially in terms of housing

(Maddus, 2008, National Council on Disability, 2003; National Center for Postsecondary Supports, 2000).

The process of dining for the students in this study presented several barriers to engagement. Standing in long lines for dining was difficult. One student decided to keep a stash of food under her bed to avoid the physical stress. As reported in research by Corton and Bing (2004), 40% of the students with disabilities in their study indicated their desire to participate in meals with non-disabled peers. Meals are a critical time for social engagement, and lack of participation in meals for students with disabilities may cause social isolation.

To better help college students with physical difficulties, a number of options should be considered to increase participation in dining. First, consultants should be hired to redesign the dining hall process, or perhaps offer alternative box lunches for students that are readily available. Dormitories with kitchens could provide group meals so that students don't have to travel to the dining halls and wait in long lines. The disabilities office and campus meal service could work together to provide catering in the dormitory kitchens or common areas one night a week. Universities should be committed to creating a mealtime campus climate that brings students with disabilities to the "table." If meals are easily accessible for students with disabilities, this will help them to engage socially and enhance their physical and mental health status.

To help with physical accessibility, institutions should hire firms to assess for physical barriers on the campus, and perhaps design classrooms, learning communities, and living arrangements that facilitate academic and social engagement (Nichols & Quaye, 2009). Engagement literature notes that student support services should be

located in residence halls and student housing (Kuh, et al., 2005). This is even more important for students with physical difficulties. An environment with buildings that center on living and learning allow students with disabilities to engage academically and socially. Several students in this study mentioned that dormitory rooms centrally located on campus were ideal and helped them to adjust.

Private bathrooms and air-conditioning were also mentioned in this study as being important for students with orthostatic intolerance. Students with this disability and other health-related disabilities might need these accommodations for health reasons. Even services like assistance with laundry and grocery shopping could help students with disabilities on campus. The more energy the students conserve, the more likely it is that they will academically and socially engage.

Recommendations for University Faculty: Faculty should consider practices that encourage physical campus engagement for students with disabilities. In this study, one student mentioned the advantage to having a schedule designed around classes that were in close proximity. Another student suffered academic engagement problems when quiz questions began immediately at the start of class. In addition, laboratories classes that limit access for wheelchairs should be redesigned. Classes that require students to stand for long periods of time should be redesigned. Curriculum or assignments that require students to physically navigate the campus, or engage in outside learning activities should offer alternative activities for students with physical needs.

**Institutional Engagement**

Institutional engagement themes in this study were associated with disability support services and accommodations, campus policies including class withdrawal,

261

academic advising, and financial support. A prevailing theme in this study was the lack of understanding of the disorder or the hidden disability within institutional services. Indeed, most of the students in this study report a lack of understanding in residence life, academic advising, disabilities services and student health services. In addition, the perception of lack of understanding of the disorder by the students in this study influenced self-disclosure. At least three students believed it was in their best interest not to be completely honest about their disability for fear of discrimination.

Recommendations for Disability Services: Student support services for students with disabilities are described in the higher education literature as fragmented, uncoordinated, and inconsistent (Malakpa, 1997; Scott, 1996). One of the problems in the literature and supported in this study is the lack of training and limited knowledge of the needs of students with disabilities in higher education faculties and support services staff (National Council on Disability, 2003). Another finding in the higher education literature and supported by this study was the uncoordinated efforts between departments such as residence life and disability services. This effected student institutional engagement, especially in terms of housing accommodations.

The engagement literature recognizes that campus support services increase student persistence in college and graduation rates (Kuh, et. al., 2006). It is also known that over 80% of students with disabilities require institutional support in the college setting (National Council on Disability, 2003). This fact is demonstrated in the study, because all students required the assistance of disability support services.

Thus campus services, especially disability services for students with disabilities, should be comprehensive, coordinated, and consistent. Disability services should be a

visible entity on campus, and they should promote students with hidden or suspected hidden disabilities to contact them. Freshman orientation should offer special sessions for students with disabilities, perhaps even a special early orientation to help the students adjust to the campus.

To assist institutional engagement in students with disabilities, universities should develop and coordinate campus wide sessions or workshops for associates in the disability services office, residence life, and student health service to introduce them to the needs of students with hidden disabilities, especially hidden health-related disabilities. The workshops should include students with disabilities on the campus to allow the students to share their stories and voice concerns. Students and administrators working together demonstrate a partnership in which the students feel validated on the campus. Administrators should invite disability staff from other institutions of higher education, experts in disability law, accommodations, universal design, and disability rights advocates to speak at the sessions.

Another common theme found in the study concerned the process of qualifying for disability services and implementing accommodations. The students in this study had favorable experiences with the support staff, but they note that the road to receiving accommodations is not easy. The processes through disability services required time and energy. This is similar to findings in the disability literature (Kravets, 1997). One students' remark clearly illustrates her frustration with the process when she declared that the energy she devotes to give the disability services "what they need" is energy that could be conserved so she might not need the accommodations. Assumedly, this energy could be used for social and academic engagement. The same student described the

difficulty she encountered trying to make up a test using her accommodations per the disability office.

The university should streamline the process for obtaining and implementing accommodations for the students. Accommodation processes should be convenient for the student and not require additional energy and stress. Outside consultants should be hired to assess forms and processes in the disability office. Yearly documentation of a lifelong disability should not be required. As noted in this study and in the literature (Hadley, 2007, Kravets, 1997), students with disabilities in college should be able to acquire and implement accommodations without excessive use of time, energy, and excessive costs.

Recommendations for Academic Advising: From an institutional engagement perspective, one consistent finding in this study was pressure on the students to take full-time classes. Full-time status is known to enhance student engagement (Kuh, 2006a), but for the students in this study, full-time status typically resulted in disaster. In fact, the full-time status gave them even less time to engage, because it exhausted many of the participants. In addition, many were unable to continue the heavy course load and suffered financial and academic penalties due to dropping classes.

Thus, the academic advisors somewhat misled the students in this study, and this may have been a factor related to the lack of understanding of the students needs. Academic advisors should design course schedules for students with a disability that are student centered. Many students with a disability require extra time for degree completion, and this is well documented in the disability literature (National Council on Disability, 2003). In this study, all but one student was behind in credit hours compared

to the total number of semesters attending college. The majority of the students in this study expressed frustration that the campus did not fully support their need for extra time.

Students should be encouraged to take only as many courses as their circumstances and health allow. A successful college experience requires academic advisors who recognize this fact. Universities should design curriculum and programs that provide part-time schedules without the implication that this is an inferior path to follow. One student in this study was denied access to a nursing program because she couldn't engage in full-time hours.

One explanation for the institutional push for full-time hours for the student with a disability must address the campus culture push to design curriculums based on students with higher FTEs or full-time equivalent hours. This institutional push is driven by economics because most colleges receive money from the state based on FTEs. This logic for students with a disability is troubling. Indeed, students with disabilities are more likely to withdraw from classes and perhaps college based on an overwhelming full-time schedule, condemning them to a life of reliance on the state for disability benefits.

Recommendation for University Administrators: One final theme in the category of institutional engagement was the financial and academic hardship that some of the students experienced secondary to their disability. Most of the students needed to withdrawal from a course at some point, and their health circumstances weren't considered for reimbursement. This was also seen in one student with an unused meal plan. Scholarships were also noted to be less attainable because of the inability to participate in extracurricular activities.

Student account offices or offices of the bursar should work with disability service administrators to adopt policies that are sensitive to the fact that students with a disability may need to drop classes. Exceptions should be made, and students should not be penalized academically or financially. Many students with disabilities accrue huge medical costs. Federal grants and university funding should be pumped into helping students with disabilities afford college. The participants in this study were affluent Whites, but other students with disabilities, particularly minority students, are at even more of a financial disadvantage. The lack of ability to engage in the institutional aspects of a college, especially in terms of college affordability could affect student persistence for students with a disability. Parents and students need more information from the financial aid offices about insurance, part-time status, and scholarships because the current institutional financial climate for these students doesn't favor their success.

Institutions should secure funds from endowments to create scholarships and educational assistance for students with disabilities. These scholarships should focus less on extracurricular activities and instead be need based. The application for scholarships should reflect students with a disability unique circumstance. Students with a disability should not have to feel as if they are "losers on paper" as expressed by Kimberly.

In summary, limited positive institutional engagement for students with hidden disabilities as demonstrated in this study may indicate to the students that the institution does not value their presence on campus. Institutions should be cognizant of the fact that this preliminary exploratory study found definite obstacles for students with hidden disabilities from a selective, highly affluent sample.

**Academic Engagement**

Key to the category of academic engagement is formal and informal student interaction with the faculty. Although the students experienced a mix of good and bad experiences with faculties, the majority of the negative experiences with the faculties revolved around implementation of accommodations. This finding is consistent with the disability higher education literature, namely that faculty attitudes are mixed. This study did not look at faculty attitudes, and instead looked at student perception of the faculty.

As seen in the higher education literature on students with hidden disabilities (National Center for the Study of Postsecondary Educational Supports, 2000), students in this study also encountered an accommodation "stigma" reporting negative, reluctant, or indifferent faculty attitudes regarding accommodation requests. The majority of students in this study reported at least one negative encounter. Some perceived their accommodation requests were a hassle for the faculty. In addition, some students felt that their disorder was not seen as legitimate by the faculties. Several students were angry at the fact that they were seen as lazy or somehow trying to "milk the system." One student was surprised with the lack of empathy she encountered. Several students in this study articulated frustration against the stigmatization.

The combined positive and negative formal interactions with the faculties for the students in this study were important in their decision whether to continue to interact with the faculties. Approachable faculty increased academic engagement; the students in this study were more likely to persist in the class. Several students reported non-judgmental interactions with their professors. On the other hand, "difficult" faculties limited

academic engagement. The student stories revealed that they avoided these individuals and were less likely to stay in the class.

Several students had informal contact with their professors that were positive. One student spoke about her desire to engage in more informal interactions similar to her father's experiences as a professor on a small campus. The students seemed to agree that smaller class size and perhaps a smaller campus would facilitate engagement with the faculties, although as shown, in one case the student found this not true.

Recommendations for College Administrators: Administrators should not only educate student support staff and services about student with a disability needs, but also the faculty should attend education sessions about students with a disability and the issues that confront them in higher education. Approachable faculty members are a critical component of academic engagement. Disability law specialists should help educate the faculties about accommodations, especially for students with hidden disabilities. Administrators should provide financial support for faculty members to attend in-services and continuing education conferences about students with a disability. It is important that the faculty understand that the majority of students with a disability on campus remain invisible, and they should project acceptance and inclusion.

Recommendations for University Disability Services: Students with a disability should be advised of their responsibilities in interactions and accommodation requests with the faculties. Mentioned by several students in this study, and supported in the higher education literature, is how students with disabilities shouldn't catch the faculties "off guard" with accommodation requests. In other words, they should present all accommodation requests at the beginning of a term and discuss them prior to using them.

Disability services should make the process of accommodation requests clear to both students and faculties in their literature and meetings with every student. Disability services should hold informal meetings and forums for students with disabilities throughout the semester that address accommodation requests.

