KEYS TO UNDERSTANDING AND SERVING COLLEGE STUDENTS WITH CHRONIC ILLNESSES

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ABSTRACT

KEYS TO UNDERSTANDING AND SERVING COLLEGE STUDENTS WITH CHRONIC ILLNESSES

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As the fields of medicine and medical technology continue to advance, more students with chronic illnesses will be able to fulfill their dreams of earning a college degree. These students who may be ill or well at any given time have health issues that affect “normal” life activities and require some form of ongoing medical care. The purpose of this study was to obtain a better understanding of serving college students with chronic illnesses through the lens of both institutions and students. It also provides an opportunity to increase awareness of this underserved population and their unique situations. It is an emerging issue in higher education that needs to be investigated. This exploratory study used the online survey instruments created by the researcher, the College and Universities Serving Students with Chronic Illnesses Survey and College Students with Chronic Illnesses Survey. Respondents were 136 college administrators solicited primarily through the Association for Higher Education and Disability (AHEAD) organization and the Disabled Student Services in Higher Education (DSSHE-L) listserv and 74 students through the snowball sampling strategy. Major themes revealed through the research included communication, training, mentoring and other support services, institutional support, and a lack of support. Almost half of the student respondents who had a chronic illness did not consider themselves to have a disability. Even though institutions pride themselves in their serving these students on a case-by-case basis, these students need different accommodations than those who have physical or learning disabilities. As such, distinct forms of communication are necessary to reach this population. Institutions perceive that they provide the information and students know where to obtain it, while students indicated they had issues obtaining support and information. Both students and institutions believe that training is essential, especially for faculty, as well as to have workshops for students on aspects of coping and managing stress and health issues. The findings of this research serve as a guideline for institutions and provide suggestions to serve this population. Students with chronic illnesses will also find this information beneficial in their pursuit of a college degree.

Keywords: Chronic Illness, College Students, Students, University, College, Postsecondary, Inclusive Education, Chronic Condition, College Adjustment, College Transition, College Accommodations, Disability Resource Offices, Higher Education, College Health Issues

DEDICATION

I dedicate this dissertation in memory of my grandparents. I know that you are looking down upon me and guided me through this process with blessings from above. I wish that you could be here to celebrate this accomplishment. Until we meet again, may God hold you in the palm of His hand.

I also dedicate this dissertation to all current and future college students with chronic illnesses. I know that living with a chronic illness is not easy, but it should not take away your dreams, especially experiencing college. I hope this paper will serve as an inspiration for you to reach the stars and not let anything get in your way, just as your stories have been an inspiration to me while writing this study.

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Finally, to quote Billy Joel:

"These are the last words I have to say
That's why this took so long to write
There will be other words some other day
But that's the story of my life ….
But now it's time to put this book away"

And go root for my Mets.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1: INTRODUCTION

"Life is not a matter of holding good cards, but of playing a poor hand well."

– *Robert Louis Stevenson*

Educational institutions are responsible for all students' experiences, including students with chronic illnesses; however, typical postsecondary policies and procedures may not be designed to support this specific student group with disabilities (Irwin & Elam, 2011). Students with chronic illnesses (SWCI) who continue to pursue their education in college and beyond are prime examples of "playing a poor hand well." These students face numerous challenges in pursuing their educational goals, particularly at the college level, where there are fewer accommodations and supports available than those at the grade school level. They may be well or ill at any given time during the academic year, making it harder to commit to their studies. Not only do they have to deal with the stress and issues of their health, but they also must deal with the stress related to maintaining academic standards and adjusting to college. Although there is a growing body of research investigating student disability and higher education, there is limited research on how students with chronic illnesses become accustomed to college life (Adler et al., 2008; Giroux et al., 2016). They are between two worlds – a world of being "normal" and a world of those with severe disabling issues (Muscari, 1998). Many of their conditions seem "invisible" or "non-visible" or considered to be a "non-apparent disability" (Kranke et al., 2013) to others.

Accommodations within higher education settings are needed as more and more students with chronic illnesses attend college. Mental health issues are also on the rise and are included in the category of non-apparent disabilities. According to the WHO

World Mental Health Surveys International College Student Project: Prevalence and Distribution of Mental Disorders, “35% of those surveyed screened positive for at least one of the common lifetime disorders assessed and 31% screened positive for at least one 12-month disorder” (Auerbach et al., 2018, p.624). Advances in pediatric medicine have decreased many chronic diseases’ mortality rates (Maslow et al., 2012). These advances enable an increasing number of individuals with chronic illness who previously died before continuing their education to participate in schools at all levels. Now, they are becoming an integral part of the educational community (Shiu, 2001). One specific example of a group more often eligible for college is the increased number of childhood cancer survivors. With this increase of survivors into adulthood, there needs to be a focus on these students’ academic needs (Gorin & McAuliffe, 2009). In addition to supporting these students’ educational needs, the students may face additional medical issues as they become older. For example, according to the National Cancer Institute, childhood cancer survivors may have late effects such as issues with their organs and tissues; growth and development; mood swings; thinking and learning; social and psychological adjustments; and the risk of second cancers depending on the type of cancer and treatment they had (PDQ® Pediatric Treatment Editorial Board, 2019). In general, individuals with chronic medical conditions have a higher risk of depression (National Institute of Mental Health, 2019). Necessary accommodations for students with chronic illness may include modified coursework plans, leaves of absence, extended course completion times, provision of time and space for medication or treatment administration, alert systems for acute conditions, special dorm arrangements, special diets at student dining areas, counseling services, peer support, and training for faculty and staff who interact with the student. Since many individuals now seek higher education as part of their career preparation, colleges and universities need to support all students, including students with chronic illnesses.

While there are several different definitions for chronic health conditions that encompass learning disabilities and mental health conditions, for the present study, "chronic health-related illness/es" was defined using the definition of Edelman et al. as well as the U.S. National Center for Health Statistics (National Health Council, 2016) as "one that affects the individual for at least three months and is likely to continue in the future" (Edelman et al., 1998, p 2). Examples include, but are not limited to Arthritis, Asthma, AIDS, Cancer, Chronic Fatigue Syndrome, Celiac Disease, Crohn's Disease, Cystic Fibrosis, Diabetes, Epilepsy, Heart Disease, Kidney Disease, Liver Disease, Lupus, Lyme Disease, Migraines, Muscular Disorders, Multiple Sclerosis, Neurological Disorders, Osteoporosis, Organ Transplant, Oxygen Impairment, Parkinson's Disease, Sickle Cell Anemia, and Spina Bifida. For the purposes of this research, mental illnesses, blindness, deafness, and mobility impairments *(unless a side effect of a chronic illness)* are excluded.

According to the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), six in ten adults in the United States live with at least one chronic health condition (NCCDPHP, n.d.). Based on the 2016-2017 National Survey of Children's Health, almost half of the children ages 12-17 had at least one health condition (Child and Adolescent Health Measurement Initiative, n.d.). According to the National Center for Education Statistics (NCES), an estimated nineteen percent of all undergraduates report having any disability (Snyder et al., 2019). This is an increase from eleven percent from the 2007-08 academic year (Snyder et al., 2015). Based on the 2011-12 National Postsecondary Student Aid Study, about 4% indicated a health impairment or problem (Hinz et al., 2017). The actual proportion of students with health-related disabilities may be much more because many individuals with such conditions do not self-identify or change their status during their time in college (Aquino & Bittinger, 2019; Henderson, 2001). It is more difficult for postsecondary institutions to recognize and serve this population when students do not self-identify. Between fall 1999 and fall 2008, the number of students with disabilities at postsecondary institutions increased almost 40% in New York and almost 20% in California public institutions (California Postsecondary Education Commission, 2010; Office of Research and Information Systems, 2009), making the need to provide services even more imperative. Some examples of illnesses where there has been an increase in survivors living longer include Cancer, End-Stage Renal Disease, Celiac Disease, Crohn's Disease, Diabetes, Asthma, Obesity, and HIV/AIDS. Due to this increase, one can infer that there has also been an increase in the number of students with chronic illnesses at the post-secondary level.

Students with Chronic Illnesses in College

As the number of children and young adults with chronic conditions has increased over the past four decades with treatment, an increasing number of them can return to school (Klienbenstein & Broome, 2000; Perrin et al., 2007; Shiu, 2001). Depending on their age, they may go back to college or eventually continue their studies in college.

Section 504 of the Rehabilitation Act of 1973 prohibits colleges and universities from discriminating against a person because of a disability. This includes students with health-related illnesses. Institutions may provide reasonable modifications and accommodations on an individualized basis. This is to ensure that qualified students with disabilities will have equal access to the regular academic program. Prior to college, K-12 schools are required by law to identify students with disabilities. In college, it is the student's responsibility to self-identify his/her disability and to provide documentation. Colleges and universities should be aware of students' expectations and individual needs. Institutions should be proactive in their communication with prospective students and be forthright with their policies and procedures, especially for students with disabilities (Rothstein, n.d.). If colleges and universities are open and receptive, students with chronic illnesses will be more willing to self-identify and have a better chance of having a successful college experience.

The Americans with Disability Act (ADA) of 1990 prohibited discrimination against individuals with disabilities. Over the years, the law was narrowly interpreted by the courts. This limited the definition of what a disability was. Diller (2000) reviewed many ADA court cases in the 1990s and found "that the ADA prohibits discrimination based on disabilities rather than medical impairments" (p. 26). During this time period, Diller researched that court cases involving plaintiffs with chronic illnesses such as breast cancer, multiple sclerosis, diabetes, epilepsy, ulcerative colitis, depression, among others, were to be excluded from the definition of disability under ADA since these conditions did not substantially limit major life activities such as working. They might have precluded someone from a specific job, but not all classes of work. In Sutton v. United Airlines in 1999, two individuals who did not meet the uncorrected vision standards of United Airlines claimed that they were discriminated against because of their disability and brought this action under the ADA. Both the United States Court of Appeals for the

Tenth Circuit and the United States Supreme Court indicated that these two individuals were not regarded as disabled since they wore glasses and were not substantially limited in the major life activity of working. They were only precluded from working as a pilot but could be employed in other types of jobs (Duncan, 2000). The 2008 ADA Amendment Act, which was placed into law January 1, 2009, clarified that a chronic condition that is "episodic or in remission is a disability if it would substantially limit a major life activity when active" even if acute episodes are shorter than six months (AHEAD, n.d. b). This amendment clarified and broadened the scope of who is covered by ADA. While these changes were in the process of being implemented, the 44th President of the United States, Barack Obama (2008), included individuals with disabilities in his agenda. In October 2009, the U. S. Government Accountability Office (U.S. GAO), in their Report to the Chairman, Committee on Education and Labor, House of Representatives, recommended that due to the increase in the number of student with disabilities at the college level over the years, the Department of Education needs to "develop and implement a coordinated approach to optimize agency resources and knowledge in providing technical assistance to postsecondary schools in supporting students with disabilities" (U.S. GAO, 2009, p. 33). In addition, changes to the Higher Education Opportunity Act and the implementation of the Post-9/11 Veterans Educational Assistance Act of 2008 also provide avenues that increased the number of students with disabilities at the college level. This new GI Bill has expanded access to college for veterans of the wars in Iraq and Afghanistan, many of whom acquired disabilities, including traumatic brain trauma. (CPEC, 2008; U.S. GAO, 2009)

In addition, the passage of the federal version of Michelle's Law, which went into effect in October 2009, shows that more attention is being brought to college-aged students with chronic illnesses. This law allows seriously ill or injured college students who already have health insurance to be able to take up to one year of medical leave without compromising their health insurance (The Michelle's Law Foundation, n.d.). This is extremely important to these students. Before the passage of this law, many insurance companies would only cover students who took a full-time course load. Therefore, if students were out for an extended period or were not full-time, they were ineligible for medical coverage, not an option for those with chronic illnesses.