Recommendations for University Faculties: Students with hidden disabilities may not engage with faculty members because they fear that they won't be believed, a finding noted in both this study and the disability literature on hidden disabilities. Although in this study a few of the students discovered that this fear was unfounded, it wasn't always the case. Several students had faculty that were described as very accepting. It is important that reluctant students with hidden disabilities disclose their needs. As suggested by one student, perhaps faculties could take the initiative and hold a session the first week of class for students needing accommodations. This approach suggests to the student that the faculty validates their needs is willing to work with them.

Faculties should encourage all students in their classes to contact disability services if needed. As noted in the literature, almost 40% of all students with learning disabilities are discovered at the postsecondary level. As a result, many of the most vulnerable students, in terms of persistence and retention, are at risk for poor outcomes if unrecognized.

Several themes from this study related to academic engagement suggested learning activities should be more student centered for students with disabilities. Attendance policies, grades, quizzes, tests, and assignments should reflect this diverse groups needs. Faculties in higher education have recently incorporated literature about other disenfranchised groups into their curriculum; likewise, the disability literature could

also be introduced. Discussions and assignments that reflect upon the discriminatory representation of disabled individuals embedded in film, art and literature would benefit both disabled and non-students with a disability. The engagement literature strongly supports the fact that student learning is enhanced when students have the ability to interact with diverse others (Kuh, et. al., 2006). Thus, educators should encourage a heterogeneous classroom "climate" that includes activities and discussion that focus on the appreciation of students with disabilities.

In summary, faculties in institutions of higher education should take the initiative to create a welcoming learning environment for students with hidden disabilities. As supported by this study, students with hidden and physical disabilities should perceive the faculty as approachable and supportive because these students are at high risk for negative interactions with them. As a consequence, negative interactions may inhibit academic engagement.

**Social Engagement**

The category of social engagement, which is primarily concerned with student participant interaction with campus peers, discovered several themes that were similar to faculty interactions. Indeed, the student experiences with campus friends described a mix of positive and negative interactions that were primarily related to lack of understanding and invisibility of the disorder. Students in this study expressed that not only did they believe their peers not understand their disorder, but also they felt that their peers didn't believe that their disorder was always legitimate. The fear of rejection was a common thread among students in this study.

Social isolation was reported in this study, and supports previous disability research. Although this study did not look at outcomes of engagement, social isolation may affect persistence for students with disabilities. Student involvement on campus is positively related to academic success and persistence in college (Fischer, 2007). As an example from this study, one student who admitted to feeling socially isolated struggled with the decision to stay on campus to continue her studies.

Recommendations for University Administrators: As discussed earlier throughout this chapter, the campus should conduct educational sessions about students with hidden disabilities not only for administrators, staff, and faculties, but students as well. Students may have very limited understanding of the needs of students with disabilities, especially those that are invisible. One problem with this group of students is that they "look so good." The apparent lack of understanding by other students of their disorder is difficult for students in this study and appears to have affected their social engagement. This finding is troublesome from a developmental perspective. Identity development theorist Eric Erikson (1959) discusses the importance of a supportive social network of friends and peers during adolescent and young adult identity formation.

The physical demands of the disorder significantly affected the students' ability to connect with peers in this study. This finding supports research in students with chronically ill adolescents (Kashikar-Zuck et al., 2007). Research by Hodges and Keller (1999) is also partially supported by this study. These researchers found that in physically challenged college students, perceived acceptance by peers and opportunities to engage in extracurricular activities were important. Similar to this study, peer group socialization was important for the participants in this study, even though some of the initial

271

interactions were reported as difficult. Most students in this study found friends over time, but much of this had to do with their own personal growth. After a period of trials and tribulations, the students found friends who accepted them with their disability.

Two other themes prominent in the category of social engagement in this study seemed to effect student social engagement. First, the students balanced their social activities around their remaining physical energy after academics. This usually resulted in little opportunity to engage with other students, especially with experiences that required a lot of energy expenditure. Also, the students tended to evolve to a point where the "typical college atmosphere" of drinking alcohol and partying was unimportant to them, and thus social interaction was built on experiences that integrated their own personal values. Several found off campus religious groups for socialization.

To help the student with a disability on campus assimilate into the campus social culture, the administration should offer a summer campus connection program designed to introduce the students with a disability to other new and returning students, disabled, and nondisabled. Summer programs that bring the student to the campus may help them cultivate new friends prior to dormitory assignments and the added stress of academics. The programs should address the barriers to social interaction for students with disabilities. Topics should include the recognition of stigmatization and discrimination against students with hidden and visible disabilities, alcohol-free activities on campus, student mentoring and study groups for students with a disability, campus safety for students with a disability, and the introduction of campus organizations that encourage membership for students with disabilities.

**Self-Disclosure and Self-Advocacy**

Prominent themes across all of the categories of engagement, self-disclosure, and self-advocacy skills were important components of campus engagement, especially in terms of accommodations. These learned behaviors are prominent throughout the disability literature, and also found in this study. Of interest is the fact that some students in this study did not believe that full disclosure with faculties and friends was always in their best interest because they feared discrimination and rejection.

Recommendations for High School and University Policies and Practice: College students with hidden disabilities should have the opportunity to develop self-disclosure and self-advocacy behaviors prior to college admission. High schools guidance counselors should help students with disabilities to learn the skills. College officials who reach out to disabled high school students with on-campus opportunities as described in the previous sections would be wise to address this issue. Retention of students with disabilities is known to be low, and perhaps engagement issues contribute. Self-advocacy and self-disclosure skills, which are demonstrated by the students in this study, are linked to engagement and may be vital to student persistence in college.

Recommendation for Parents and Health Care Providers: Parents and healthcare providers should provide students with the tools they need to be successful in college. Health care providers can assist parents and their child to discuss strategies necessary to succeed in college with a disability like orthostatic intolerance. A college brochure for students with orthostatic intolerance was created based on this study.

# References

Abes, E. S., Jones, S. R., & McEwen, M. K. (2007). Reconceptualizing the model of multiple dimensions of identity: The role of meaning-making capacity in the construction of multiple identities. *Journal of College Student Development, 48(*1), 1-22.

Adreon, D., & Durocher, J. S. (2007). Evaluating the college transition needs of individuals with high-functioning autism spectrum disorders. *Intervention in School and Clinic, 42*(5), 271-279.

American College Health Association. (2009, February 24) from www.acha-ncha.org

Anderson, P.L., & Meier-Heidde, R. (2001). Early case reports of dyslexia in the United States and Europe. *Journal of Learning Disabilities, 34*(1), 9-21.

Anglin, D. M. & Wade, J. C. (2007). Racial socialization, racial identity and Black students' adjustment to college. *Cultural Diversity Ethnic Minority Psychology, 13*(3), 207-215.

Antonak, R. F., & Livneh, H. (2001). Measurement of attitudes towards persons with disabilities. *Disability and Rehabilitation,* 22(5), 211-224.

Aponte, L. (2004). *Two cases of students with complex partial epilepsy in search for inclusive educators* (Masters Thesis). The University of Toledo, Toledo, OH.

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469-480.

Ashmore, R. D., Kay, D. & McLaughlin-Volpe, T. (2004). An organizing framework for collective identity: Articulation and significance of multidimensionality. *Psychological Bulletin, 130*(1), 80-114.

Astin, A.W. (1984).  Student involvement: A developmental theory for higher education. *Journal of College Student Personnel,* 25*, 297-308.*

Astin, A. W. (1993). What matters in college? Four critical years revisited. San Fransisco, CA: Jossey-Bass.

Atkinson, D. R.,  Morten, G. & Sue, D. W. (1979).  *Counseling American Minorities (1^{st}ed.).* Dubuque, IA: William C. Brown.

Bandura, A. (1986).  *Social foundations of thought and action.* Englewood Clifts, NJ: Prentice-Hall, Inc.

Bandura, A. (1989). Human agency in social cognitive theory.  *American Psychologist, 44*, 1175-1184.

Barnard, L. Stevens, T., Siwatu, K, O. & Lan, W. (2008).  Diversity beliefs as a mediator to facutly attitudes toward students with disabilities. *Journal of Diversity in Higher Education, 1*(3), 169-175.

Barón-Esquivias, G., Gómez, S., Aguilera A., Campos, A., Romero, N., Cayuela, A., et al. (2003). Short-term evolution of vasovagal syncope: Influence on the quality of life. *International Journal of Cardiology 102*(2), 315-319.

Baxter- Magolda, M. B. (2004).  *Making their own way: Narratives for transforming higher education to promote self-development*. Sterling: VA: Stylus Publishing, LLC.

Beers, C. W. (1910). A mind that found itself: An autobiography. New York, NY: Longmans, Green, and Co.

Belch, H. A. (2004/2005).  Retention and students with disabilities. *Journal of College Student Retention, 6*(1), 3-22.

Benrud-Larson, L. M., Dewar, M. S., Sandroni, P., Rummans, T. A., Haythornthwaite, J .A., & Low, P.A. (2002). Quality of life in patients with postural tachycardia syndrome. *Mayo Clinic Proceedings 77*, 531-537.

Bento, R. F. (1996). Faculty decision-making about "reasonable accommodations" for disabled college students: Informational, ethical, and attitudinal issues. *College Student Journal, 30*(4), 494-5001.

Berzoff, J. N. (2002). *Inside out and outside in: Psychodynamic clinical theory and practice in contemporary multicultural contexts.* Lanham, MD. Roman & Littlefield Publishers, Inc.

Bishop, M. (2005). Quality of life and psychosocial adaptation to chronic illness and disability: Preliminary analysis of a conceptual and theoretical synthesis. *Rehabilitation Counseling Bulletin, 48*(4), 219-231.

Black, E. (2003). *War against the weak: Eugenics and America's campaign to create a master race.* New York, NY: Thunder's Mouth Press.

Bond, T. G. & Fox, C. M. (2007). *Applying the Rasch Model.* Mahwah, NJ: Lawrence Erlbaum Associates, Inc., Publishers.

Brandt, E. N. & Pope, A. M. (Eds). (1997). *Enabling America: Assessing the Role of Rehabilitation Science and Engineering.* Institute of Medicine, Committee on Assessing Rehabilitation Science and Engineering. Washington, DC: National Academy Press.

Bridges, B. K., Cambridge, B., Kuh, G. & Leegwater, L. H. (2005) Student engagement at minority serving institutions: Emerging lessons from the BEAMS project. In G.

H. Gaither (Ed.), *What works: achieving success in minority retention. new directions for institutional research.* San Francisco, CA: Jossey-Bass.

Brisenden, S. (1998). Independent living and the medical model of disability. In Shakespeare, T. (*Ed.*) pp.20-27. *The disability reader.* New York, NY: Continuum International Publishing.

Bruno, J. D., Giordano, G. & Cross, T. L. (1996). Improving teachers' attitudes through teacher education toward the inclusion of students with disabilities into their classrooms. *The Teacher Educator, 31*, 304-312.

Brown, R, I. (1997). *Quality of life for people with disabilities: models, research and practice.* (2$^{nd}$ ed.). Cheltenham, UK. Stanley Thornes (Publishers) Ltd.

Buggie-Hunt, (2008). Psychosocial and disability identity development among college students with disabilities. *Dissertation Abstracts International, 68*(9-A), 157. (AAT No. 3282934).

Carini, R. M., Kuh, G. D. & Klein, S. P.(2006). Student engagement and student learning: Testing the linkages. *Research in Higher Education, 47*(1), 1-29.

Chickering, A. W. (1969). *Education and identity.* San Francisco, CA: Jossey-Bass.

Chickering, A. W., & Reisser, L. (1993). *Education and identity.* (2$^{nd}$ ed). San Francisco, CA: Jossey-Bass.

Cook, B., G. (2001). A comparison of teachers' attitudes toward their included students with mild and severe disabilities. *Journal of Special Education, 34*(4), 203-213.

Cosden, M. A. & McNamara, J. (1997). Self-concept and perceived social support among students with and without learning disabilities. *Learning Disability Quarterly, 20*, 2-12.

Coston, C. T. M. & Bing, R.L. (2004). The invisible among us: Exploring criminal

victimization experiences and perceptions of college students with physical

disabilities. *The Southwest Journal of Criminal Justice, 1*(2), p.3-10.

Creswell, J. W. (2005). *Educational research: Planning, conducting, and evaluating

quantitative and qualitative research.* NJ: Pearson.

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five

Approaches.* Thousand Oaks, CA: Sage Publications, Inc.

Cross, W. E., Jr. (1991). *Shades of black: Diversity in African American identity.*

Philadelphia, PA: Temple University Press.

Cummins, R. A. (1997). Assessing quality of life. In Brown, R. E. (Ed), *Quality of life

for people with disabilities: Models, research and practice (2$^{nd}$ ed,* pp.116-150).

Cheltenham, UK: Stanley Thornes (Publishers) Ltd.

Curtin, M. & Gill, C. (2005). Listening to young people with physical disabilities

experiences of education. *International Journal of Disability, Development, and

Education, 52*(3), 195-214.

Dahl, M. (1993). The role of the media in promoting images of disability-disability as

metaphor: The evil crip. *Canadian Journal of Communication, 18*(1). Retrieved

February 24, 2009 from www.cjc-online.ca

Denzin, N. K. & Lincoln, Y. S. (2005). *The Sage handbook of qualitative research.*

Thousand Oaks, CA: Sage Publications, Inc.

DeSousa, J. D. & Kuh, G. D. (1996). Does institutional racial composition make a

difference in what black students gain from college? *Journal of College Student

Development, 37*(3), 257-267.

Duderstadt, J. J. (2005).  Delicate balance: Market forces versus the public interest. In D.

      G. Stein (Ed.), *Buying in or selling out: The commercialization of American*

      *research universities* (pp.56-74). Piscataway, NJ: Rutgers University Press.

Dunn, D. S. & Brody, C. (2008).  Defining the good life following acquired physical

      disability. *American Psychological Association, 53*(4), 413-425.

DYNA. Dysautonomia Youth Network, Inc. Available online. www.dynakids.org.

DYNA. (2009).  Educating the Dysautonomia Student: Dysautonomia In The College

      Setting.

Edwards, S. D. (2004).  Disability, identity, and the "expressivist objection". *Journal of*

      *Medical Ethics, 30*(4), 418-420.

Erikson, E. (1980).  *Identity and The Life Cycle.* New York, NY: Norton. (original work

      published in 1959).

Estrada, L., Dupoux, E., & Wolman, C. (2006).  The relationship between locus of

      control and personal-emotional adjustment and social adjustment to college life in

      students with and without learning disabilities. *College Student Journal, 40*(1),

      43-54.

Evans, N. J., Assadi, J. L., & Herriot, T. K. (2005).  Encouraging the development of

      disability allies. *New Directions for Student Services, 110*, 67-79.

Evans, N. J.,  Forney, D. S. & Guido-DiBrito, F. (1998).  *Student development in college:*

      *Theory, Research, and Practice.* San Francisco: CA: Jossey-Bass.

Fairweather, J. S. & Shaver, D. (1990).  A troubled future? Participation in postsecondary

      education by youths with disabilities. *Journal of Higher Education, 61*(3), 332-

      348.

Ferdman, B. M. & Gallegos, P.I. (2001). Racial identity development and Latinos in the
United States. In Wijeyesinghe, C. L. & Jackson, B. W. (Eds.), *New perspectives
on racial identity development: A theoretical and practical anthology* (pp.32-66).
New York: New York University Press.

Ferri, B. A. & Connor, D. J. (2005). Tools of exclusion: Race, disability, and
(re)segregated education. *Teachers College Record, 107*(3), 453-474.

Fichten, C. S. (1988). Students with physical disabilities in higher education: Attitudes
and beliefs that affect integration. In H. E. Yuker (Ed.), *Attitudes toward disabled
persons* (pp.171-186). New York, NY: Springer

Fischer, M. J. (2007). Settling into campus life: Differences by race/ethnicity in college
involvement and outcomes. *The Journal of Higher Education, 78*(2), 125-156.

Fitch, F. (2003). Inclusion, exclusion, and ideology: Special education students'
changing sense of self. *The Urban Review, 35*(3), 233-252.

Filkins, J. W. & Doyle, S. K. (2002, June). *First generation and low income students:
Using the NSSE data to study effective educational practices and students. Self-
reported gains*. Paper presented at the annual forum of the Association for
Institutional Research, Toronto. (2009 February, 24) from www. nsse.iub.edu

Flyvbjerg, B. (2006). Five misunderstandings about case study research. *Qualitative
Inquiry, 12*(2), 219-245.

Foubert, J., Nixon, M. L., Sisson, S. V. & Barnes, A. C. (2005). A longitudinal study of
Chickering and Reisser's vectors: Exploring gender differences and implications
for refining the theory. *Journal of College Student Development, 46*(5), 461-471.

Friedlander, L. J., Reid, G.J., Shupak, N. & Cribbie, R. (2007). Social support, self-esteem, and stress as predictors of adjustment to university among first-year undergraduates. *Journal of College Student Development, 43*(3), 259-274.

Fu, Q., Arbab-Zadeh, A., Perhonen, M. A., Zang, R., Zuckerman, J. H., & Levine, B. D. (2004). Hemodynamics of orthostatic intolerance: implications for gender differences. *American Journal of Physiology. Heart and Circulatory Physiology, 286*(1), 449-457.

Gans, A. M. Kenny, M. C. & Ghany, D. L. (2003). Comparing the self-concept of students with and without learning disabilities. *Journal of Learning Disabilities, 36*(3), 287-295.

Ganschow, L., Phillips, L., & Schneider, E. (2001). Closing the gap: Accommodating students with language learning disabilities in college. *Topics in Language Disorders, 21*(2) 17-37.

Gray, P.(2002). *Disability discrimination in education: A review of the literature on discrimination across the 0-19 age range*. Disability Rights Commission. London.

Gersten, R., & Smith-Johnson, J. (2000). Songs of experience: Commentary of "dyslexia the invisible" and "promoting strategic writing by postsecondary students with learning disabilities: A report of three case studies." *Learning Disability Quarterly, 23*(3), 171-174.

Getzel, E. E. (2008). Addressing the persistence and retention of students with disabilities in higher education: Incorporating key strategies and supports on campus. *Exceptionality, 16*(4), 207-219.

Getzel, E. E. & Wehman, P.(Eds.) (2005). *Going to College: Expanding Opportunities for People with Disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co.

Giada, F., Silvestri, I., Rossillo, A., Nicoters, P.G., Manzillo, G.F. & Ravieke, A. (2005). Psychiatric profile, quality of life and risk of syncopal recurrence in patients with tilt-induced vasovagal syncope. *The European Society of Cardiology 7*(5), 465-471.

Gill, C. J. (1997). Four types of integration in disability identity. *Journal of Vocational Rehabilitation, 9*(1), 39-46.

Glesne, C. (2006). *Becoming qualitative researchers: An introduction* (3rd ed.). White Plains, NY: Longman.

Gobbo, K., & Shmulsky, S. (2007). Meeting the needs of students with complex psychological and educational profiles. *College Teaching, 55*(3), 134- 136.

Graham-Smith, S. & Lafayette, S. (2004). Quality disability support for promoting belonging and academic success within the college community. *College Student Journal, 38*(1), 90-99.

Green, T. G., Marti, N. C. & McClenney, K. (2008). The effort-outcome gap: Differences for African American and Hispanic community college students in student engagement and academic achievement. *Journal of Higher Education, 78*(5), 513-539.

Grubb, B. P.(2008). Postural tachycardia syndrome. *Circulation* 117: 2814-2817.

Grubb, B. P.(2007). *The Fainting Phenomena*, (2nd ed). Malden, MA: Blackwell Futura Press.

Grubb, B. P (2006).  A simple faint? *Journal of Cardiovascular Electrophysiology, 17*,
    1004.

Grubb, B. P.(2005a).  Dysautonomia (orthostatic) syncope. In B. P. Grubb & B.
    Olshansky (eds.) *Syncope: Mechanisms and Management*, (2nd ed.) (pp.273-286).
    Malden, MA: Blackwell Publishing.

Grubb, B.P.(2005b).  Neurocardiogenic syncope and related disorders of orthostatic
    intolerance. *Circulation* 111:2997-3006.

Grubb, B. P.(2005c).  Neurocardiogenic syncope. *New England Journal of Medicine*
    352:1004-1010.

Grubb, B.P.& Friedman, R. (2005).  Syncope in the child and adolescent. In B. P. Grubb
    & B. Olshansky (eds.) *Syncope: Mechanisms and Management*, (2nd ed.) (pp.273-
    286). Malden, MA: Blackwell Publishing.

Grubb, B. P., Kanjwal, Y., Karabin, B. & Imran, N. (2008).  Orthostatic hypotension and
    autonomic failure. *Clinical Medicine: Cardiology, 2*, 271-291.

Grubb, B.P.& Kosinski, D. (2001).  Update on recent developments in the study of
    disorders of orthostatic intolerance. *Cardiac Electrophysiologial Review 5*(4),
    425-426.

Grubb, B. P.& Olshansky, B. (Eds.). (2005).  *Syncope: Mechanisms and management*
    (2nd ed.) Malden, MA: Blackwell Publishing.

Gobbo, K. & Shmulsky, S. ( 2007).  Meeting the needs of students with complex
    psychological and educational profiles. *College Teaching, 55*(3), 134-136.

Goldstein, D. S., Holmes, C., Frank, S. M., Dendi, R, Cannon, R. O., Sharabi, Y, Esler,

      M. D. & Eisenhofer, G. Cardiac sympathetic dysautonomia in chronic orthostatic

      intolerance. *Circulation, 106*, 2358-2365.

Graham-Smith, S., English, R. & Vasek, D. (2002).  Student and parent involvement in

      the transition process for college freshman with learning disabilities. *College*

      *Student Journal*, *36*.

Guiffrida, D. A. (2004).  Friends from home: Asset and liability to African American

      students attending a predominantly white institution. *NASPA Journal, 41*(3) 693-

      708.

Hadley, W. H. (2006).  L.D. students' access to higher education: Self-advocacy and

      support. *Journal of Developmental Education, 30* (2). 10-16.

Hadley, W. M (2007, Spring).  The necessity of academic accommodations for first-year

      college students with learning disabilities. *Journal of College Admissions,* 9-13.

Hamill, R.W. & Shapiro, R.E. (2004).  "Peripheral autonomic nervous system." In

Robertson D., Biggioni, I., Burstock, G. & Low, P.A. (eds.) *Primer on the Autonomic*

      *Nervous System*, 2nd ed.,  pp.20-27. San Diego, CA: Elsevier Academic Press.