With the various legislative changes and the increases in the number of young adults with chronic illnesses, more attention needs to be focused on this population at colleges and universities. Institutions need to provide ways that encourage these students to self-identify their illnesses. This will enable schools to provide the necessary support to help them become productive citizens.

Statement of the Problem

As the fields of medicine and medical technology continue to advance, more students with chronic illnesses will be able to fulfill their dreams of earning a college degree. Advances include new procedures, medications, treatments of acute illnesses, and early diagnosis of chronic illnesses that allow for the maintenance of the disease. No longer are these individuals living with what was previously considered a "death sentence." They are able to live productive lives and contribute to society. Universities and colleges provide individuals with the means to do this.

Postsecondary institutions have supported students with physical disabilities using academic accommodations and, more recently, provided specific programs for students with learning disabilities. Due to the increasing number of students with chronic illnesses in colleges and universities (U. S. GAO, 2009), these institutions need to be prepared to serve these students. Much of the research that has been conducted on students with disabilities in colleges and universities has focused on physical and learning disabilities and not on health-related disabilities.

Students with chronic illness face many challenges, including ongoing illness management and follow-up doctor's visits. They may have to monitor their diet; take medications around the clock; deal with potential side effects from medications; maintain prescriptions; schedule doctor's appointments, blood tests, and other diagnostic tests around class schedules; have possible physical limitations or other ailments; keep up with coursework with limited energy levels, and deal with the unpredictability of the chronic illness – feeling well some days and not as much other days. Not only do they face dealing with their illness, but also they must deal with the various other anxieties a young adult faces, such as adjusting to college life, making new friends, having a social life, and new "found" freedom, including living away from home (Edelman et al., 1998). Students with chronic illness in colleges and universities may struggle with balancing the desire to socialize and be part of the culture and the possibility of compromising their health. (Houman & Stapley, 2013). For example, many college students stay up late and socialize; however, some students with chronic illnesses such as multiple scoliosis need their sleep and need to find the right mix for them. Sometimes, this is the first time these students can be part of a social context, and for some, they are negotiating being on their own and balancing college and their condition for the first time. Students with chronic illnesses will always have to live with their condition. This does not prevent them from living their life and moving forward. However, chronic conditions due add additional layers of complexity.

Students with chronic illnesses are more likely to succeed in school if everyone involved; students, their family, health professionals, and school administrators work together (National Diabetes Education Program, 2016). If students do not have the support necessary to deal with their chronic illnesses and postsecondary education, it increases their chances of dropping out. This results in fewer students obtaining their degrees and becoming self-sufficient, productive citizens (Edelman et al., 1998). Based on the *1996/01 Beginning Postsecondary Students Longitudinal Study*, 42% of students with disabilities had a six-year completion rate, compared to 52% of those who entered college without a disability (National Center for Education Statistics, 2010).

The postsecondary environment provides experience for the future, essential life skills, and is mandatory for many fields. It is where students are empowered to become life-long learners who contribute to society. Therefore, colleges and universities provide opportunities for students to better themselves. *University Business* (2007), a magazine for Higher Education Management, listed accommodating students with chronic illnesses as their top 14th out of 30 Smart Business Ideas for Colleges in their December 2007 edition. Stating that “Students facing any illness may be particularly eager to keep learning, so do what you can to help them succeed.” Therefore, it is essential for institutions to understand the issues faced by these students and the types of services they will need for them to succeed.

As the public, state, and federal governments, and accreditation agencies, increase their demands for accountability in postsecondary education, colleges and universities must conduct assessments that are more meaningful and evaluations as part of their on-going decision-making activities. They need to present data that their students, including those with chronic illnesses, are succeeding. Policy makers requested colleges to improve the undergraduate education's effectiveness, systematically assess outcomes, and improve completion rates. Accreditation agencies have been changing their focuses on resources and processes to concentrating on assessment and evidence that institutions are achieving their goals of educating and preparing students to be successful citizens of the world. For example, beginning in the 2008-2009 reporting year, postsecondary institutions must report to the federal government the approximate percentage of the number of students with disabilities who officially register with offices of disability services because of the Higher Education Opportunity Act. This is now available through the College Navigator Web Site of the Department of Education Web Site for the public to search and compare institutions on data such as enrollment, financial aid, ethnicity, retention rates, graduation rates, and percentage of students with disabilities.

Rationale: The Need and Significance of the Study

If colleges and universities are to serve as the foundation for students' continued success, they must be effective in serving all students, including those with chronic illnesses. Shiu (2001) notes the following:

> If the special needs of students with chronic illness are not taken into account, the school setting can quickly become a place of failure, both academically and socially. The limited amount of recent research addressing the educational needs

> of students with chronic illnesses is paralleled by the scant attention directed toward determining present practice in the delivery of services to students with chronic illness. (p270).

Despite the increasing number of students with chronic illnesses, few studies focus specifically on this specialized sub-population at the postsecondary level and how institutions can identify and provide necessary supports for student success. For example, the Association on Higher Education and Disability (AHEAD) publishes various pamphlets for members to obtain an overall understanding of a specific topic dealing with college students and disabilities. The majority of these include a list of additional resources outside of the institution. The brochure on *Students with Chronic Illnesses* (AHEAD, 2011) is one of the few pamphlets that does not provide a resource list. Many websites that provide information for students with chronic illness provide details on how to deal with being in elementary/secondary school, but not at the postsecondary level. The present study provides information that can be of use to University administrators in developing policies and instituting practices for support of the target population within the post-secondary context.

Many individuals at colleges and universities are not familiar with chronic illnesses, as they are sometimes considered to be or referred to as “invisible” illnesses. Therefore, many administrators and faculty do not understand how to assist these students. As there has been little or no research on students with chronic illnesses, even less has been devoted to those working with these students in the educational setting and their sensitivity to these students. Educators may not fully comprehend the situation and may have undue anxiety over the student being in their class. Faculty and administrators could benefit from professional development that focuses on this issue, mainly if it includes health professionals' guidance (Olson et al., 2004). Educational professionals are in a critical position to provide an environment that fosters resilience. Not only does the faculty often lack the understanding of the illness, but they also do not understand the legal requirements for supporting these students (U. S. GAO, 2009). Educators may need to go the "extra mile" to help create an environment that allows students with chronic illnesses to have a typical classroom experience. Administrators and faculty must also understand that these students' parents have a different perspective than most other parents. These parents usually have been involved with every aspect of the students' lives. They have more adjustments than most and might have difficulty distinguishing between an actual academic issue and an issue related to the chronic illness. The present study provides information that can support effective professional development for university personnel on the topic.

Since this population is and continues to grow in enrollment at the postsecondary level, the study highlighted the best and current practices of serving students with chronic illnesses. The researcher established benchmark data in this area and identified how universities serve students with chronic illnesses. This study reviewed university activities such as outreach, education to the university community, and particular services provided to this specific group of students. Topics were also examined from the aspect of the student. This included what services they believed are necessary for students with chronic illnesses and how satisfied they are with their needs being met. This research serves as a guideline for college administrators and provides suggestions for future innovations to support this population. Students with chronic illnesses may not always turn to Disability Resource Offices, as they might not consider themselves to have a "disability." This study highlights how schools could inform and support this population. According to McKinney (2001), many individuals with chronic illnesses probably would not identify with the "disability" label or receive these services. Since their illness is "invisible," some individuals are afraid to request accommodations fearing that they were asking for "special treatment" or will be looked upon differently or could be discriminated against. Colleges need to keep this in mind when developing programs to support these students. Therefore, this research provides current and prospective college-aged students with chronic illnesses additional information to assist in their pursuit of a college degree. This could lead to more students with chronic illnesses being encouraged to self-identify and access the available services.

Research Questions

The following research questions were used to understand better, how institutions are serving students with chronic illnesses. They were also used to identify services these students expect in a college or university, see where both expectations and services matched, and identify gaps. Questions one through three focused on the institutional perspective of serving students with chronic illnesses, while questions four through six highlighted the students' perspective

1. How do colleges and universities serve students with chronic illnesses?
2. What policies and procedures are in place at colleges and universities for students with chronic illnesses?
3. What experiences have institutions had with students with chronic illnesses?
4. How do students with chronic illnesses know that colleges and universities can

assist them?

5. What services do students with chronic illnesses want and expect from an institution of higher education?
6. How satisfied are students with chronic illnesses in how college and universities are serving their needs?

Definition of Terms

The following terms were relevant to this research:

Americans with Disabilities Act (ADA) – US Federal Law enacted in 1990 prohibiting discrimination on the basis of disability.

Association on Higher Education and Disability (AHEAD) - This organization is a professional membership organization for individuals involved in developing policy and providing quality services to meet the needs of persons with disabilities involved in all areas of higher education.(AHEAD, n.d.a)

Chronic Illnesses – "One that affects the individual for at least three months and is likely to continue in the future" (Edelman et al., 1998, p 2). It originates from the Greek word *Chronos,* meaning time. Examples include, but are not limited to Arthritis, Asthma, AIDS, Cancer, Chronic Fatigue Syndrome, Celiac Disease, Crohn's Disease, Cystic Fibrosis, Diabetes, Epilepsy, Heart Disease, Kidney Disease, Liver Disease, Lupus, Lyme Disease, Migraines, Muscular Disorders, Multiple Sclerosis, Neurological Disorders, Osteoporosis, Organ Transplant, Oxygen Impairment, Parkinson's Disease, Seizure Disorder, Sickle Cell Anemia, and Spina Bifida. For the purposes of this research, mental illnesses, blindness, deafness, and mobility impairments *(unless a side effect of a chronic illness)* are excluded.

Disability – refers to any long- or short-term reduction of a person's activity as a result of an acute or chronic condition – from the National Health Interview Survey (National Center for Health Statistics, 1999)

Disability Services – "Programs designed to provide reasonable academic accommodations and support services to empower students who have disabilities to competitively pursue postsecondary education. May also include assistance to campus departments in providing access to services and programs in the most integrated setting possible" (National Center for Education Statistics, n.d). Even though the surveys for this research used the terminology of Office of Disabled Services, it will be referred to as Disability Resource Office within this document's text.

Postsecondary institution or Colleges/Universities – "An institution which has as its sole purpose or one of its primary missions, the provision of a formal instructional program whose curriculum is designed primarily for students who are beyond the compulsory age for high schools. This includes programs whose purpose is academic, vocational, and continuing professional education, and excludes avocational and adult basic education programs" (National Center for Education Statistics, n.d).

Section 504 of the Rehabilitation Act of 1973 – U.S. Federal Law prohibits schools from discriminating against students with disabilities whether or not they require special education services.

Student – is an individual attending a post-secondary education institution either at the undergraduate or graduate/first professional level.

CHAPTER 2: REVIEW OF RELATED RESEARCH

As noted by Sharkey et al. (2018), “College students with a chronic medical condition [is] an understudied and uniquely challenged population” (p. 557). This chapter discusses the relevant literature highlighting how colleges and universities serve students with chronic illnesses. Additionally, this chapter summarizes college-aged students’ experiences with chronic illnesses and the importance and role of higher education in the students’ lives.