Hamrick, F. A., Evans, N. J. & Schuh, J. H. (2002).  *Foundations of student affairs*

      *practice.* San Fransisco, CA:  John Wiley & Sons, Inc.

Harper, S. R., Carini, R. M., Bridges, B. K. & Hayek, J. C. (2004).  Gender differences in

      student engagement among African American undergraduates at historically black

      colleges and universities. *Journal of College Student Development, 45*(3), 271-

      284.

Hardiman, R. & Jackson, B. W. (1997). Conceptual foundations for social justice

    courses: A sourcebook. In Adams, M., Bell, L. A. & Griffin, P.(Eds.) *Teaching*

    *for Diversity and Social Justice (*pp.16-29). London: Routledge.

Hawkins, R., & Paris, A. E. (1997). Computer Literacy and Computer Use among

    College Students: Differences in Black and White. *Journal of Negro Education.*

    *66* (2), 147-158.

Heiman, T. (2006). Social support networks, stress, sense of coherence and academic

    success of university students with learning disabilities. *Social Psychology of*

    *Education*, *9*(4), 461-478.

Helms, J. E. (1990). *Black and White racial identity: Theory, research and practice.*

    Westport, CT: Praeger.

Henderson, C. (1995). *College freshman with disabilities: A triennial statistical profile*.

    Heath Resource Center, American Council on Education. Washington, DC.

Hergenrather, K. (2007). Exploring undergraduate student attitudes toward persons with

    disabilities: Application of the disability social relationship scale. *Rehabilitation*

    *Counseling Bulletin, 50*(2), 66-75.

Hersh, R. H. & Merrow, J. (2005). *Declining by degrees.* New York, NY: Palgrave

    MacMillan.

Hindes, Y. & Mather, J. (2007). Inclusive education at the post-secondary level:

    Attitudes of students and professors. *Exceptionality Education Canada, 17* (1), 1

    107-128.

Hingston, R., Heeren, Winter, M. & Wechsler, H. (2005). The magnitude of alcohol

    Related morbidity and mortality among U. S. college students ages 18-24:

    Changes from 1998-2001. *Annual Reviews of Public Health, 26*, 259-279.

Hodges, J. S. & Keller, J. M. (1999). Perceived influences on social integration by

    students with physical disabilities. *Journal of College Student Development,*

    *40*(6), 678-686.

Hodges, J. S. & Keller, J. M. (1999). Visually impaired students' perceptions of their

    social integration in college. *Journal of Visual Impairment & Blindness, 93*(3),

    153-165.

Hotchkiss, J. L. (2004). A closer look at the employment impact of the Americans with

    Disabilities Act. *Journal of Human Resources, 39*(4), 887-911.

Hermes, J. J. (2008, June 13). Attempt to broaden disabilities act concerns some college

    officials. *The Chronicle of Higher Education, 54*(40).

Hu, S, & Kuh, G. D. (2003). Diversity experiences and college student learning and

    personal development. *Journal of College Student Development, 44*(3), 320-334.

Hurtdao, S., Han, J. C., Sainz, V. B., Espinosa, L. L, Cabrera, N. L. & Cerna, O. S.

    (2007). Predicating transition and adjustment to college: biomedical and

    behavioral science aspirants' and minority students' first year of college.

    *Research in Higher Education, 48*(7), 841- 887.

Johnson, S. D. (1997). The multiple hats of identity: Addressing the various components

    of African American identity in student development. *College Student Affairs*

    *Journal, 16*(2), 65-72.

Janiga, S. J. & Costenbader, V. (2002). The transition from high school to postsecondary education for students with learning disabilities: A survey of college service coordinators. *Journal of Learning Disabilities, 35*(5), 462-479.

Jones, S. R. & McEwen, M. K. (2000). A conceptual model of multiple dimensions of identity. *Journal of College Student Development, 41*(4), 405-414.

Josselson, R. (1987). *Finding herself: Pathways to identity development in women.* San Franscisco, CA: Jossey-Bass.

Junco, R. & Mastrodicasa, J. (2007). *Connecting to the Net.Generation: What higher education professionals need to know about today's students.* Waldorf: MD. National Association of Student Personnel Administrators (NASPA).

Kashikar-Zuck, S., Lynch, A. M., Graham, T. B., Swain, N. F., Mullen, S. M. & Noll, R. B. (2007). Social functioning and peer relationships of adolescents with juvenile fibromyalgia syndrome. *Arthritis & Rheumatism, 57*(3), 474-480.

Kim, J. (1981). *The process of Asian American identity development: A study of Japanese American womens' perceptions of their struggle to achieve positive identities.* Unpublished doctoral dissertation, University of Massachusettes at Amherst.

Kinavey, C. (2006). Explanatory models of self-understanding identity in adolescents born with spina bifida. *Qualitative Health Research, 16*(8), 1091-1107.

Kinzie, J., Thomas, A. D., Palmer, M. M., Umbach, P.D. & Kuh, G. D. (2007). Women students at coeducation and women's colleges: How do their experiences compare? *Journal of College Student Development, 48*(2), 145-165.

Klinger, L. (2005). Occupational adaptation: Perspectives of people with traumatic brain injury. *The Journal of Occupational Science, 12*(1), 9-16.

Kraska, M. (2003). Postecondary students with disabilities and perceptions of faculty members. *Journal for Vocational Special Needs Education, 25*(2/3), 11-19.

Kravets, M. (2006). Hidden abilities: Another diverse population. *Journal of College Admission, 190*, 18-25.

Kuh, G. D. (2003). What we're learning about student engagement from the NSSE: Benchmarks for effective educational practices. *Change, 35*(2), 24-32.

Kuh, G. D. (2001). Assessing what really matters to student learning: Inside the National Survey of Student Engagement. *Change, 33*(3), 10-17.

Kuh, G. D., Kinzie, J., Buckley, J., Bridges, B. & Hayek, J. C. (2006a). *What Matters To Student Success: A Review of the Literature.* Bloomington, IN: Indiana University Bloomington, Final report from the National Postsecondary Education Cooperative and National Center for Educational Statistics, University Center for Postsecondary Research.

Kuh, G. D., Kinzie, J., Cruce, T., Shoup, R. & Gonyea, R. M. (2006b). *Connecting the dots: Multi-faceted analysis of the relationship between student engagement results from the NSSE, and the institutional practices and conditions that foster student success.* Bloomington, IN: Indiana University Bloomington, Center for Postsecondary Research.

Kuh, G. D., Kinzie, J. Schuh, J.H., Whitt, E, J., et al. (2005). *Student success in college: Creating conditions that matter.* San Franscisco, CA: Jossey-Bass.

Kuh, G. D., Pace, C. R. & Vesper, N. (1997). The development of process indicators to estimate student gains associated with good practices in undergraduate education. *Research in Higher Education, 38*, 435-454.

LaFrombise, T. D., Trimble, J. E. & Mohatt, G. V. (1990). Counseling intervention and American Indian tradition: An integrative approach. *The Counseling Psychologist, 18*(40) , 628-654.

Laird, T. F. N. Bridges, B. K., Morelon-Quainoo, C. L.,Williams, J. M. & Holmes, M. S. (2007). African American and Hispanic student engagement at minority serving and predominantly white institutions. *Journal of College Student Development, 48*(1), 40-56.

Leedy, P.& Ormrod, J. E. (2004). *Practical research: Planning and design.* (8th Ed.). Upper Saddle River, NJ: Prentice Hall.

Leyser, Y. & Greenberger, L. (2008). College students with disabilities in teacher education: Faculty attitudes and practices. *European Journal of Special Needs Education, 23*(3), 237-251.

Leyser, Y., Vogel, S., Wyland, S. & Brulle, A. (1998). Faculty attitudes and practices regarding students with disabilities: Two decades after implementation of Section 504. *Journal on Postsecondary Education, and Disability, 13*(3).

Lindstrom, L. E. & Benz, M. R. (2002). Phases of career development: Case studies of young women with learning disabilities. *Council for Exceptional Children, 69*(1), 67-83.

Lipka, S. (2006). For the learning disabled, a team approach to college. *The Chronicle of Higher Education,* 53(17), 1D 15.

Linzer, M., Varia, I., Pontinen, M., Divine, G. W., Grubb, B. P.& Estes, N. A. III (1992). Medically unexplained syncope: relationship to psychiatric illness. *American Journal of Medicine, 92*(1A), 185-255.

Linzer, M., Gold, D., Pontinen, M., Divine, G., Felder, A. & Brooks, B.W. (1994). Recurrent syncope as a chronic disease. *Journal of General Internal Medicine, 9*(4), 1525-1497.

Lipsitz, L. & Grubb, B.P.(2005). "Syncope in the Elderly." In *Syncope: Mechanisms and Management*, 2nd ed., edited by Blair P. Grubb and Brian Olshansky, pp.301-314. Malden, Massachusetts: Blackwell Publishing.

Lock, R. H. & Layton, C. A. (2001). Succeeding in postsecondary education through self advocacy. *Teaching Exceptional Children, 34*(2), 66-71.

Longmore, P.K. (2003). *Why I burned my book and other essays on disabilities.* Philadelphia: PA: Temple University Press.

Low, P.(2004). Neropathic postural tachycardia syndrome. In D. Robertson, I. Biggioni, G. Burstock & P. Low (Eds.), *Primer on the Autonomic Nervous System*, (2nd ed) (pp.341-342). San Diego, CA: Elsevier Academic Press.

Low, P., Opfer-Gehrking, T., Textor, S., et al., (1995). Postural tachycardia syndrome. *Neurology* 45:519-525.

Lundberg, C. A. (2007). Student involvement and institutional commitment to diversity as predictors of Native American student learning. *Journal of College Student Development, 48*(4), 405-416.

Lundberg, C. A., Schreiner, L. A., Hovaguimian, K. D. & Miller, S. S. (2007). First

    generation status and student race/ethnicity as distinct predictors of student

    involvement and learning. *NSPA, 44*(1), 57-83.

Lynch, R. T. & Gussel, L. (1996). Disclosure and self-advocacy regarding disability

    related needs: Strategies to maximize integration in postsecondary education.

    *Journal of Counseling & Development, 74*, 352-357.

Madaus, J. W. (2006). Employment outcomes of university graduates with learning

    Disabilities. *Learning Disabilities Quarterly, 29*(1), 19-31.

Madaus, J. W. (2000). Services for college and university students with disabilities: A

    historical perspective. *Journal of Postsecondary Education and Disability, 14*(1),

    4-21.

Malakpa, S. W. G. (1997). The problems in the admission and retention of students with

    disabilities in higher education. *Journal of College Admission, 156*, 12-19.

Mangan, K. S. (2004). Students with disabilities sue over medical-school admissions

    test. *The Chronicle of Higher Education, 50*(48), A33.

Marcia, J. E. (1980). Identity in adolescence. In J. Adelson (Ed). *Handbook of*

    *Adolescent Psychology (pp.159-187).* New York, NY: John Wiley

Marom, M., Cohen, D. & Naon, D. ( 2007). Changing disability-related attitudes and

    self-efficacy of Israeli children via the "Partners to inclusion programme."

    *International Journal of Disability Development, and Education, 54*(1), 113-127.

Marshall, C. & Rossman, G. B. (2006). *Designing qualitative research.* Thousand Oaks,

    CA: Sage Publications, Inc.

McDougall, J., Dewit, D. & King, G. (2004).  High school-aged youths' attitudes toward

their peers with disabilities: The role of school and student interpersonal factors.