Theoretical Framework

Medical Model of Disability

Traditionally, many Disability Resource Offices were developed based on the medical model of disability. This medical model identifies the disability as a problem of the individual and needs a form of treatment to make that person become “normal” (Mitra, 2006). According to Fitzgerald (2006), the disability becomes the major characteristic used to describe the individual. It becomes the focus of the person and is a deficit. Considering the disability to be a deficit brings negative connotations to it. This model is based on the premise that the individual needs to be cured or is a problem that needs to be solved or fixed. (Marks, 2000). The individual needs to be treated for their disability, or if the disability cannot be cured, additional help is given based on the diagnosis. An issue of the medical model of disability is that it is the professionals such as doctors who have the final say as to the type of treatment or services an individual may receive. It is the hierarchy of doctor and patient, and the patient is the subject of research. The patient’s opinion is immaterial. It also categorizes and treats individuals with the same impairment even though different treatments maybe more beneficial to certain individuals. Colleges and Universities use the medical model of disability to ask college students to submit documentation of their disability. Once the documentation is reviewed and approved, institutions will provide the appropriate assistance such as interpreters, note-takers, or extra time on exams to allow these students to be “normal.” Typically, it is the same blanket service regardless of the specific needs of the individual.

Social Model of Disability

In response to the Medical Model of Disability is the Social Model of Disability. This model sees disability as a social construct (Haegele & Hodge, 2016; Howard, 2003; Mitra, 2006). The critical distinction is where society places the boundaries on the individual and is not from the physical functions of the body (Barney, 2012). According to Marks (2000), the issue is how society reacts to the differences of individuals. Therefore, as a society, we need to accept these individuals as equals. It is up to society to remove the barriers (Howard, 2003). The individual with disabilities is an active participant in the process and decision-making. This model has been popular for scholars in academia for years, but it is not yet universally accepted (Barney, 2012; Connor & Valle, 2015). However, there are some issues with this model as well. It forgets the individual’s impairment and does not account for the differences (Haegele & Hodge 2016). Even though the Social model of disability has its limits, it brings additional light to the understanding of disabilities and the idea of inclusion (Terzi, 2004). According to Oliver (2013), one of the creators of this social model of disability, it is meant to be another tool to assist in enhancing lives. The social model of disability can broaden our view of individuals with disabilities from a perspective that they are a problem that needs to be fixed to seeing them as individuals that are a valuable part of society who have something to contribute.

Universal Design

One aspect of the Social Model of Disability is to create access through Universal Design. This was first used with architects and other designers to make physical environments accessible to everyone. Extending Universal Design to the learning environment included rethinking components of the physical classroom and lesson plans. When this is fully implemented in the classroom, it is more than just physical access but access to the educational materials and all aspects of the curriculum for everyone. Universal Design aims to create a community of learners where everyone is welcome regardless of their abilities, backgrounds, or learning styles (Connor & Valle, 2015). This theory embraces inclusivity for all. If this were fully incorporated into the curriculum, students with disabilities no longer would need to identify and “ask” for accommodations, as these accommodations would already be incorporated into the course material (Silver et al., 1998). However, the institution must be pro-active in encouraging faculty members to adopt such practices. This may take time upfront but will save time later. Students will not need to obtain accommodations and eliminate the time typically spent in coordination between Disability Resource Office and the faculty. Once faculty have created their courses with Universal Design, they would only have to update it occasionally for a unique request. The benefit is that it encourages student-centered learning for all diverse learners (Bunbury, 2020).

Related Research

Prevalence of Chronically Ill Individuals

Advances in pediatric medicine have decreased the mortality rate of many chronic diseases (Maslow et al., 2012). As the number of children and young adults with chronic conditions has increased over the past four decades with treatment, an increasing number of them are able to return to school (Klienbenstein & Broome, 2000; Perrin et al., 2007; Shiu, 2001). Based on the 2016-2017 National Survey of Children's Health, almost half of the children ages 12-17 had at least one health condition. (Child and Adolescent Health Measurement Initiative, n.d.) Some examples of illnesses where there has been an increase in survivors living longer include Cancer, End-Stage Renal Disease, Celiac Disease, Crohn's Disease, Diabetes, Asthma, Obesity, and HIV/AIDS.

The research of Gorin and McAuliffe (2009), as well as that of the National Cancer Institute (2009), indicated that from the 1980s to the first decade of the twenty-first century, treatments for childhood cancers survival rates increased by 45%, to nearly 77% with 80% of children diagnosed with cancer in 1990 expected to survive into adulthood. Bhatia and Meadows (2006), cited in Gorin and McAuliffe (2009), estimated that one in 570 individuals, ages 20-34, in the United States is a childhood cancer survivor. One specific type of childhood cancer, Acute Lymphoblastic Leukemia (ALL), is the most common childhood leukemia. According to St. Jude's Hospital (2019), the survival rate for ALL was four percent in 1962 and increased to 94%. About 3,000 children under the age of 20 are diagnosed with ALL every year. According to the National Cancer Institute (2009), even though these cancer patients are considered cured, long-term effects, including chronic illnesses, called "late effects," are a growing issue for this population. The *Childhood Cancer Survivor Study,* sponsored by the National Cancer Institute, is a multi-institutional research project throughout the United States and Canada that follows children who are cancer survivors and their siblings. Thirty-seven percent of those surveyed, ages 25 and older, graduated from college or graduate school. This is compared to 46% of these survivors' siblings (*U24 CA55727 Childhood Cancer Survivor Study*, n.d.). Another 25% of the cancer survivors old enough to have graduated from college attended and obtained some college credits. Employment rates for survivors were lower than that of cancer-free siblings (Gurney et al., 2009; Mody et al., 2008; Pang et al., 2008).

The chances for living have drastically improved over the years for students with chronic illnesses, such as these cancer patients. However, the college graduation rate has not kept pace. A college education is valued and in many fields necessary for obtaining employment. According to data from the US Census Bureau (Torpey, 2019), the median annual wage by typical entry-level education of a person with a bachelor's degree is $72,830, 101% higher than wages for those with only a high school diploma. In addition to higher salaries, good jobs usually come with benefits such as health insurance. This benefit is invaluable to individuals with chronic illnesses. Therefore, colleges and universities need to assist students with chronic illnesses in gaining the education required to obtain desired employment and increase their chance of a better life.

End-Stage Renal Disease (ESRD) is another chronic illness that affects children and young adults. According to the United States Renal Data System (2018), from 1996 to 2016, there was a 21% increase in the total number of individuals 14-21 years living with ESRD. This leads to more than 6,000 individuals living with ESRD. Newly diagnosed cases decreased slightly for this age population during this time. Decrease in the mortality rate of those with ESRD by approximately 12% per 1,000. Medication and transplants have helped increase the total number of individuals living with ESRD.

Celiac Disease is a lifelong digestive disorder affecting children and adults when they eat gluten. It is a genetically based-autoimmune disease that affects one out of every 100 people worldwide, including young adults in the United States (Celiac Disease Foundation, 2019). The Celiac Disease Foundation (2019) also indicates that the number of people affected doubles every 15 years. Those who have a first-degree relative of a parent, sibling, or child of someone with celiac disease have a 1 in 10 chance of developing the celiac disease themselves (Celiac Disease Foundation, 2019). It is considered the most common genetic condition in the world, with most individuals undiagnosed. During the past decade, increased attention has been focused on Celiac Disease in the United States, leading more individuals to be diagnosed.

Another chronic condition is inflammatory bowel disease, which is usually divided into two main categories: Crohn’s Disease and Ulcerative Colitis. Colitis affects the colon, and Crohn’s can affect any part of the gastrointestinal tract. About 33,000 individuals are newly diagnosed in the United States each year. According to the Crohn’s and Colitis Foundation (2018), Crohn’s disease may occur in people of all ages. Still, it is primarily a disease of adolescents and young adults, affecting mainly those between 15 and 35. Most are diagnosed in their late teens and early twenties. An estimated 10% of those affected are under 18 years of age. There are no cures, and individuals need to adjust to living with these chronic illnesses. Individuals with Crohn’s can go through periods where the disease flares up and periods where symptoms lessen to where they are unnoticed. A study of 31 college students with active Crohn's or Colitis at the University of Michigan showed that these students did not adjust well to college and that more needs to be done to study students with chronic illnesses, especially students with Crohn's or Colitis (Adler et al., 2008).

According to the Center for Disease Control and Prevention (CDC), in 2017, approximately 200,000 children and adolescents under the age of 20 were reported as having diabetes. "The increasing frequency of both type 1 and type 2 diabetes in young people is a growing clinical and public health concern" (CDC, 2017a, p. 7). Based on data from the Search for Diabetes in Youth Study, funded by the CDC and the National Institutes of Health (NIH), the rate of newly diagnosed cases of type 1 diabetes in youth increased by about 1.8 percent each year and cases of type 2 diabetes increased even more quickly, at 4.8 percent during the time frame of 2002-2012 (Mayer-Davis et. al., 2017). Type 2 diabetes was a disease previously only diagnosed in adults over the age of 40. In diabetes, one does not make or properly use insulin, inhibiting the body from changing food into energy. Diabetes is manageable, but only with constant monitoring of one's blood glucose levels, administering insulin, and watching one's diet and exercising.

There is also an increase in asthma and obesity in children and young adults (Van der Lee et al., 2007). Asthma is a chronic lung disease that causes the narrowing of the airways. It is one of the leading chronic childhood diseases in the United States and cannot be prevented or cured, only managed. According to the CDC, asthma prevalence has increased since the early 1980s (Asthma and Allergy Foundation of America, 2019). In 2017, the CDC reported around 6 million children ages 0-17 years have asthma (CDC, 2019). This equates to approximately one out of every 12 children having asthma.

According to the CDC, an additional 1.5 million individuals ages 20-24 have asthma (Asthma Center for Disease Control and Prevention, 2019). College students, who believe that they are invincible, are more prone to not acknowledging their asthma and ignoring preventative treatments resulting in their condition worsening. Many tend to pay attention to their condition only when they have an asthma attack (Martinez & Martinez, 2006). According to the 2019 Spring National College Health Assessment, the seventh most prevalent self-reported health problem experienced by college undergraduate students during the previous year was asthma, accounting for 9% of the responses (American College Health Association, 2019).

Data from the 1976 -1980 and the 2015-2016 *National Health and Nutrition Examination Survey* show an increase in the percentage of adolescents' age 12-19 who are overweight from 5% in 1976-1980 to 21% in 2015-2016 (Hales et al., 2017; Ogden et al., 2002). More than a third of college students are overweight, according to the 2019 Spring National College Health Survey (American College Health Association, 2019b). Obesity leads to various chronic illnesses such as diabetes, asthma, and heart disease. It can also cause high blood pressure, high cholesterol, increased risk for bone and joint problems, sleep apnea, and possible social and psychological problems (CDC, 2015). With more and more children, adolescents, and young adults considered overweight; there is an increasing presence of these chronic illnesses.

AIDS cases, while still relatively rare among adolescents and young adults, are increasing in prevalence for this age group. In 2017, approximately 21% of those diagnosed with HIV/AIDS were 13-24 years old, with 8,164 new cases (National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, 2019). Compared to the early eighties, when many individuals who contracted HIV/AIDS had a limited life span, individuals today have treatment options. Drug treatments allow individuals to live longer and healthier lives as the medication suppresses the virus (National Institute of Allergy & Infectious Diseases, 2020). Following their drug regimen allows them to participate in life activities, including attending college and not only focusing on treating their illness.

A study using the Wave IV (2008) of the National Longitudinal Study of Adolescent Health (Maslow et al., 2011) reviewed the data of respondents who had childhood-onset cancer, heart disease, diabetes, or epilepsy with those who did not report these conditions. The researchers compared the data from these groups on various outcomes, including social and educational attainment and career outcomes. Even though there were similar outcomes between both groups when reviewing social aspects of life, those with these childhood onsets of chronic illnesses significantly lagged behind those without these conditions in college graduation rates (18% vs. 32%) and have a lower mean income by $12,000 (Maslow et al., 2011). These researchers recognize that additional research needs to be done to include other childhood-onset conditions and understand these differences to develop appropriate actions to alleviate these differences. Houman & Stapley (2013) performed an exploratory study with a purposive sample of five students with chronic illness, focusing on their college experiences. These researchers believed that since there is a growing number of SWCI in colleges and universities, they need a voice in the literature. They were encouraged to publish their research even though it was a small study.