*International Journal of Disability Development, and Education, 51*(3), 287-313.

McGrady, A., Kern-Buell, C., Bush, E., Khuder, S. & Grubb, B.P.(2003).  Psychological

and physiological factors associated with tilt table testing for neurally mediated

syncopal syndromes. *Pacing and Clinical Electrophysilogy, 24*(3), 296-301.

McPhail, J. C. & Freeman, J. G. (2005).  Beyond prejudice: Thinking toward genuine

inclusion. *Learning Disabilities Research & Practice, 20*(4), 254-267.

Mfofu, E. & Harley, D. A. (2006).  Racial and disability identity: Implications for the

career counseling of African Americans with disabilities. *Rehabilitation*

*Counseling Bulletin, 50*(1), 14-23.

Milsom, A. & Hartley, M. T. (2005).  Assisting students with learning disabilities

transitioning to college: What school counselors should know. *Professional*

*School Counseling, 8*(5), 436-441.

Mitchell, D. T. & Snyder, S. L. (2001).  The uneasy home of disability in literature and

film. In G. L. Albrecht, K. G. Seelman & M. Bury (Eds.), *Handbook of Disability*

*Studies.* (pp.195-218 ). Thousand Oaks, CA: Sage Publications, Inc.

Murray, C. & Wren, C. T. (2003).  Cognitive, academic, and attitudinal predictors of the

grade point averages of college students with learning disabilities. *Journal of*

*Learning Disabilities, 36*(5), 407-415.

Murray, C., Wren, C. T. &  Keys, C. (2008).  University faculty perceptions of students

with learning disabilities: Correlates and group differences. *Learning Disabilities*

*Quarterly, 31*(3), 95-113.

National Center on Addiction and Substance Abuse at Columbia University (2003).

     Annual Report 2003.

National Center for Educational Statistics (2006). *Profile of undergraduates in U.S.*

     *postsecondary education institutions:* 2003-2004 (NCES 2006-84). U.S.

     Department of Education. Washington, DC: U.S. Government Printing Office.

National Center for the Study of Postsecondary Educational Supports (NCSPES) (2000).

     *Technical report: Postsecondary education and employment for students with*

     *disabilities: Focus group discussions on supports and barriers in lifelong*

     *learning.* National Center for the Study of Postsecondary Educational Supports.

     Honolulu, HI: University of Hawaii at Manoa, Center on Disabilities Studies.

National Council on Disability (2008, January). *National disability policy: A progress*

     *Report.* Washington, DC: Author.

National Council on Disability. (2003, September). *People with Disabilities and*

     *Postsecondary Education.* Washington, DC: Author.

National Survey of Student Engagement. (2001). *Improving the college experience:*

     *National benchmarks for effective educational practices.* Bloomington, IN:

     Indiana University, Center for Postsecondary Research

National Survey of Student Engagement. (2009). Retrieved February 18, 2009 from

     www.nsse.iub.edu.

Nichols, A. H., and Quaye, S. J. (2009). "Beyond Accommodation: Removing barriers to

     academic and social engagement for students with disabilities." In *Student*

     *Engagement in Higher Education: Theoretical Perspectives and Practical*

*Approaches for Diverse Populations,* edited by Shaun R. Harper and Stephen John Quaye, pp.39-60. New Yourk, NY: Routledge.

Nochi, M. (2000). Reconstructing self-narratives in coping with traumatic brain injury. *Social Science and Medicine, 51*(12), 1795-1804.

Novak, v., and Lipsitz, L.A. (2004). "Aging and the autonomic nervous system." In *Primer on the Autonomic Nervous System*, 2$^{nd}$ ed., edited by editor in chief David Robertson, editors Italo Biggioni, Geoffrey Burstock and Phillip A. Low, pp.191-193. San Diego, California: Elsevier Academic Press.

Norton, S. M. (1997). Examination accommodations for community college students with learning disabilities: How are they viewed by faculty and students? *Community College Journal of Research and Practice, 21*(1), 57-69.

Nowicki, E. A. (2006). A cross-sectional multivariate analysis of children's attitudes towards disabilities. *Journal of Intellectual Disability Research, 50*(5), 335-348.

Ong-Dean, C. (2005). Reconsidering the social location of the medical model: An examination of disability in parenting literature. *Journal of Medical Humanities, 26*(2/3), 141-158.

Ownsworth, T., Merrill, T., Brooke, A. & Fleming, J. (2008). Participant perspectives on an individualized self-awareness intervention following stroke: A qualitative case study. *Neuropsychological Rehabilitation, 18*(5-6), 692-712.

Pascarella, E. T. & Terenzini, P.T. (2005). *How college affects students.* San Francisco, CA: Jossey-Bass.

Patston, P.(2007).  Constructive functional diversity: A new paradigm beyond disability
and impairment. *Disability and Rehabilitation: An International,
Multidisciplinary Journal, 29*(20-21), 1625-1633.

Pennington, H. (2004, December).  *Fast Tract to College: Increasing Postsecondary
Success for All Students.* Boston: Jobs for the Future.

Perry, W, G., Jr. (1970).  *Forms of Intellectual and Ethical Development in The College
Years: a Scheme.* New York, NY: Holt, Rinehart, and Winston.

Peter, D. (1997).  A focus on the individual. Theory and reality; Making the connection
through the lives of individuals. In Brown, R. E. (Ed), *Quality of life for people
with disabilities: Models, research and practice* (2nd ed., pp.27-55). Cheltenham,
UK: Stanley Thornes (Publishers) Ltd.

Petrella, L., McColl, M., Krupa, T. & Johnson, J. (2005).  Returning to productive
activities: Perspectives of individuals with long-standing acquired brain injuries.
*Brain Injury, 19*(9), 643-655.

Phillip, P.(1990).  A self-advocacy plan for high school students with learning
disabilities. *Journal of Learning disabilities, 23*(8), 466-471.

Phinney, J. S. (1990).  Ethnic identity in adolescents and adults: A review of the research.
*Psychological Bulletin, 108*, 499-514.

Phinney, J. S. (1992).  The multi-group ethnic identity measure: A new scale for use with
diverse groups. *Journal of Adolescent Research, 7*, 156-176.

Pickler, R. H. (2007).  Evaluating qualitative research studies. *Journal of Pediatric
Health Care, 21*, 195-197.

Pike, G. R. (1999). The effects of residential learning communities and traditional residential living arrangements on educational gains during the first year of college. *Journal of College Student Development, 40*(3), 269-284.

Pike, G. R. & Kuh, G. D. (2005). First- and second-generation college students: A comparison of their engagement and intellectual development. *Journal of Higher Education, 76*(3), 276-300.

Pike, G. L., Kuh, G. D. & Gonyea, R. M. (2007). Evaluating the rationale for affirmative action in college admissions: Direct and indirect relationships between campus diversity and gains in understanding diverse groups. *Journal of College Student Development, 48*(2), 1-17.

Pocock, A., Lambros, S., Karvonen, M., Test, D. W., Algozzine, B., Wood, W., & Martin, J. E. (2002). Successful strategies for promoting self-advocacy among students with LD. *Intervention in School and Clinic, 37*(4), 209-216.

Polczynska-Fiszer, M. & Mazaux, J. M. (2008). Second language acquisition after traumatic brain injury: A case study. *Disability and Rehabilitation, 30*(18), 1397 1407.

Praisner, C. L. (2003). Attitudes of elementary school principals toward the inclusion of students with disabilities. *Exceptional Children, 69*(2), 135-145.

Putman, M. (2005). Conceptualizing disability. *Journal of Disability Policy Studies, 16*(3), 188-198.

Rao, S. (2004). Faculty attitudes and students with disabilities in higher education: A literature review. *College Student Journal, 38*(2).

Ramsay, S., Jones. E. & Barker, M. (2007). Relationship between adjustment and

    support types: young and mature-aged local and international first year students.

    *Higher Education, 54*(2), 247-265.

Reis, S. M., McGuire, J. M. & Neu, T. W. (2000). Compensation strategies used by

    high-abiltiy students with learning disabilities who succeed in college. *Gifted*

    *Child Quarterly, 44*(2), 123-

Rhodes, P., Nocon, A., Small, N. & Wright, J. (2008). Disability and identity: The

    challenge of epilepsy. *Disability and Society, 23*(4), 385-395.

Rolfe, G. (2006, December). Validity, trustworthiness, and rigor: quality and the idea of

    qualitative research. *Methodological Issues in Nursing Research.* 304-310.

Rollinson, N.L. (2005) Understanding and managing neurally mediated syncope in the

    adolescent. *Journal of School Nursing 21*(4): 200-207

Rose, M. (2000). The relationship between health-related quality of life and the

    frequency of spells in patients with syncope. *Journal of Clinical Epidemiology*,

    *53*(12), 1209-1216

Ryan, J. (2007). Learning disabilities in Australian universities: hidden, ignored

    unwelcome. *Journal of Learning Disabilities, 44*(5), 436-442

Saghatoleslami, M. (2005). *Adjustment to college: College students with learning*

    *disabilities.* Alder School of Professional Psychology. Publication Number

    AAT3173693

Santhouse, J., Carrier, C., Arya, S., Fowler, H. & Duncan, S. A. (2007). Comparison of

    self reported quality of life between patients with epilepsy and neurocardiogenic

    syncope. *Epilepsia, 48*(5), 1019-1022.

Santos, S. J., Ortiz, A. M., Morales, A. & Rosales, M. (2007). The relationship between campus diversity, students' ethnic identity and college adjustment: A qualitative study. *Cultural Diversity and Ethnic Minority Psychology, 13*(2), 104-114.

Schaller, J. E. (2008). Reconfiguring disability: Multiple and narrative constructions of self. *Pastoral Psychology, 57*, 89-99.

Schlossberg, N. K., Waters, E. B. & Goodman, J. (1995). *Counseling adults in transition: Linking theory to practice.* New York, NY: Springer

Schwandt, T. A. (2007). *The SAGE dictionary of qualitative inquiry.* Thousand Oaks, CA: Sage Publications, Inc.

Schwartz, C. E., Anderson, E. M., Nosek, M. A., Krahn, G. & the RRTC Expert Panel on Health Status Measurement. (2007). Response Shift Theory: Important implications for measuring quality of life in people with disability. *Archives of Physical Medicine and Rehabilitation, 88*(4), 529-536.

Schwartz, S. J., Cote, J. E. & Arnett, J. J. (2005). Identity and agency in emerging adulthood. *Youth & Society, 37*(2), 201-229.

Schutz, P.F. (2002). Transition from secondary to postsecondary education for students with disabilities: an exploration of the phenomenon. *Journal of College Reading and Learning, 33*(1), 46-61.

Scott, S. S. (1996). Understanding colleges: An overview of college support services and programs available to clients form transition planning through graduation. *Journal of Vocational Rehabilitation, 6*, 217-230.

Shakespeare, T. (1996). "Disability, identity and difference". In Barnes, C. & Mercer, G. (eds.), *Exploring the divide.* pps. 44-113. Leeds: The Disability Press.

Shaw-Zirt, B., Popali-Lehane, L., Chaplin, W. & Bergman, A. (2005). Adjustment, social skills, and self-esteem in college students with symptoms of ADHD. *Journal of Attention Disorders, 8*(3), 109-120.

Singh, D. K. (2005). Students with disabilities and higher education. *Journal of American College Health, 53*(5), 210.

Stage, F. K. & Milne, N. V. (1996). Invisible scholars: Students with learning disabilities. *Journal of Higher Education, 67*(4), 426-445.

Stake, R. E. (1995). *The art of case study research*. Thousand Oaks, CA: Sage Publications.

Stake, R. E. (2006). *Multiple case study analysis.* New York, NY: The Guilford Press.

Stearns, P.N. (1994). *The encyclopedia of social history*. New York, NY: Garland.

Stewart, J. M. (2004). Chronic orthostatic intolerance and the postural tachycardia syndrome (POTS). *Journal of Pediatrics, 145*, 725-730.

Sunderland, S. (2008). Opening the door to higher education: Rights of the Intellectually different to access and peace. *Disability Studies Quarterly,* 28(4).

Swain, J. & French, S. (2000). Towards an affirmation model of disability. *Disability & Society, 15*(4), 569-582.

Syed, M. & Azmitia, M. (2008). A narrative approach to ethnic identity in emerging adulthood: Bringing life to the identity status model. *Developmental Psychology, 44*(4), 1012-1027.

Taub, D. J. & McEwen, M. K. (1992). The relationship of racial identity attitudes to autonomy and mature interpersonal relationships in black and white undergraduate women. *Journal of College Student Development, 33*(5), 439-446.

Taylor, M. (2004).  Widening participation into higher education for students with a
    disability. *Education and Training, 46*(1), 40-48.

Taylor, S. & Epstein, R. (1999).  *Living well with a hidden disability: Transcending
    shame and doubt and reclaiming your life.* Oakland, CA: New Harbinger
    Publications.

Test, D. W., Fowler, C. H., Wood, W. M., Brewer, D. M. & Eddy, S. (2005).  A
    conceptual framework of self-advocacy for students with disabilities. *Remedial
    and Special Education, 26*(1), 43-54.

The National Center on Addiction and Substance Abuse (CASA) at Columbia
    University.(2003).  *Depression, substance abuse, and college student
    engagement: A review of the literature.* New York: The National Center on
    Addiction and Substance Abuse (CASA) at Columbia University.

Torres, V., Howard-Hamilton, M. F. & Cooper, D. L. (2003).  *Identity development of
    diverse populations: Implications for teaching and administration in higher
    education.* ASHE-Eric Higher Education Report: *29*(6). Hobokin: NJ. Jossey-
    Bass.

Tyson, A. (1998).  *How I retired at 26! A step-by-step guide to accessing your freedom
    and wealth at any age*. Dearborn, MI: ATD Publishing.

Ullah, H. & Wilson, M. A. (2007).  Students' academic success and its association to
    student involvement with learning and relationships with faculty and peers.
    *College Student Journal, 41*(4), 1192-1202

Umana-Taylor, A. J., Vargas-Chanes, D., Garcia, c. D. & Gonzales-Baken, M. (2008). A longitudinal examination of Latino adolescents' ethnic identity, coping with discrimination, and self-esteem. *The Journal of Early Adolescence,* 28, 16-50.

Umbach, P.D. & Wawrzynski, M. R. (2005). Faculty do matter: The role of college faculty in student learning and engagement. *Research in Higher Education, 46*(2), 135-182.

United States Congress. (2009 September, 9) *Americans with Disabilities Act.* Public Law 101-336. www.sba.gov

University of Washington (2000). *College survival skills: Tips for students with disabilities to increase college success.* Seattle, WA.

Van Dijk, N., Sprangers, M.A., Colman, N., Boer, K.R., Wieling, W., & Linzer, M. (2006). Clinical factors associated with quality of life in patients with transient loss of consciounsness. *Journal of Cardiovascular Electrophysiology, 17*(9), 998-1003.

Velde, B. P.(1994). Quality of life through personally meaningful activity. In Brown, R. E. (Ed), *Quality of Life for People with Disabilities: Models, Research and Practice (2$^{nd}$ ed),* pp.116-150. Cheltenham, UK: Stanley Thornes (Publishers) Ltd.

Walling, L.L. (Eds). (1996). Hidden abilities—visible disabilities. In L. L. Walling (Ed.), *Hidden abilities in higher education: New college students with disabilities.* (Monograph Series No. 21). Columbia, South Carolina: South Carolina University, National Resource Center for the Freshman Year Experience and Students in Transition.

Wasley, P.(2006).  Underrepresented students benefit most from "engagement." *The Chronicle of Higher Education, 53*(13), 1N17.

Watters, J. K. & Biernacki, P.(1989).  Targeted sampling: Options for the study of hidden populations. *Social Problems, 36*(4), 416-430.

Weber, M. C. (2002).  Disability discrimination in higher education. *Journal of College and University Law, 28*(2), 439-465.

Weeber, J. E. (2004).  *Disability community leaders' disability identity development: A journey of integration and expansion.* Unpublished doctoral dissertation, North Carolina State University, Raleigh.

Wilson, L. (2004).  Towards equality: the voices of young disabled people in Disability Rights Commission research. *Support for Learning, 19*(4), 162-188.

Wolf-Branigin, M., Schuyler, V. & White, P.(2007).  Improving quality of life and career attitudes of youth with disabilities: Experiences from the adolescent employment readiness center. *Research on Social Work Practice, 179*(3), 324-333.

Zucker, D., M. (2001).  Using case study methodology in nursing research. *The Qualitative Report, 6*(2).

*Request to Use Web Site to Recruit Participants*

**Foundations of Education**
**Judith Herb College of Education**
**Mail Stop 914**
**2901 West Bancroft Street**
**Toledo, OH 43606-3390**

THE UNIVERSITY OF
**TOLEDO**
1872

Debbie Dominelli, President DYNA, Inc.
1301 Greengate Court
Waldorf, MD  20601
Phone: 301-705-6995
Email: www.dynakids.org
Date:  August 16, 2008


Dear Ms. Dominelli,


As per our previous conversation in July 2008 at the Dysautonomia Youth Network (DYNA)  "Summer Chill", we would like to recruit college age students diagnosed with dysautonomia/orthostatic intolerance to participate in a research study titled "Student Engagement in the College Setting for Students with the Hidden Disability of Orthostatic Intolerance: How level is the playing field? Briefly, we would like to interview 4 students about their college experience as a student with the hidden disability of orthostatic intolerance, and observe each student for a few hours in their campus setting. This will include accompanying them for a "typical day" on campus over several days.

We would like to recruit a list of potential participants from a posting on the DYNA website. Please see the attached web site posting for the details. Please indicate your approval for a web site posting to recruit participants by signing below. You may contact us at any time for further questions or clarification.

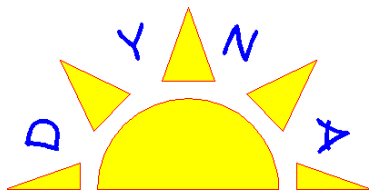Thank you for your consideration,

Sincerely,

Lynne Hamer, PhD. Department of Foundations of Education
    Phone Number: (419) 530-7749
    Email: lynne.hamer@utoledo.edu

Beverly Karabin, MSN. Judith Herb College of Education
    Phone Number:  (419) 205-3136
    Email: beverly.karabin@utoledo.edu

Appendix B:

*Permission for Web Site Recruitment*



**Dysautonomia Youth Network of America, Inc.**

*"A Ray of Hope"*

*Foundations of Education*

Judith Herb College of Education
Anne Hornak, PhD. Assistant Professor
Beverly Karabin, MSN
Mail Stop 914
2901 West Bancroft Street
Toledo, OH 43606-3390

January 27, 2009

Dear Ms. Karabin,

It is with sincere pleasure that, as President of the Dysautonomia Youth Network of America, Inc, (DYNA, Inc), I authorize your request to recruit college age students diagnosed with dysautonomia associated with orthostatic intolerance to participate in your research study titled "Student Engagement in the College Setting for Students with the Hidden Disability of Orthostatic Intolerance: How level is the playing field?

Respectfully,

Debra L. Dominelli

President

**1301 Greengate Court, Waldorf, Maryland 20601**
**(301) 705-6995**
http://www.dynakids.org
Email: info@dynakids.org

305

*Call for Recruitment of Participants*

**Foundations of Education**
**Judith Herb College of Education**
**Mail Stop 914**
**2901 West Bancroft Street**
**Toledo, OH 43606-3390**

**You are invited to participate in a research study entitled "Student Engagement in the College Setting for Students with the Hidden Disability of Orthostatic Intolerance: How level is the playing field?**

Principal Investigator:
Lynne Hamer, PhD.
Phone Number: (419) 530-7749
Email: lynne.hamer@utoledo.edu

Co-Investigator:
Beverly Karabin, MSN.
Phone Number: (419) 205-3136
Email: beverly.karabin@utoledo.edu

**Purpose:**

The purpose of this study will allow college students diagnosed with orthostatic intolerance to tell their stories about their engagement or participation in the college setting. This may allow those in higher education to design programs to assist students with similar hidden disabilities. The study seeks to explore the issue from the student

perspective. The research will ask you about academic, institutional, financial, physical, and social barriers that you may have experienced as a student with a hidden disability, and if so, how this may have affected your college experience, quality of life, and your ability to participate in the college setting. In addition the research will ask you to describe aspects of the college experience that have been helpful in the transition to college life from a the perspective of a student with a hidden disability.

**Procedures and Duration**

If you decide to participate in this research study, you will be asked to participate in two, one time, audio taped, one-on-one interviews with the Co-Investigator that are expected to last no longer than 120 minutes total. In addition the Co-Investigator will accompany you 4-6 hours on your "typical" college day, over a period of 2-3 days and would like you to share documents related to the campus experience. This observation time will allow the researcher to observe you in your campus setting. Thus, we anticipate approximately 8 hours or less for the entire participation time. The interview will be scheduled sometime in February 2009 through April 2009.

**Risks and Discomforts/ Benefits:**

Very minimal discomfort is anticipated; you are not obligated to answer any questions that you are uncomfortable with. The study will be conducted to protect your confidentiality as per the Institutional Review Board protocol. Some benefits to you from participation may be self-reflection and the opportunity to tell your story. The results may

help others to see your point of view and experiences, which may help to validate your experiences.

**Inclusion Criteria:**

1.  College students between the ages 18-25 currently enrolled in a four-year university or college.

2.  Diagnosed with disorder of the autonomic nervous system associated with orthostatic intolerance (POTS, NCS)

3.  Your medical condition must be fairly stable and without severe symptoms.

**If you meet the above criteria, please email your name and contact information to the Co-Investigator. From the candidates, 4 participants will be chosen with hopes to create a diverse sample of different majors, gender, races/ethnic groups, campus settings, and class ranking. If you are selected, you will be contacted via email within thirty days. If not, you may ask for a summary of the study to be emailed to you and to be updated if future research is conducted. Any further questions should be emailed to the Co-Investigator.**

Appendix D:

*Interview Protocol*

***Foundations of Education***
**Judith Herb College of Education**
**Mail Stop 914**
**2901 West Bancroft Street**
**Toledo, OH 43606-3390**

Principal Investigator:
  Lynne Hamer, PhD.
  Phone Number: (419) 530-7749
  Email: lynne.hamer@utoledo.edu

Co-Investigator:
  Beverly Karabin, MSN.
  Phone Number:  (419) 205-3136
  Email: beverly.karabin@utoledo.edu

**Purpose:**

The purpose of this study is to interview college students diagnosed with

orthostatic intolerance about their engagement behaviors in college. The study seeks to

explore the issue from the student perspective.