These chronic illnesses are only a sampling but are representative in showing how chronic illnesses have been growing in children and young adults. Therefore, it is reasonable to deduce that the population with chronic illnesses at the postsecondary level has been increasing as well. In addition, there are many other issues these students face when continuing their education.

Transitioning to College and Identifying as Having a Chronic Illness

In following the aspects of the Social Model of Disability, Perfect et al. (2017) used the literature and input from professionals and students to develop seven principles for enhancing students' experiences with health-related conditions. One of their principles was for institutions to work within the social model of disability to reduce barriers and create inclusive campuses. This would eliminate the need for students to self-identify, especially when first entering an institution. It would also support those students who need services and do not consider themselves to have a disability that requires them to identify with the institution. In support of working within the social model of disability, these researchers suggested that the school's documents should be written to support the social model of disability and diminish the idea of the medical model of disability where the disability is central. This study acknowledges challenges to enhancing services to become more inclusive to students with health-related conditions such as funding, school size, and student participation. However, these researchers believe that institutions need to monitor all aspects of the university to ensure inclusivity and eliminate the need for one-off accommodations.

In contrast, much of the research comes from the medical model of disability, which requires students to self-identify to qualify for services. This can be difficult for SWCI, as many do not always relate to having a disability. There is a fine line as some students are willing to share their diagnosis while others are not (Houman & Stapley, 2013). Students with Chronic Illness want to maintain a “normal healthy self” and try to distance themselves from what they considered to be negative labels of disability (Balfe, 2007; Spencer et al., 2018)—having to identify and provide “proof of being ill” contradicts the idea of being normal to these students. These students had a hard time navigating what they considered complex university structures when they believed they were not sick. They also wanted to be recognized as hard-working students who did not want any special treatment. They have a hard time determining if and how they should disclose (Hoffman et al., 2019). Due to some illnesses' invisible nature, students may be reluctant to self-identity, especially when faculty doubt there is a need for an accommodation since they do not see a physical impairment (Royster & Marshall, 2008). This invisibility leads students trying to manage fluctuating health status and the threat of ill health independent of support services in an attempt to preserve their preferred health identities (Spencer et al., 2018). However, some SWCI need the services in order to access the same educational opportunities as their healthy peers. In these cases, the student must identify as having a disability to conform to the institutional process for receiving support services rather than identifying as having a chronic illness that they are used to identify with (Giroux et al., 2016). In Spencer’s et al. (2018) research, some students found that managing all the aspects of life as a college student with chronic health issues and navigating the process of seeking support while simultaneous keeping up with academic studies was too much for them, so they ultimately chose to self-manage and did not disclose, while others in the study who did self-identify found the support beneficial. This research (Spencer et al., 2018) showed how institutions are more likely following the medical model of disability and need to be more in the social model of disability. These institutions focus on the validation of students' disabilities rather than capabilities and disregard how social context and structures can shape the health-seeking strategies available to these students.

In the spirit of the medical model of disability, some believe that SWCI must be mandated to identify so that it is more straightforward for the institution to communicate with them. This way, the institutions can ensure the appropriate support in students' adjustment to college and during their college years (Adler et al., 2008; Hoffman et al., 2019). Therefore, students who never considered themselves persons with disabilities prior to college must self-identify with an identity that they are unfamiliar with to obtain the services and support to ensure their attainment of a college degree (Giroux et al., 2016). In a study of first-time first-year college students, less than 20% of SWCI registered with their college support service program (Herts et al., 2014). A survey of university health coordinators (Lemly et al., 2014) indicated that almost half of those who responded had no system in place to identify SWCI.

Institutions should provide more outreach to identify SWCI before matriculation to track and build a relationship that enables the institution to provide the appropriate support and resources for these students during this time of transition and during their college career (Herts et al., 2014; Lemly et al., 2014). In addition to providing more outreach, it should be done so that SWCI do not feel ashamed (Spencer et al., 2018). School Counselors recommend that it is best to collaborate with the student and institutional staff members to ensure a successful transition from high school to college (Hamlet et al., 2011).

Adjustment to College/University Life

A pilot study at the University of Michigan (Adler et al., 2008) specifically looked at the adjustment of students with Crohn's disease and Ulcerative Colitis and found that they were less likely to adjust well to university life. They believe that these students have a more difficult transition to college than other students do. They also fall through the cracks of pediatric and adult medical care, which is further complicated by being far from home with the possibility of needing medical treatment. Since they understand the importance of researching this adjustment, they have expanded this research to compare students with Crohn's or Colitis throughout the country to fellow healthy students. A study of college students with Multiple Sclerosis (MS) (Hoffman et al., 2019) transitioning to college indicate that these students are now taking on the responsibility to identify their health status and register with disability services and most likely taking over responsibility for more of their medical management. This might be difficult for those with MS as they may be the first ones at their institutions with their condition, but in a way, they are leading the way for other students with MS to follow their path into higher education. In another study, researchers recommend that institutions offer general wellness programs that promote well-being among SWCI (Sharkey et al., 2018). Childhood cancer survivors in college suggested that a collaborative effort between the student's health care team and the institutions' health services could offer additional support and guidance to these students (Cantrell & Conte, 2016).

A survey of university health coordinators (Lemly et al., 2014) indicated that their institutions could manage health conditions such as asthma, depression, and diabetes on campus. These researchers revealed that college health services comprise a significant and likely overlooked part of the health care ecosystem available to support SWCI. In addition to making the transition to college, a time of learning to become more autonomous, this is also when SWCI might also be making a transition in health care from pediatric to adult units. Therefore, SWCI must have supportive health care services at their institution, and this service should be made more prominent to SWCI. There should be more collaboration between various areas of the university and health services to educate students about health issues and focus on their health objectives (Dusselier et al., 2005). In the study of first-time first-year college students by Herts et al. (2014), students indicated that they did not take advantage of health services available to them. The students with MS (Hoffman et al., 2019) were concerned with knowing where their students could obtain medical assistance.

Coping

Coping is needed for everyone in all aspects of life. However, it is especially true during one's college years of dealing with the social, emotional, and academic challenges that occur during this critical transitional period. It is particularly true for SWCI as not only do they have to deal with the same challenges as everyone else, but they have a chronic illness to deal with as well. How one copes in college helps them succeed in college and life in the years to come.

Wodka & Barakat (2007) performed an exploratory study of SWCI by researching how these students coped during their transition to college along with family support. They compared this group of students to a group of students who had Negative Life Events and a group with Positive Life Events using the *Life Experiences Survey* (Sarason et al., 1978). Their results indicated that SWCI reported more anxiety symptoms and a trend towards more symptoms of depression than those who mainly experienced Positive Life Events. However, all three groups of students seemed to adjust to college as none of these students reported symptoms that ranged in the clinical area of depression or anxiety. The SWCI group only had passive coping positively associated with anxiety. Another study by Barakat & Wodka (2006) showed that SWCI have post-traumatic stress symptoms that can affect life activities during college. A study with college-aged students with diabetes in the United Kingdom found that younger students were more apt to take on risky behavior such as drinking alcohol to fit in and feel normal compared to older college students who had adjusted to college (Balfe, 2007). Research on first-semester, first-year college students indicated that SWCI reported a lower Health-Related Quality of Life, based on the CDC scale, and greater loneliness than healthy first time, first-year college students using the UCLA loneliness scale (Herts et al., 2014). Two studies used the Health-Related Quality of Life survey with individuals with asthma and allergies. In both, these students had a lower score on total and mental health-related quality of life scales than the healthy control group (Fedele et al., 2009; Molzon et al., 2013). These outcomes suggest that chronic illness affects students' quality of life, including school, social and future professional life. These studies' findings indicate that programs should be developed for SWCI that focus on coping strategies in their transition to college and after college. It might even be beneficial to have group settings or peer mentorship where SWCI might share how they deal with stressful situations (Herts et al., 2014). Being proactive and assisting incoming SWCI with the development of coping skills needed to transition to college, the real world, and their illness should help student efficacy (Fedele et al., 2009; Haemmelman & McClain, 2013; Houman & Stapley, 2013; Wodka & Barakat, 2007).

In support of the use of coping mechanisms, a qualitative study of 22 students with chronic pain at one Midwest University indicated that these students used a variety of coping mechanisms to deal with their pain and were able to continue with their daily activities at the institution (Firmin et al., 2011). They included ignoring and distractions, minimizing the pain, advantageous comparisons, and attempts to find meaning in their pain. Another study indicated that chronic illness is a contributing factor of stress in college students. (Dusselier et al., 2005) Therefore, ways to incorporate coping mechanisms to help reduce stress for students are imperative. In a study with college students with MS, these students expressed interest in having coping strategies (Hoffman et al., 2019).

Resiliency and grit are coping techniques used by many students. SWCI used internal assets in combination with external resources to build resiliency to navigate their time in higher education (Scheese, 2018). Scheese's research was based on the anti-deficit achievement framework and resiliency theory, where the examination of any marginalized group looks not to where they fail but where they succeed despite various barriers. Internal assets include being positive, personal agency, adaptability, awareness of self and their environment, and faith. External resources included family members, friends, professors, and institutional support areas such as the Disability Resource Office and Health Services. The combination of internal and external resources supported these students to build resiliency to deal with the challenges of their chronic illness along with the day-to-day challenges of college. Through a path analysis, grit was found to be directly associated with decreased symptoms of depression and anxiety and increased emotional well-being in SWCI (Sharkey et al., 2018). To determine what types of assistance or support could be given to SWCI, grit could be used to provide intervention to those who need support to balance their health with college.

A pilot study of students with chronic illness (Ravert et al., 2017) looked to see if a personal health incidence diary could help these students and the institution. This diary consisted of a series of email surveys, one every three days for nine weeks. The participants had to describe an incident the past day that might or might not have affected their health condition and what resources could help them in this situation. Areas cited were categorized into Activities/exercise, Monitoring/managing condition, Problem solving, managing medicine, psychological adaption, dangerous circumstances, and diet. Respondents also identified resources that they felt were useful: knowledge, peer support, campus health expert, relaxation/recreational, local health provided, financial assistance, and knowledge of campus services. Some comments included peer support for SWCI, flexibility from instructors, and support from family and friends. Opportunities for stress release on campus were also noted. Data from this survey was shared with university administrators and faculty at this institution with the hopes that this method could be used in the future to inform and improve services for SWCI.

Increasing Awareness at Institutions

A qualitative study of school counselors (Hamlet et al., 2011) indicated that these individuals believed that collaboration with all members of the school community is key when working with SWCI. All college administrators, faculty, and staff working with SWCI need to increase the awareness of the various support services available to these students in order to enable an effortless transition to college for this specific population of students (Giroux et al., 2016; Herts et al., 2014). One of the major themes developed in interviews with parents of, and students, with MS, was an increased understanding and education of MS by members of the institution, including faculty (Hoffman et al., 2019). By having the institutional community better understand this condition, students may be more willing to self-identify and therefore receive the institutional support that allows them to be more successful. Faculty knowledge and understanding are imperative (Girourx et al., 2016). A recommendation from Hoffman's et al. (2019) research was for institutions to create a database of information sheets on various conditions and illnesses that could be provided to faculty to give them an overview and help them develop inclusive environments where students could flourish. Members of the Disability Resource Office must foster supportive environments that inform faculty so that the appropriate accommodations are consistent with academic integrity and provide an inclusive environment for students (Korbel et al., 2011).