**Procedures:**

In order to participate in the research study, the participant agrees to participate in

a two time, audio taped, one-on-one interview with the Co-Investigator

**Interview Protocol:**

The proposed research study will explore the question, how do students with the hidden disability of orthostatic intolerance (OI) engage in the campus setting? Sub-questions will seek to discover specifically, what factors contribute to (a) academic engagement patterns, (b) patterns of student social engagement, and (c) engagement in the campus physical and institutional environment.

(a)Academic engagement includes behaviors directed toward learning activities and interaction with the faculty, e.g., participation in practicum, internships, field experience, research, and clinical assignments. Further, academic engagement include activities such as participation in service learning projects, study abroad activities, attending gallery and dance exhibits, theater performances, and community based projects. In addition, academic engagement includes student use of assistive technologies to aid academic success, e.g., note-taking, computer software, texts on tape, study partners, tutors, and faculty mentors.

(b)Social engagement includes behaviors directed towards activities with friends and other classmates, participation in co-curricular activities such as clubs, sororities, fraternities, and recreational activities. Social engagement includes a description of barriers or support that hinder or enhance social activities.

(c)Physical engagement includes behaviors or activities that rely on structural or architectural accessibility on campus, e.g., dormitories, parking, classroom locations, food service location/process, and location of student lounges, student union, and other structural accommodation issues. Institutional engagement refers to behaviors or activities that relate to campus policies, e.g., registration,

310

scheduling, testing procedures and accommodations, and grading. Institutional engagement includes activities that relate to institutional programs or services such student services, disability services, counseling services, and student health services. In addition, institutional engagement includes financial aid factors that contribute to student involvement such as grants, scholarships, tuition costs, and penalties for withdrawal.

Thus, potential themes cutting across all three areas of engagement are expected to center around the following research questions:

1. How do college students with orthostatic intolerance describe their ability to engage in the academic, social, physical structure and institutional campus environment?

2. What experiences do students with orthostatic intolerance perceive as helpful in promoting participation in the campus environment?

3. What obstacles exist in the campus environment that prohibits engagement for students with the hidden disability of orthostatic intolerance?

4. What kind of behaviors and skills do students with orthostatic intolerance perceive to be necessary to achieve successful engagement in the college environment?

5. What kind of campus support exists for students with hidden disabilities?

6. Do students with hidden disabilities perceive the faculty, peer group and college personnel (disability services, student services staff, etc.) as supportive and accepting of his or her condition, and does these perceptions affect their ability to engage in the campus environment?

**Interview Questions:**

1. How do college students with orthostatic disorders describe adjustment to college?

311

a. How would you describe your adjustment to college life thus far?

b. In what way if any has your medical condition of orthostatic intolerance has impact your adjustment to college life?

2. How do college students with orthostatic disorders describe their quality of life?

a. What does quality of life mean to you? Tell me how you describe your quality of life as a college student. Does your illness affect this? If so, how does this impact participation?

3. Has your current perception of your quality of life changed since high school? Through college?

4. How do you describe yourself? (self-identity)

5. What behaviors and skills have you had to develop to achieve a successful college experience?

a. What kind of campus support exists for you as a student with a hidden disability? Have you contacted disability support services about your disability?

b. Have you requested any accommodations? If so, have they helped you to participate?

c. Have you shared your disability with your friends? Faculty? If no, why not?

d. Have you experienced acceptance from faculty and friends? How has this helped you participate?

6. How do college students with orthostatic disorders engage in the college environment?

a. Please describe or talk about your participation with college life.

b. What activities are you a part of on campus?

c. What activities would you like to participate in?

d. What factors contribute to your participation or lack of participation (engagement) in the campus environment?

e. Tell me about your living arrangements.

f. How much of your energy is focused on your college experience? How has that affected the rest of your life?

g. Have you had to make any adjustments in living arrangements based on your disability?

7. What barriers do students with orthostatic intolerance encounter in the college setting?

a. Describe the academic barriers you may have experienced that make your college experience more difficult.

b. How would you generally describe faculty acceptance of your disability? How about friends? Does this perception affect your ability to or desire to participate in academic or social activities?

c. Describe any institutional policy barriers you may have experienced.

d. Have you any noted financial difficulties based on your disability, if so describe these. How has this affected participation or involvement?

e. Have you experienced any physical structural barriers on your campus that add to your difficulty getting around campus? If so, has this affected your ability to participate? What helps in the physical environment of campus?

8. What experiences have been helpful for students to succeed with orthostatic intolerance in the college setting?

    a. Describe positive experiences that have enhanced your ability to succeed and participate despite your disability.

9. How does your engagement experience compare with what you have hoped for?

Although the questions will be used to structure the proposed study and interviews, the interviews will be semi-structured. The questions developed by the researcher are etic or "outside" issues that the researcher brings to the study of the case (s). But according to Stake (1995), the issues and interview questions in qualitative case study research evolve. Other issues may emerge which are important to the participants in the study. These are called emic issues. The interview questions may change depending on the observations and interviews with the participants. Thus, the initial interview questions presented in this proposal may be modified or improved to increase our understanding of the issue, a term called "progressive focusing" (Parlett & Hamilton, as quoted by Stake, 1995, p.9).

*Letter to Students Member Checking*

**Foundations of Education**
**Judith Herb College of Education**
**Mail Stop 914**
**2901 West Bancroft Street**
**Toledo, OH 43606-3390**

June 16, 2009

Dear Students:

Thank you again for the opportunity to share time with you on campus for the study. I am forwarding the transcribed interviews. Please note the identifying information—names, towns, colleges have been changed. You all have a new name! I have several blanks from the tapes, inaudible, or my transcriptionist could not determine. Please feel to fill in the blanks if you wish.

If there is any part of the transcription that you need to clarify please indicate that as well. The key is for me to get to the real meaning of your words—to increase validity of the study (does my question illicit the true meaning from you), this is called member checking—you review your transcripts. Finally, if there is anything else you would like to add, feel free. I am about ½ ways done with the results section. I will present preliminary findings at the DYNA Summer Chill.

Best regards,

Beverly Karabin, University of Toledo, Department of Educational Leadership

Appendix F:

*Document Guidelines*

**Foundations of Education**
**Judith Herb College of Education**
**Mail Stop 914**
**2901 West Bancroft Street**
**Toledo, OH 43606-3390**

Principal Investigator:
   Lynne Hamer, PhD.

   Phone Number: (419) 530-7749

   Email: lynne.hamer@utoledo.edu

Co-Investigator:
   Beverly Karabin, MSN.

   Phone Number:  (419) 205-3136

   Email: beverly.Karabin@utoledo.edu

**Purpose:**

The purpose of this study is to interview college students diagnosed with

orthostatic intolerance about their engagement behaviors in the college setting. The study

seeks to explore the issue from the student perspective.

**Procedures:**

In order to participate in the research study, the participant may share documents

with the researcher. The documents (s) are chosen by the participant and represent

meaning for the student as a college student with the disability of orthostatic intolerance.

The document (s) will not be photographs of individuals, and may not identify the

college. In qualitative inquiry, documents add validity to the research; they assist in

316

describing an experience. The document(s) will be returned to the participant if requested within one year of the interview.

**General questions:**

1. Why did you choose to share this particular document(s)?

2. What does the document say about you as a college student with a hidden disability?

Appendix G:

*Transcription Conventions*

| Description of transcription conventions | | |
|---|---|---|
| Paralinguistic | Notation on transcript | Example |
| Laughter | (laughter) | |
| Pause (less 3 sec) | … | |
| Silence (greater 3 sec) | (Silence) | |
| Emphasis | Bold | right |
| Strong emphasis | BOLD | EXACTLY! |
| Emotional emphasis of word or phrase | *italics* | It was *unbelievable* |
| Incomprehensible speech | _____?? | |
| Omitted words "ums" | not delineated | some |
| Retelling a story in 3<sup>rd</sup> person | "text" | she said, thought, believed |
| Identifiers | CAPITAL LETTERS | COLLEGE, CITY |

Appendix H:

*Themes from Cases*

| Theme |
| --- |
| 1. Physical adjustment to campus |
| 2. Picking your battles/learn to accept/play game |
| 3. Acceptance/Belongingness |
| 4. Loneliness/ Social Isolation |
| 5. Live and learn |
| 6. Skill development |
| 7. Independence/Control |
| 8. Frustration/Hassle |
| 9. Fragmented communication |
| 10. Incongruence: required vs. practice |
| 11. Invisibility of disorder |
| 12. Privacy |
| 13. Embarrassment / fear disclosure |
| 14. Feel like burden |
| 15. Felt disbelief / doubt illness / faking it |
| 16. Felt need to defend self |
| 17. Dispelling myth of laziness |
| 18. * |
| 19. Lack understanding of illness |

Appendix H continued

| Theme | |
|---|---|
| 20. | Lack of individuality "cookie cutter" / lack of student centeredness |
| 21. | * |
| 22. | Curriculum pressure |
| 23. | Disconnect / feel like outsider |
| 24. | Unpredictability / uncertainty of disorder |
| 25. | Prioritizing activities based on energy / balance /self focus |
| 26. | Reinvent self / identity changes |
| 27. | Physical overwhelmed: involvement not worth effort |
| 28. | Less influence from opinion of others / self acceptance / integration |
| 29. | In transition |
| 30. | Perception vs. reality (fears, discrimination) |
| 31. | Overcoming disability / attempt to disprove myths |
| 32. | Physical functioning day-to-day |
| 33. | Educational aspirations: unanticipated change in plan |
| 34. | Delay of educational goals |
| 35. | Pick and choose whom to tell |
| 36. | Inaccessible campus |
| 37. | Treated different than if visible disability / discrimination |
| 38. | Candid about realities / "that's the way it is" |
| 39. | Learn limitations / self regulation |

Appendix H continued

---

Theme

---

40.     Evaluate / clarify values

41.     *

42.     Studying easier

42.     Studying easier

43.     Unnecessary expenditure of energy

44.     Peer pressure to fit in

45.     Parental support

46.     Question purpose

47.     Lack empathy

48.     Lack knowledge how to access services

49.     Financial penalties

50.     Off campus connections

51.     Take control

52.     Fear of full disclosure

53.     Want special treatment / not defined by illness / disability

54.     Use illness experience to advantage

55.     Supportive / Non-judgmental

56      Self-determination

* 18, 21, 41 condensed into other categories
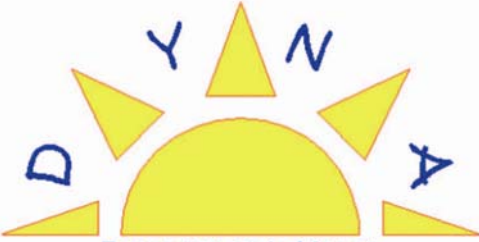
Appendix I:

*Themes into Categories*

| | Categories | Text Notation | Associated Themes |
|---|---|---|---|
| 1. | Academic Engagement | AE | 2, 3, 5, 6, 8, 9, 10, 13, |
| | a. Faculty | | 14,15,16,17,19, |
| | b. Learning Activities | | 20,25,27,29,30, |
| | | | 31, 32, 38, 43, 47, 55 |
| | | | |
| 2. | Social Engagement | SE | 1, 3, 4, 5, 11, 13, 14, 15, |
| | a. Friends | | 6,17,19,23,24,25,27 |
| | b. Campus Groups | | 28,31,32,38,39,40,44,50 |
| | | | |
| 3. | Campus Physical Engagement | CPE | 1, 7, 25, 27, 32, 38, 39 |
| | a. Living Arrangements | | 41,43 45 |
| | b. Campus Setting | | 1,6,13, 33, 42, |
| | c. Transition to College | | |
| | | | |
| 4. | Institutional Engagement | IE | 2, 3, 5, 6, 8, 9, 10, 11, |
| | a. Disability Support Services | | 12,13,16, 17,19,20, |
| | b. Accommodations | | 22, 23,29,30,31,33 |
| | c. Residence Life | | 35, 36,37,38,39,43 |
| | d. Campus Policies | | 45,48,49,52 |
| | e. Financial Support | | |
| | f. Other Services | | |

| | Categories | Text Notation | Associated Themes |
|---|---|---|---|
| 5. | Self-Disclosure | SD/SA | 3,5,6,11,13,24,35 |
| | Self-Advocacy | | 31,38,51 |
| | | | |
| 6. | Identity | I | 2,4,6,11,23,24,26,28, |
| | | | 31,40,44,46,51,53,54,56 |

Appendix J:

Educating the Dysautonomia Student: Dysautonomia n the College Setting

## Awareness Series

# Educating the Dysautonomia Student: Dysautonomia In The College Setting

**Dysautonomia Youth Network of America, Inc.**
"A Ray of Hope"

www.dynakids.org

## What is Dysautonomia?

Dysautonomia is an umbrella medical term that is utilized for a group of complex conditions that are caused by a malfunction of the autonomic nervous system (ANS). The ANS regulates all of the unconscious functions of the body, including, but not limited to, the cardiovascular system, gastrointestinal system, metabolic system, and endocrine system. Orthostatic intolerance (the inability to remain in the upright position without symptoms) is a hallmark of the various forms of dysautonomia. Dysautonomia conditions can range from mild to debilitating and, on rare occasions, can be life threatening. Dysautonomia conditions can be extremely life impacting.

## An Invisible Disability

Prior to the onset of their illness, most college age students that are afflicted with dysautonomia were very athletically, academically, and socially involved young people.

Researches from respected medical facilities [1] have noted that a majority of dysautonomia patients have hyper-mobile joints, fair skin and long, lean body frames. Thus, in our society, dysautonomia patients tend to have the physical traits that we automatically associate with healthy good looks. **Dysautonomia is an invisible illness.**

Students afflicted with dysautonomia may be experiencing any number of the symptoms listed on the opposite page and yet still appear healthy to the casual observer. Furthermore, these symptoms can be unpredictable, continual or intermittent, appear in any combination, and vary in severity. Students with dysautonomia may face skepticism from uninformed professors, friends, roommates, class mates, and society in general.

[1] Autonomics Disorders Clinic—University of Toledo Medical Center, Johns Hopkins Children's Center, Mayo Clinic, National Institute of Health, Children's Heart Clinic

2

## What are the Symptoms?

TACHYCARDIA (EXTREMELY FAST HEART RATE)

BRADYCARDIA (EXTREMELY SLOW HEART RATE)

ORTHOSTATIC HYPOTENSION (LOW UPRIGHT BLOOD PRESSURE)

ORTHOSTATIC INTOLERANCE (INABILITY TO REMAIN UPRIGHT)

SYNCOPE AND NEAR SYNCOPE (FAINTING)

SEVERE DIZZINESS

EXCESSIVE FATIGUE

EXERCISE INTOLERANCE

MIGRAINES

GASTROINTESTINAL ISSUES

NAUSEA

INSOMNIA

SHORTNESS OF BREATH

THERMOREGULATORY ISSUES
(BODY TEMPERATURE REGULATION/INTOLERRANCE TO HEAT)

ANXIETY

TREMULOUSNESS

FREQUENT URINATION

COGNITIVE IMPAIRMENT ("BRAIN FOG")

VISUAL BLURRING OR TUNNELING

SEIZURES

**The only thing predictable about dysautonomia is that it is unpredictable.**

3

## Cognitive Considerations

Students afflicted with dysautonomia conditions may experience periods of hypoxia (low oxygen levels) that can significantly reduce their cognitive capabilities and cause periods of disabling "brain fog" and cognitive impairment.

Alterations in the dysautonomia student's blood flow and neurotransmitters (brain chemicals such as serotonin, dopamine, and adrenaline), as well as blood pressure and blood sugar all contribute to the cognitive issues associated with these conditions.

Brain fog is typically described as confusion and/or a lack of mental clarity. It can feel like a heavy cloud that reduces visibility or clarity of mind. It can cause patients to experience episodic disorientation, forgetfulness, and feelings of detachment from their surroundings. In severe cases brain fog may even manifest as temporary confusion regarding surroundings and the inability to recall names.

The cognitive impairment that is associated with dysautonomia conditions typically involves difficulties with regard to memory, **word finding and word substitution, retrieving and recalling information,** multi tasking, problem-solving, attention, and comprehension.



4

325

## Brain Strain

The aggravating, seemingly minor little things that go wrong each college day and the noisy irritating things which tend to go bump in the night in dorm housing situations — causing stress, disrupting routines and interrupting sleep – can have a cumulative effect on the brain and its ability to remember and learn.

- Metabolic equilibrium can be easily disrupted in dysautonomia patients and thus these students will be sensitive to the impact of stress.

- Due to disruption in the regulation of certain brain chemicals dysautonomia patients are prone to insomnia and require a healthy sleep environment.

- Routine is important. Out of medical need dysautonomia students typically go to bed at scheduled times.

- Dysautonomia students do not have the luxury of maintaining an active social nightlife.

- Noise and light reduction at night is usually necessary for sleep.

A private dorm room may be best, otherwise selection of a respectful and cooperative roommate is absolutely essential.



It is unfair to expect a chronically ill dysautonomia patient to "adapt" to a negative and stressful college roommate situation when their systems are not capable of handling such adaptations.

5

## Physical Limitations

Physically healthy college students are able to rush across campus for classes, meetings, and tutoring sessions. Healthy individuals can stand in lines at the dining hall and book store, sit out in the sun during discussion groups, and attend clubs and activities without health concerns. The dysautonomia student is likely to encounter problems in such settings.

- **Avoid Unnecessary Walking**

Consideration should be made to the distance required to walk to classes, appointments with professors, tutors, study groups, and even to meetings with disability resource staff members.

When possible, schedule such activities near their dorm building or a location that the student can access without over-taxing their systems. Help them conserve their energy for everyday, necessary walking and for their medically approved physical therapy sessions.

- **Avoid Long Lines**

These students may need to avoid unnecessary standing (especially in long lines). Even standing to talk to professors after class can be taxing on their systems. They may need to sit when waiting, lean against a wall, squat, etc. They are not being disrespectful to authority — they are respecting their bodies limitations and conserving their energy and trying not to faint.

- **Allow Breaks**

Sitting too long and prolonged concentration can lower blood pressure, inducing or aggravating many symptoms of dysautonomia. Long lectures and exams may be particularly challenging to a dysautonomia student. A student with dysautonomia may need to stretch and take frequent breaks.

6

326

## Flexibility is a Must

Remember to allow for flexibility as the symptoms of dysautonomia are often inconsistent and the conditions are noted to wax and wane. This unpredictable nature can result in:

- Frequent, unexpected and/or sudden absences. These absences may be brief or they may extend for long periods of time.

- Difficulty meeting deadlines. Even long term assignments may be delayed.

Adaptations for symptomatic days and/or medical relapses may be necessary.

## Testing Accommodations

Testing accommodations are usually necessary.

- Schedule tests in the afternoon.

- Test in a quiet, cool, well ventilated area.

- Allow breaks, extra time, water and salty snacks.

- Unexpected/sudden cancellations may occur.

## Sensory Issues

At various times, the student may not be able to screen out sensory distractions, making it especially hard to focus and function in large group settings. They may not have the necessary "sensory stamina" to tolerate certain types of stimulation.

A student with dysautonomia may find it difficult to tolerate harsh smells, bright lights, loud noises, or other sensory stimuli.

7

## Air Conditioning is Good

Disruption of autonomic function impacts the body's thermoregulatory system. Students afflicted with dysautonomia conditions can not tolerate warm/hot or stuffy environments. Air conditioning is essential.

## Bathrooms are an Issue

Dysautonomia patients may experience frequent urination during the day and night. Allow bathroom breaks during classes and testing.

If possible they should be placed in a dorm room with it's own bathroom due to frequent urination, immune system concerns, fainting and dizziness.

## Mornings are Bad

Early morning classes and exams can pose a significant hardship. This is because blood pressure and blood volume tends to be lowest in the morning. Before running off for the day's activities, dysautonomia patients need time to take their medications, drink plenty of water, eat a healthy breakfast, and allow time for their systems to respond and for the medications to take effect.
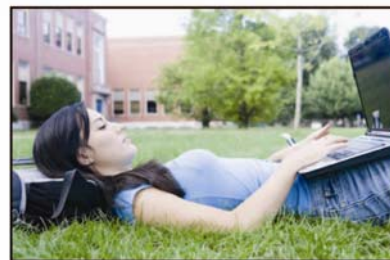


**The college student with a hidden disability is virtually unrecognizable from the non-disabled student on campus.**

8

## Unique Situations

Students afflicted with dysautonomia are even unique among themselves. Those with the exact same medical diagnosis may have very different abilities and disabilities and will often require different accommodations.

## Communication is a Must

- Faculty should work with dysautonomia students on a one-on-one basis.

- Open and comfortable lines of communication are essential to a greater understanding.

- The student afflicted with dysautonomia is the best source of information regarding their condition.

- The student should take an assertive role in communicating with faculty about their disability, adaptations, and accommodations.
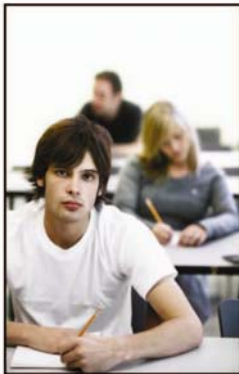
Because of the invisibility of the disability, many students may not be given the same consideration for their disability, such as a student with a visible physical disability. It has been suggested that the "playing field" for this distinct cohort of college students is not level (Kravetz, 1997).

9
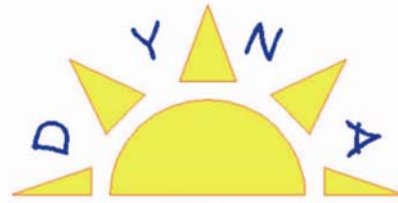
DYNA, Inc.
1301 Greengate Court
Waldorf, MD 20601

Phone: 301-705-6995

Email: info@dynakids.org

STUDENT'S NAME

CELL PHONE NUMBER

EMAIL ADDRESS

CLASS (AND SECTION NUMBER IF AVAILABLE)

NOTES:

Special Thanks To:

Beverly Karabin, RN, MSN, CNP
University of Toledo
Department Educational Leadership
"Student Engagement in the College Setting for Students with the Hidden Disability of Orthostatic Intolerance: How Level is the Playing Field?"

© 2009

www.dynakids.org