In another study, researchers believed that by understanding how a chronic illness affects a student's ability to succeed in college, academic advisors would be able to navigate their institution's system to best assist the student in adjusting and eventually graduating (Houman & Stapley, 2013). This may include social networks/peer relationships or engaging with other departments/individuals at the university. For example, students with MS identified challenges of meeting the demands of college while navigating having MS; balancing work and class schedules; using institutional support services such as disability services and campus health services and counseling services (Hoffman et al., 2019). It might be challenging for advisors to obtain that a student has a chronic illness. Therefore, advisors must make advisement sessions open and inclusive enough that the student feels comfortable enough to share so that advisor may assist. In another study (Maslow et al., 2012), school connectedness was significantly associated with college graduation based on their research of the National Longitudinal Study of Adolescent Health. Once SWCI are identified, college administrators can develop programs such as mentorships that can increase school connectedness for this population.

In addition, training for various members of the university community is also important in trying to provide the appropriate support, including psychosocial support, to this specific population (Cantrell & Conte, 2016). A master's level thesis (Abdullah, 2015) at Rowan University in New Jersey surveyed both tenured and tenure-seeking faculty along with students with invisible and other disabilities to observe how both groups viewed faculty knowledge in areas of legal matters of disability services; accommodations; interaction and engagement with students with all types of disabilities including those invisible. Both groups indicated a high importance level of interaction and engagement. This research recommended the idea of different workshops for faculty. Topics included the use of faculty's academic freedom to assist and engage students with disabilities; differences between accommodation policy and willingness; and disability laws beyond physical access to enhance interaction with students with disabilities, including those with invisible conditions.

Another theme from parents of students with MS was the future employment of their children (Hoffman et al., 2019). One study looked at the association of health symptoms to short-term career outcomes to find information that might help college career counselors in their work with students with health issues such as SWCI (Bouchard

& Nauta, 2018) by using established survey instruments and scales. Unhealthy days were significantly negatively associated with work volition, and work volition was significantly associated with each of the short-term career outcome variables in the expected directions. Unhealthy days were positively associated with discrepancies between one's real versus ideal career aspirations and were negatively associated with major satisfaction. The associations of unhealthy days with educational persistence intentions and leadership aspirations were not significant. Bouchard & Nauta (2018) found that:

> They do not have data about students' actual career-entry behaviors, the findings regarding the short-term career outcome variables we assessed suggest work volition may help explain why individuals with health concerns have been found to have lower educational and occupational attainments" (p. 401).

Therefore, this is essential knowledge for career counselors and a possible point of intervention. Career counselors can use this information to ask the appropriate questions of students with health issues and use this to empower students through their strengths and opportunities.

Institutional Examples

Some examples of institutions specifically supporting students with chronic illnesses are DePaul University and the University of Connecticut (UCONN). DePaul University, a Vincentian institution, in Chicago, Illinois, responded to the need of students with chronic illnesses. In the fall of 2003, they established the Chronic Illness Initiative (CII) within their School for New Learning to assist this population with the opportunity to earn a college diploma. "It offers specific, research-and experience-based approaches to service chronically ill students" (Royster & Marshall, 2008, p.120) as they understand that the needs of SWCI can differ. These students vary from other students who are typically served by disability services as those students typically need one type of accommodation that is generally established during the beginning of a semester. SWCI needs may change from needing nothing at the beginning of the semester to needing various accommodations in the middle of a semester when they are hospitalized. The CIII staff provided respect, compassion, and a desire to assist SWCI (Royster & Marshall, 2008). The CII staff educates faculty and other university members to respond appropriately and understand the unpredictable waxing and waning course of these illnesses that can result in relapse or even hospitalizations. They do this to try to eliminate any mistrust these students might have experienced before coming to DePaul. Support services include scholarships; design your own major; social events; and a Buddy Program that links new students with an experienced Peer. The CII developed networks with various community organizations to reach potential students and educate parents, health professionals, and employers to create public awareness about this population's needs and capabilities. Unfortunately, this program is no longer a separate entity anymore but was absorbed in the Center for Students with Disabilities at DePaul University.

The University of Connecticut believes that serving students with disabilities, including SWCI, is not only the responsibility of the Center for Students with Disabilities but is an institutional responsibility and recognizes that SWCI are an important and growing population. This shared responsibility allows this Center to create relationships and have liaisons in other departments/offices such as the individual schools and colleges, Admissions, Facilities, Health Services, Registrar, Dining Services, and Career

Services. These liaisons share information on students with disabilities within their department; explore opportunities for new or additional programming for these students; provide technical assistance regarding access; and communicate information to students to keep them apprised of opportunities for involvement. This encourages collaboration; increases efficiency; and ensures that all community members understand these students' needs and do not unintentionally discriminate (Korbel et al., 2011). This institution also participates in a daylong program for secondary personnel to learn more about resources and students' needs with disabilities transitioning to college. They also participate in a program for parents and students with disabilities to learn more about their transition to college and their ADA rights. The also has Lunch and Learn workshops on campus for members of Student Affairs and other offices. These workshops allow for sharing knowledge and resources to promote the inclusion of students with various disabilities. They believe that collaboration is the key for accessibility and transition to college to support student success. (Korbel et al., 2011)

Relationship Between Prior Research and Present Study

The research shows that there are still gaps with SWCI. The research over the years and this study hope to provide insight and interventions that could help SWCI better their experiences and ultimately graduate from college and be prepared for the "real" world. This study adds to the research by identifying the services provided to this population and how these students want to be served. It also brought the added benefit of increasing students' awareness of chronic illnesses and their unique situations. If colleges and universities are to serve as the foundation for students' continued success, they must be effective in serving all students, including those with chronic illnesses. Administrators must understand these students’ needs and desires. Chapter 3 will describe the methods used to investigate the research questions in this current study.

CHAPTER 3: METHODS AND PROCEDURES

This chapter presents the methodology and procedures of this research study. Moreover, this chapter includes a detailed explanation of the survey instruments, participants, implementation of the surveys, and data analysis methods used in this study.

Research Questions

The following research questions were investigated to understand better, how institutions are serving students with chronic illnesses. They were also used to identify services these students expect in a college or university, see where both expectations and services matched, and identify gaps. Questions one through three focused on the institutional perspective of serving students with chronic illnesses, while questions four through six highlighted the students' perspective.

1. How do colleges and universities serve students with chronic illnesses?
2. What policies and procedures are in place at colleges and universities for students with chronic illnesses?
3. What experiences have institutions reported with students with chronic illnesses?
4. How do students with chronic illnesses perceive that colleges and universities can assist them?
5. What services do students with chronic illnesses want and expect from an institution of higher education?
6. How satisfied are students with chronic illnesses with how colleges and universities are serving their needs?

Instrumentation

Overview

This investigation utilized the following two instruments: *Colleges and Universities Serving Students with Chronic Illnesses Survey (Institutional Survey) and College Students with Chronic Illnesses Survey (Student Survey).* The researcher created both surveys. These two surveys included scaled and open-ended response questions. Version Five 5 of SurveyPro™ was used to administer all surveys online, and responses were anonymous. An optional paper version in Adobe Acrobat was available if requested by a participant. The survey's opening page provided participants with the definition of which chronic illnesses were included in this research. The following section asked for informed consent and described the study. This included the purpose, procedures, risks, benefits, alternative procedures, and contact information. Participants could not complete the actual survey online until this section had been submitted with the appropriate acknowledgment of consent. Paper surveys also included an informed consent page, which was to be signed. This was separated from the survey to keep the anonymity of the survey responses.

Both surveys were formatted using the SurveyPro™ software package. The online versions were fully accessible and easy to complete. According to the Apian Software Product Accessibility Statement of January 12, 2007, "the web forms created follow standard HTML protocol. So, movement around the form can be done with a keyboard or cursor" (p. 6). The researcher successfully tested a sample survey in SurveyPro™ with an individual using a screen reader. To ensure compliance with AHEAD's guideline for surveys to be accessible to everyone, the researcher reviewed a survey sponsored by

AHEAD in October of 2008, *Serving Wounded Warriors – Current Practices*, for formatting and style (Vance & Miller, 2008). The *Institutional* and *Student Surveys' electronic versions* were placed on an Information Technology server through the Office of Institutional Research at the researcher's institution. Responses were stored automatically into a database that would be exported to additional data analysis packages. Paper versions of both surveys in Adobe® Acrobat were also available for anyone who requested this format. These were primarily prepared for students completing the *Student Survey but* were also available for the *Institutional Survey*. No participant, either student or administrator, chose to use the paper version

Five individuals reviewed a draft of the surveys for clarity and content validity. They included three experienced University Institutional Researchers, a Coordinator of Disabled Student Services, and a Health Services Administrator. Their comments and suggestions were incorporated into the final version of the documents as appropriate. In addition, members of the researcher's committee reviewed and provided guidance for the surveys. An additional four individuals reviewed the surveys and verified the approximate time to complete the surveys included in the consent form as well as to test the ease of the online survey.

In addition, the researcher has a personal interest in this study as part of the research study's context. The researcher received a kidney transplant while in high school and attended college and graduate school with a chronic illness. This individual has been employed for over fifteen years as an administrator in higher education. The combination of the two provided the researcher with a familiarity with the issues related to this topic from both a student and professional perspective. This reduces bias but could influence the interpretations of the data, becoming a validity threat at the same time. Diligent research design and analysis helped to minimize any adverse effects.

Instrumentation – Institutional Survey (Administrators)

The Colleges and Universities Serving Students with Chronic Illnesses Survey (Appendix C) has five sections. The first section includes questions regarding how the institution serves students with chronic illnesses and the institution's approximate number of these students. The second section contains questions about the institution's policies and procedures in serving students with chronic illnesses, university activities such as outreach to students, and availability of particular services to this specific group of students. The third section of this survey asks participants to provide information on university awareness and how members of the university community are educated on serving students with chronic illnesses as well as how other areas of the institution, external to disability services, serve this population. The fourth section provides scenarios that allowed participants to share how these situations would be handled at their institution and if procedures were established to address such events. The last section pertains to institutional characteristics such as the size of the institution and geographical location. The Institutional survey went live on April 28, 2009.

Instrumentation – Student Survey

The *College Students with Chronic Illnesses Survey* (Appendix D) contains questions divided into seven sections. This survey varied from the *Institutional Survey* as the first section of the online version was an eligible to participate page with a question asking if the respondent had a chronic illness(es) that fit the definition used in this research. If the participant clicked "no," he/she was directly taken to the "Thank you very much" exit page of the online survey. If the participant clicked "yes," the next section of the survey appeared on the screen. The paper version was created with the first question, asking the respondent if they had a chronic illness that fit the definition used in this research. After this question, a "Thank you very much for participating" statement if the answer was "no" and a "Please continue with the rest of the survey," if the answer was "yes."

The second section contains the background information on the students, including the type of illness(es); how long they have had the condition; academic status of degree and year in college; and whether they considered themselves having a disability.

The third section of the student survey includes questions about students' entry into their institution; when and if they informed their institution of their condition; and the importance and satisfaction of obtaining information from their school/college on services to students with chronic illnesses.

The fourth section pertains to the students once they had enrolled in the institution. Questions included what information they received from the institution about available services; their overall adjustment to college; the importance and satisfaction of particular activities geared towards students with chronic illnesses; the availability, importance, and satisfaction of specific accommodations that might be useful to students with chronic illnesses; whether or not they would do anything differently than they had done; and if they would provide any advice to others who would be following in their footsteps entering college; whether or not they encountered issues because of their chronic illness(es); and their interaction with various departments on campus due to their condition.

Section 5 contains scenarios. This is where students express how they would handle specific situations in dealing with their illness(es) and academics. One scenario asked what they would do if they were to have a health episode during final exams. The other scenario asked what they would do if they were in a biology class and the syllabus indicated that their particular illness(es) was going to be discussed.

Section 6 includes demographic questions such as age, gender, ethnicity, and information such as location, type, and religious affiliation of their institution. Once a student submitted the answers to this survey, section seven, in a completely different form, popped up that allowed the student to enter his/her e-mail address if he/she wished to participate in a drawing for a $100, $75, $50, or $25 gift card to Barnes and Noble Bookstore. The committee recommended that an incentive be added. The e-mail addresses submitted were recorded in a separate database not associated with the survey. This maintained the anonymity of the responses to the survey. One participant was selected for each amount after the survey was closed. An e-mail was then sent to these selected participants, who then provided their name and address to receive the gift card. The *Student Survey* went live on April 15, 2009.

Participant Recruitment

Overview

This study's participants consisted of two main groups: administrators who completed the *Institutional Survey* and students who completed the *Student Survey.* The two surveys were used to obtain opinions from both perspectives on how colleges and universities serve students with chronic illnesses.

Participant Recruitment - Institutional Survey (Administrators)

The *Institutional Survey* was completed by the institutional representatives from the Disability Resources Offices (or similar offices) completing the *Colleges and Universities Serving Students with Chronic Illnesses Survey* for their college/university. According to the National Center for Education Statistics (Snyder et. al, 2009) and the Association for Colleges and Universities of Canada (n.d), over 4,400- degree-granting postsecondary institutions exist between the two countries. Since it is challenging to reach representatives at each of these institutions, a sample was used. This sample was the unique members of the following groups: the AHEAD organization, members of the Disabled Student Services in Higher Education Listserv (DSSHE-L), disabled services coordinators in the State of New York, and members of the DePaul University Chronic Illness Coalition.

The researcher submitted an application for collaborative research with the AHEAD organization. This was done by completing a research request of membership to the AHEAD organization initially in October of 2008 for their Board Meeting. The researcher selected AHEAD for various reasons. According to its mission, AHEAD is the premier professional organization on higher education serving students with disabilities (AHEAD, 2008). Therefore, having support from this organization was invaluable. Since it is also the largest and leading organization that deals with students with disabilities, of which students with chronic illnesses are a subpopulation, it was an ideal organization to collaborate with for this research. In addition, this would provide immediate access to individuals who were to be targeted to complete the *Institutional Survey*. The application to AHEAD was well received and generated interest among board members. (S. Hamlin-Smith, personal communication, October 22, 2008). St. John's University's Institutional Review Board granted final approval on April 2, 2009, after permission was received from AHEAD. Copies of all these approvals may be found in Appendices A and B.

As of November 14, 2008, the AHEAD membership within the United States and Canada was approximately 2,500 representing over 1,300 unique institutions, about 30% of postsecondary institutions in the United States and Canada (AHEAD, n.d. c). Not every disability coordinator is a member of AHEAD. As AHEAD is a member-based (or fee-based) organization and disability coordinators may be in offices that might not be able to support such expenditures, not every disabled student coordinator can be a member. In addition, many disabled student coordinators have other responsibilities than just working with students with disabilities and can only participate in a limited number of professional organizations. Reviews of previous research of surveys based on this membership indicate that response rates can vary significantly. The 2008 AHEAD Survey had 621 United States and Canadian respondents (Harbour, 2008), while Allison Shipp had 162 responses for her dissertation on Learning Disabilities (Shipp, 2008).

Other tools used by these administrators were employed to reach the largest possible pool of disability coordinators. This included the Disabled Student Services in Higher Education (DSSHE-L) listserv. This listserv, hosted at the University at Buffalo, had a subscription of 2,466 members as of 11-14-08 (University of Buffalo, 2008). Listservs are free and useful avenues for professionals to network and obtain support, resources, and additional knowledge from colleagues.

New York State disability coordinators were also contacted to participate in this research. All State of New York institutions are required to provide a Disabilities' Services Coordinator to the New York State Education Department. This group includes 364 public, private, two-year, four-year, and graduate schools within New York State (Office of Research and Information Systems, 2008). This list is available on the New York State Education Website to the public but was obtained as an electronic excel list through the New York State Department of Education Office of Research and Information Systems.

The DePaul University Chronic Illness Coalition e-mail group was also included. This is an interactive group of approximately ten institutions in the Chicago, Illinois, area interested in assisting students with chronic illnesses. This coalition meets quarterly at various member institutions. It was created to provide a network of similar professionals where members could share their experiences, processes, and knowledge as well as try to find new ways to assist students with chronic illnesses. This is extremely useful as members tend to be employed in offices small in size.

Participant Recruitment - The Student Survey

College-aged students with chronic illnesses completed The *Student Survey*. It was essential to incorporate these students' needs and expectations into this research. Therefore, even though it was not possible to obtain as large a sample as from the *Institutional Survey*, due to the nature of this population and sensitivity to their privacy, it was still vital to have some representation in this study. This was a convenience sample. Respondents were surveyed through various avenues to try to obtain as many participants as possible.

In efforts to reach as many students with chronic illnesses as possible, the researcher recruited students with chronic illnesses to complete the survey in many ways. There is no one way to reach students with chronic illnesses. Primarily, the snowball sampling effect was used to obtain participants. The Disabled Student Services in Higher Education (DSSHE-L), the DePaul University Chronic Illness Coalition, and New York State disability coordinators were contacted to forward information to their students with chronic illnesses. At the researcher's institution, she participated in Faculty Research Day and Student Research Day, as well as worked with the Disabled Student Services Coordinators, Counseling Centers, Nurses, and colleagues to spread the word to reach students with chronic illnesses who would be willing to complete the survey. Through various phone calls and e-mails, the following organizations agreed to send out communications regarding the survey: New Jersey Chapter of Crohn's and Colitis Foundation of America; The Kidney and Urology Foundation of America; Commission on Mental and Physical Disability listserv of the American Bar Association. In continuing to try and reach as many students as possible to participate, the researcher also posted the request to complete the survey on specific chronic illness discussion boards, listservs, and social networks, including The American Cancer Society Survivors Network; Celiac Disease Listserv; National Kidney Foundation; Chronic Kidney Disease Support Forum; College Students with Chronic Illnesses; Kidney Disease, Dialysis, and Transplant; Type 1@ College; Transplant Recipients International Organization (TRIO); Cancer for College; Students with Cancer; and Support for Students with Fibromyalgia &/or CFS. Even though many e-mails and postings occurred, from which organization or method that a student responded to was not obtained or tracked in this research to maintain anonymity.

Procedures in Data Collection

Overview

Both surveys' distribution was primarily done through electronic communications, through either e-mails or postings to discussion boards, social networks, and listservs. The majority of the targeted e-mails, especially to the administrators for the *Institutional Survey,* were sent Monday afternoon through Thursday afternoon since most individuals spend their Monday morning cleaning out their inbox and getting back into the "work mode." Fridays were avoided as many are preoccupied with wrapping up the week and not starting any new projects. These times were chosen, as there was an increased likelihood that the recipient would be more apt to read their e-mails and respond to the survey and provide a better response rate. In a survey of Business to Business and Business to Consumer marketers by Silverpop Systems, an e-mail marketing company, 50% of the respondents believed that "identifying the best time to send emails was a tactic that worked for them" (Silverpop Systems, 2010, p. 4). According to a poll taken by Bronto Software, over 60% of the respondents believed that Tuesdays/Wednesdays were the best days to send an e-mail. (Smith, 2008). Tuesday seems to be a favorite day for retailers to get their message out (White, 2007). In a study by EROI, an e-mail marketing company, based on the second quarter of 2007, Wednesday followed by Thursday and Monday were the days with the highest rates for e-mails to be opened and presumably read (EROI, 2007). Some of the e-mails/postings for promoting the *Student Survey* were sent throughout the week since these were more social networks/listservs which students would be more apt to check any time of the week. Some communication for promoting the *Student Survey* also occurred through word of mouth and paper flyers. The Institutional Review Board of St. John's University approved sample copies of e-mails and the flyers/postcards (Appendix E). E-mails were modified slightly to meet the needs of the various organizations and specific illnesses.

Procedures in Data Collection – Institutional Survey

Data collection included sending e-mails to various constituents. Table 1 summarizes this component of the data collection. On the morning of Tuesday, May 5, 2009, the AHEAD organization sent an e-mail to all its members asking for their participation in completing the *Institutional Survey.* A copy of this e-mail may be found in Appendix F. This e-mail included a brief description of the survey, the importance of participating, institutional review approval, contact information, and a hyperlink to the survey. Follow-up e-mails and e-mails to other constituents were spaced accordingly to be used as a reminder if individuals were members of multiple groups. In addition, two colleagues in Kentucky and Colorado, on their own, also forwarded the e-mail for participation to the members of their local state listservs, encouraging them to participate. To provide further reminders, the researcher e-mailed colleagues she knew at colleges and universities throughout this period to have them encourage their disability coordinator to complete the survey if they had not already done so. In addition to the e-mail to DePaul University Chronic Illness Coalition members, the information in the e-mail was converted to a flyer, which was electronically sent to the coordinator of the DePaul University Chronic Illness annual symposium to be printed and distributed at their conference.

Over 5,000 e-mails were sent to administrators to complete the survey for their institution. It should be noted that this number is inflated as many administrators might have received duplicate e-mails through the various venues and there could be multiple administrators at an institution. The *Institutional Survey* closed on August 31, 2009.

Table 1

Dates and Times of Major Targeted E-mails Sent to Administrators to Participate

Group	Date	Day	Time of Day	Sent By
AHEAD – initial	05/05/2009	Tuesday	Morning	AHEAD
DSSHE-L – initial	05/11/2009	Monday	Afternoon	Researcher
AHEAD - follow-up	05/19/2009	Tuesday	Morning	AHEAD
NYS Coordinators – initial	05/28/2009	Thursday	Morning	Researcher
DSSHE-L - follow-up	06/01/2009	Monday	Afternoon	Researcher
AHEAD - Final Call	06/02/2009	Tuesday	Afternoon	AHEAD
DePaul Chronic Illness Coalition – initial	06/02/2009	Tuesday	Morning	Researcher

Procedures in Data Collection – The Student Survey

An e-mail asking students to participate was created. (Appendix G) This e-mail included a brief description of the survey, the importance of participating, institutional review approval, contact information, and a hyperlink to the survey. The researcher also took the basic information from this e-mail and incorporated it into a flyer and postcard used for physical distribution. (Appendix E) The Institutional Review Board of St. John's University approved all samples of communications. Electronic versions of the flyer and postcards were sent to the coordinator of the annual DePaul University Chronic Illness Symposium for distribution to students at this event. Additionally, through the snowball effect, or word of mouth, to other students/faculty/administrators, these flyers/postcards or similar e-mails were used to reach students who were eligible to complete the survey. The researcher also posted the request to complete the survey on specific chronic illness discussion boards, listservs, and social networks. Permission was obtained when necessary. In all cases, the surveys were anonymous, and participants had to complete the informed consent form. The survey was kept open until the end of August, so respondents had time to complete it. A summary of the significant outreach efforts is in Table 2 at the end of this section. Due to the participants' confidentiality, the researcher can only share where e-mails and flyers were distributed.

E-mails were sent to all the contacts used for the *Institutional Survey* except for AHEAD to ask for their assistance in recruiting students to complete the *Student Survey*. This e-mail (Appendix H) included an introduction asking for their help in forwarding the e-mail to students with chronic illnesses to participate in the *Student Survey*. The bottom of the e-mail contained a letter to students asking for their participation in the *Student Survey*. The first of these e-mail requests were sent on April 16, 2009. One New York institution sent the e-mail to their Institutional Review Board before sending it to their students. A copy of their approval is in Appendix I.

The researcher also placed copies of the request for participation on social network groups through Facebook. The following groups were included: Chronic Kidney Disease Support Forum; College Students with Chronic Illnesses; Kidney Disease, Dialysis, and Transplant; Type 1@ College; Transplant Recipients International Organization (TRIO); Cancer for College; Students with Cancer; Support for Students with Fibromyalgia &/or CFS. The researcher also posted on the Transplant Café, a social network for individuals who have received or need an organ transplant. The researcher also sent e-mails to other organizations asking for their permission to forward the request for participation on their listserv. Some were granted, as seen in Table 2, but for others, the invitation was posted without either informing the researcher, was ignored, or these listservs were no longer active. These listservs were specific to diabetes, lupus, osteoporosis, transplant recipients, Parkinson's disease, dialysis patients, kidney and diabetes, liver disease, and heart transplant recipients.

Instructions were if recipients did not fit the criteria, for them to pass along the e-mail to someone else who was eligible to participate. Since these e-mails were distributed through various organizations, the researcher cannot quantify the actual number of sent e-mails. With discussion boards, listservs, and postings on social network pages, one does not know how many individuals read the e-mails and postings. The researcher believed that using each of these avenues increased the possibility of additional participants.

Table 2

Summary of Major Outreach for Student Participation

Group	Date	Day
Faculty Research Day – poster of What are Chronic Illnesses and distribution of flyers/postcards	4/2/2009	Thursday
DSSHE-L	4/16/2009	Thursday
American Cancer Society Survivors Network Discussion Board	4/16/2009	Thursday
DePaul Chronic Illness Coalition	4/17/2009	Friday
Student Research Day-poster of What are Chronic Illnesses and distribution of flyers/postcards	4/23/2009	Thursday
NYS Coordinators	4/23/2009	Thursday
DePaul Chronic Illness Coalition Flyer	4/24/2009	Friday
Students from DePaul U. Symposium	5/12/2009	Tuesday
Word of Mouth/Snowball effect	4/2/2009 -	6/1/2009
Distribution flyers/postcards to own institution's health offices, Disability Resource Offices, and Counseling Centers	Late April	
Postings on Social Network groups through Facebook	Month of June	
Distribution flyers/postcards to own institution's health offices, Disabled Student Services, and Counseling Centers	Late April	
Postings on Social Network groups through Facebook	Month of June	
Posting on Transplant Café	6/2/2009	Tuesday

(Table 2 Continued)

Table 2 (Continued)

Summary of Major Outreach for Student Participation

Group	**Date**	**Day**
Commission on Mental and Physical Disability listserv	6/9/2009	Tuesday
E-mails sent via New Jersey Chapter of Crohn's and Colitis Foundation of America	6/12/2009	Friday
Celiac Disease Listserv	6/21/2009	Sunday
National Kidney Association Posting	6/22/2009	Monday
E-mails sent via the Kidney & Urology Foundation of America	7/17/2009	Friday

Looking at Institutional Websites

To provide additional insight, the researcher reviewed 100 college and university websites for content analysis in 2012. Sometime after, the federal law went into effect to provide information on disabled student services on the web. This analysis looked for the words chronic illness or medical conditions on a school's website for disability services. These institutions of higher education were selected by the researcher based on their location and type of institution to try to mirror the characteristics of those institutions that participated in this research. This data was incorporated into the findings of this study.

Sample

Sample: Institutional Survey (Administrators)

After excluding those who did not consent to participate, there were a total of 136 participating colleges and universities in this survey. It was split approximately equally between higher education institutions that specifically have policies in place for students with chronic illnesses and those that did not. Almost eighty percent of the schools provided specific services to students with chronic illnesses serving a vast range of students with chronic illnesses over the 2008-2009 academic year. These Institutions represented 38 states, the District of Columbia, and Canada. Fifty-six percent, or 75 institutions, are east of the Mississippi; thirty-five percent, or 47 institutions, are west of the Mississippi; 5%, or seven institutions, from Canada; and 1%, or five institutions, unknown. The top states that participants listed were New York, California, and Pennsylvania. The majority of higher education institutions, 47%, were private four-year institutions, followed by public four-year institutions at 34%. An additional 16% were public two-year institutions; 2% for-profit institutions and 1% were private two-year institutions. The most common religious affiliation was Roman Catholic (32%).

Sample: Student Survey

A total of 86 students initiated the survey. After eliminating students younger than 18 years of age and those who did not have a chronic illness, data from 74 students were included in the *Student Survey* analysis. Almost half of the respondents with chronic illness considered themselves as not having a disability. Sixty-nine percent of the respondents had notified their institution of their chronic illness(es), with 44% indicating this during their first year at the institution. Forty-three percent reported having a chronic illness for five or fewer years. Chronic illnesses identified included arthritis, migraines, celiac disease, chronic fatigue syndrome, asthma, anemia, Crohn’s disease, diabetes, neurological diseases, muscular disorders, seizures, ulcerative colitis, fibromyalgia, kidney disease, lupus, multiple sclerosis, and cystic fibrosis. The counts and percentages are listed in the table below.

Table 3

Distribution of Chronic Illnesses identified by Students

Chronic Illness	*One or More Chronic Illnesses* Duplicate Count	*One or More Chronic Illnesses* Percent of Respondents (n=73)	*One Chronic Illness* Distinct Count	*One Chronic Illness* Percent of Respondents (n=73)
More than one Illness: n = 37				
One Illness: n = 36				
Other	22	30%	4	5%
Celiac Disease	16	22%	6	8%
Arthritis	16	22%	3	4%
Migraines	16	22%	1	1%
Chronic Fatigue Syndrome	12	16%	2	3%
Asthma	10	14%		
Anemia	8	11%		
Crohn's Disease	7	10%	4	5%
Diabetes	7	10%	4	5%
Neurological Diseases	6	8%	1	1%
Ulcerative Colitis	4	5%	2	3%
Seizure Disorder	4	5%	1	1%
Fibromyalgia	4	5%		
Muscular Disorders	4	5%		
Multiple Sclerosis	3	4%	3	4%
Kidney Disease	3	4%	2	3%
Lupus	3	4%		
Cystic Fibrosis	2	3%	1	1%
Organ Transplant	2	3%	1	1%
Epilepsy	2	3%		
Heart disease	2	3%		
Spina Bifida	1	1%	1	1%
HIV/AIDS	1	1%		
Liver Disease	1	1%		
Lyme Disease	1	1%		
Osteoporosis	1	1%		
Sickle Cell Anemia	1	1%		

Females completing this survey outnumbered the males 4 to 1. Forty-eight percent of the students were 25 years of age or older, with 21% being 22-24, 14% being 20-21, and 18% being 18-19 years of age. Eighty-three percent of the respondents were White and 15% were considered Hispanic, Black, Asian/Pacific Islander, and American Indian. Students came from institutions representing 21 states and Canada. The top states represented were 26% from New York; 15% from Illinois, 12% from Ohio; and 5% from Colorado. Four percent each came from California, Michigan, New Jersey, and Pennsylvania. Three percent each came from Minnesota, Mississippi, and Virginia. One percent each came from Delaware, Idaho, Iowa, Kansas, Massachusetts, Missouri, North Carolina, Tennessee, Texas, Wisconsin, and Canada.

The majority of the students were undergraduates, with 22% seniors, 16% juniors, 15% sophomores, and 12% first-time undergraduate students. An additional 34% were graduate students. Students were enrolled in programs from the certificate to the doctorate level. Twenty-nine percent transferred into their institution. Thirty-four percent believed that they had an excellent overall adjustment to college who entered as freshmen. The top two reasons they chose their institution were academic reputation and closeness to home/physicians. An additional 10% decided on their institution because of a specific program/services dealing with students with chronic illnesses. The majority, or 58% of students, were enrolled for 11 or more credits during the semester. Fifty-one percent considered that they have fallen behind in the number of credits taken compared to other students who started class with them. Sixty percent attended either a public two- or four-year institution. Of those who reported religious affiliation of their institution, 36% attended an institution that was affiliated with the Roman Catholic Church. Twenty-one percent lived in residence facilities at their institution, while 25% lived with their family, and 47% lived independently.

Research Design and Data Analysis

All research questions were addressed by a combination of descriptive and qualitative analyses. Descriptive analyses included cross-tabulations, means, difference in mean scores, standard deviations, frequencies, summative scores of item responses, and chi-squared analysis of survey variables as appropriate. In addition, variables in relevant groups (e.g., workshops, services) were ranked in order by mean scores and relative importance to colleges and students and compared. Contingency Tables, where appropriate, were used to analyze the relationship between various demographic characteristics of the students such as gender, ethnicity, degree program, age, geographic area of the school, year in school, and other qualitative variables, including institutional type.

Quadrant analysis was performed on items to identify areas of importance and satisfaction as well as identify gaps in areas of service to SWCI. Emerging themes were summarized at the end of each question. Results were presented in tables and charts.

This study used a mixed methods design, a combination of qualitative and quantitative surveys that provided a more comprehensive overview of how colleges and universities serve students with chronic illnesses. According to Creswell (2003), “The advantages of collecting both closed-ended quantitative data and open-ended qualitative data prove advantageous to best understand a research problem” (p. 12). This study used the concurrent triangulation approach. This is where two different models are used at the same time in an attempt to confirm, cross-validate, or corroborate findings within a single study (Greene et al., 1989). “This model generally uses separate quantitative and qualitative methods as a means to offset the weaknesses inherent within one method with the strengths of the other method” (Creswell, 2003, p. 217). According to Kroc (2007), mixed methods are essential to using triangulation as a means to establish greater validity of the findings.

Therefore, the qualitative data were collected to understand better, how colleges serve students with chronic illnesses from institutional and student perspectives. Answers to the open-ended questions were reread numerous times and were examined question by question and coded based on themes developed from these responses. Data collection of the qualitative questions focused on saturating emerging themes or categories, working towards a point where “no new relevant data seem to emerge regarding a category, the category is well developed in terms of its properties and dimensions demonstrating variation, and the relationships among categories are well established and validated” (Strauss & Corbin, 1998, p. 212). Triangulation occurred by comparing these findings with that of the quantitative research to corroborate the quantitative data results. Institutional response data were compared with external data from institutional websites to examine consistency.

CHAPTER 4: RESULTS

The purpose of this study was to obtain a better understanding of how institutions are serving students with chronic illnesses (SWCI) and to provide an opportunity to increase awareness of this underserved population. This study analyzed the current practices of colleges and universities serving these students through the *Institutional Survey*. The research also examined this topic from the perspective of students with chronic illnesses through the *Student Survey*. This chapter summarizes the key findings of this study. The following research questions were used to obtain a better understanding of how institutions are serving SWCI. They were also used to identify services these students expect in a college or university, see where both expectations and services matched, and identify gaps. Questions one through three focused on the institutional perspective of serving SWCI, while questions four through six highlighted the students' perspective.

1. How do colleges and universities serve students with chronic illnesses?
2. What policies and procedures are in place at colleges and universities for students with chronic illnesses?
3. What experiences have institutions reported with students with chronic illnesses?
4. How do students with chronic illnesses perceive that colleges and universities can assist them?
5. What services do students with chronic illnesses want and expect from an institution of higher education?
6. How satisfied are students with chronic illnesses with how colleges and universities are serving their needs?

Even though the responses to these surveys were anonymous, the researcher coded each survey with a number to provide identification within this research. Therefore, each written response begins with an ‘S’ for a student response and an ‘I’ for an institution response, followed by the number of that survey response. Appendix J includes the distribution of the responses used within this research to indicate that a wide range of responses was used. Sixty-four percent of the Institutional responses and 38% of Student responses were included in this study's qualitative data. Not all student or institutional respondents completed the open-ended questions.

Research Question 1: How do colleges and universities serve students with chronic illnesses?

Communication, services, and training were themes that emerged from the questions from the survey instrument. Administrators believe that they are serving SWCI and pride themselves in serving students on a case-by-case basis. However, for the most part, the perception of SWCI is that their needs are not fully met. Institutions acknowledge the absence of training, and both students and institutional respondents feel that training for all members of the community would be quite beneficial for SWCI. Both Institutional and Student Respondents indicated that workshops geared toward SWCI would be advantageous to these students.

Communication

Dissemination of information to potential students

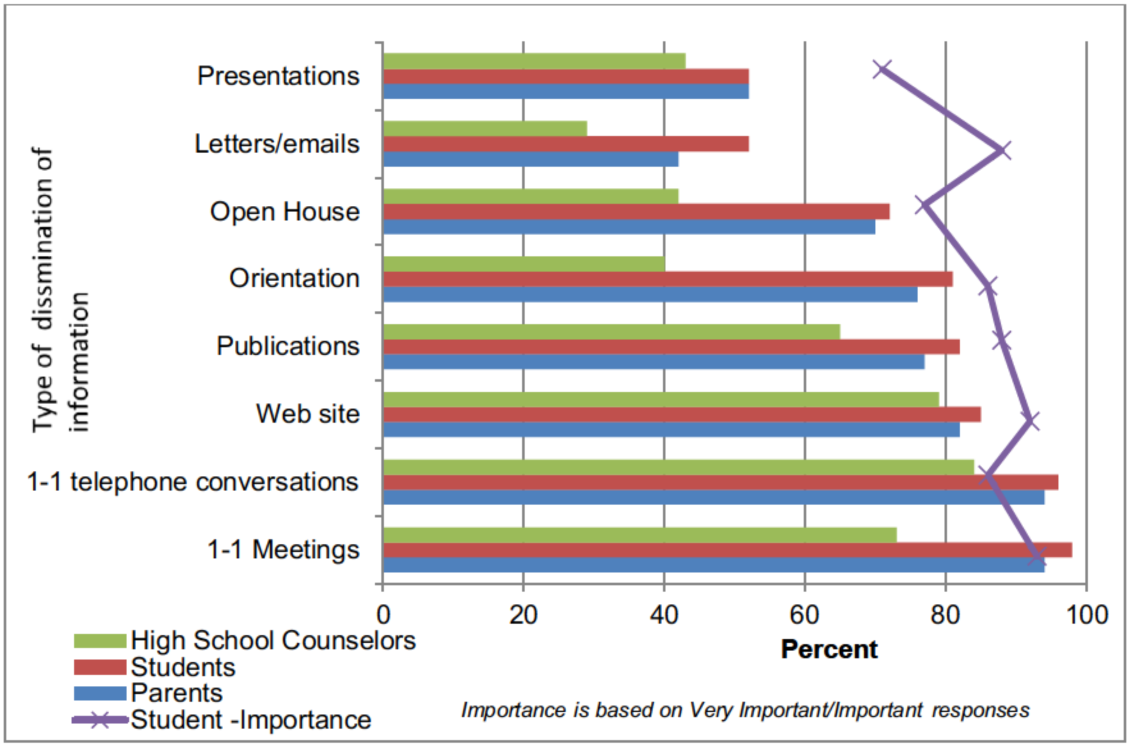
Communication begins with providing the appropriate information about available services to students with chronic illnesses to potential students, their families, and high school counselors. Students want to know and hear from their institutions.

Institutional respondents were asked how they provide this information to these constituents. Students were also asked to rate the importance of each of these methods. Results are represented in Figure 1. Almost all institutional respondents used one on one meetings and telephone conversations with potential students and parents. One-on-one telephone conversations were the most frequently chosen method of communication to high school counselors. Almost as popular were websites, publications, orientations, and open houses.

Students rated one-on-one meetings as the most important method of communication. Besides one-on-one meetings and one-on-one telephone conversations, there was a difference in the ranking of what is offered by institutions and students' perception of what is important. It should be noted that the *Institutional/Student Surveys* were distributed before the July 1, 2010, federal government deadline, which mandated institutions to make information for students with disabilities readily available on an institution's website. Due to this, the researcher expects the use of websites to increase. There was a significant difference (.016) between SWCI who considered having a disability (1.38) and those who did not (1.92) when it came to the importance of obtaining information about how their institution services SWCI from the website (Appendix K). The effect size Cohen's d is approximately .8, which is larger than typical.

Figure 1

Dissemination of information by institutions to potential students, their parents, and high school counselors and the importance to students



Students were also asked how important it was to obtain information from specific individuals. Students felt it was extremely important to receive information from social workers and physicians, Disability Resource Offices' staff, and faculty members.

Dissemination of information to current students

Communication does not stop once a student enrolls in an institution. Institutional and Student survey respondents were asked how information was disseminated to current students (Table 4). More than two-thirds of the institutions used informal conversations, e-mail address to answer questions, websites, student orientation, and letters/e-mails as means of communication to current students, with the first two being used by almost everyone. About 5% of the schools had a resource center on chronic illnesses. Less than

50% of the students responded that they received information by any of these means. Administrators perceive that they provide the information, but students believe that they are not receiving this information. Through the open-ended part of this question to students, 13% percent wrote that they had no idea how information on SWCI was provided to the university community. A few students even noted that they had not received any information. Comments included that they “never seen any information” (S14); “they don’t [provide]” (S22); “no information at all” (S29); and “I have got nothing” (S42). When students were asked if they knew where to go for support and information, 52% said only sometimes or never.

Table 4

How institutions disseminate information to students regarding services for students with chronic illnesses and students' opinion of how they receive this information

	Institutions		Students	
Means of Communication	%	Rank	%	Rank
Informal conversations	95	1	34	2
E-mail address to answer questions	90	2	21	5
Web sites/web announcements	80	3	43	1
Student Orientation	80	3	18	6
Letters/memos/e-mails	67	5	32	3
Bulletins/Course Catalogs	65	6	16	8
Presentations	62	7	11	10
Health days	31	8	18	6
Newsletters	24	9	11	10
Other	21	10	9	12
Listservs	18	11	16	8
Focus Groups	16	12	7	13
Employee Orientation	12	13	-	
Training sessions through Human Resources	9	14	-	
Resource Center on Chronic Illnesses	6	15	32	3
Wikis	0	16	0	13

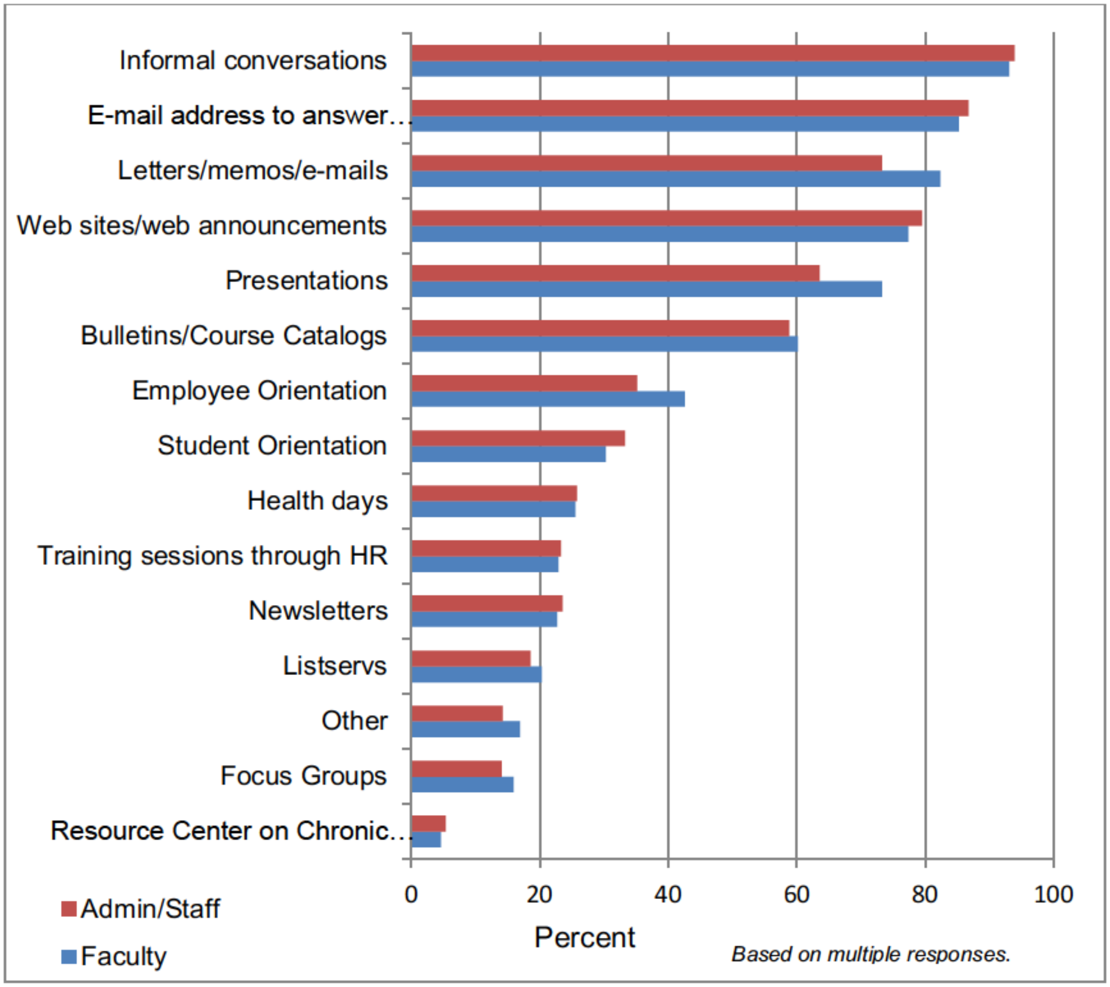
Note. Based on multiple responses. The order of the Means of Communication is based on descending Institutional percentages.

Communication to faculty, administrators, and staff members

Institutions were asked to provide the means of communication to faculty, administrators, and staff about the services offered to students with chronic illnesses. The most popular avenues to these constituents were informal conversations and e-mails answering specific questions, as indicated in Figure 2. Letters/emails, websites, presentations, and bulletins/course catalogs were also popular means of communication.

Figure 2

Means of Communication to faculty, administrators, and staff used by institutions to provide information on students with chronic illnesses



When asked how various departments such as the Deans' offices, academic advisors, and facilities provide specific services to SWCI, many wrote positive answers to this open-ended question indicating that communication occurs across campuses from the institutional perspective. For example, respondents at thirty-four institutions reported that the deans "collaborated with," "worked with," or "refer students to" the Disability

Resource Office. When it came to academic advisors, 45 indicated that these individuals would "refer students" to the Disability Resource Office. Eleven respondents from institutions showed that health services work collaboratively with the Disability Resource Office in serving the needs of SWCI. Twenty-one comments specified that facilities work closely with Disability Resource Office to ensure that reasonable and appropriate accommodations are met. Similar comments were also provided for the Offices of Student Affairs, Residence Life, and Career Center.

Although communication about serving students with chronic illnesses is available, it is not fully understood by all, as evidenced by the following qualitative statements. "The point I am making here is getting faculty and staff to know who I am and what my staff and I do on a daily basis so that they know who to refer students to – and this is currently working-maybe, not 100 percent-but it is working" (I32). Another respondent stated, "They [Academic advisors] don't know anything" (I7). One respondent felt that Disability Resources Offices are small and are asked to do many things; however, it would be helpful for them to have workshops or "modules designed to present to faculty groups, student groups, parents, high school counselors, and special education teachers/counselors" (I107).

Overall, institutional respondents believed that 50% or more of the members of their institutional community are aware that specific services are available to students with chronic illnesses: Administrators (64%), Faculty (62%), and students (50%).

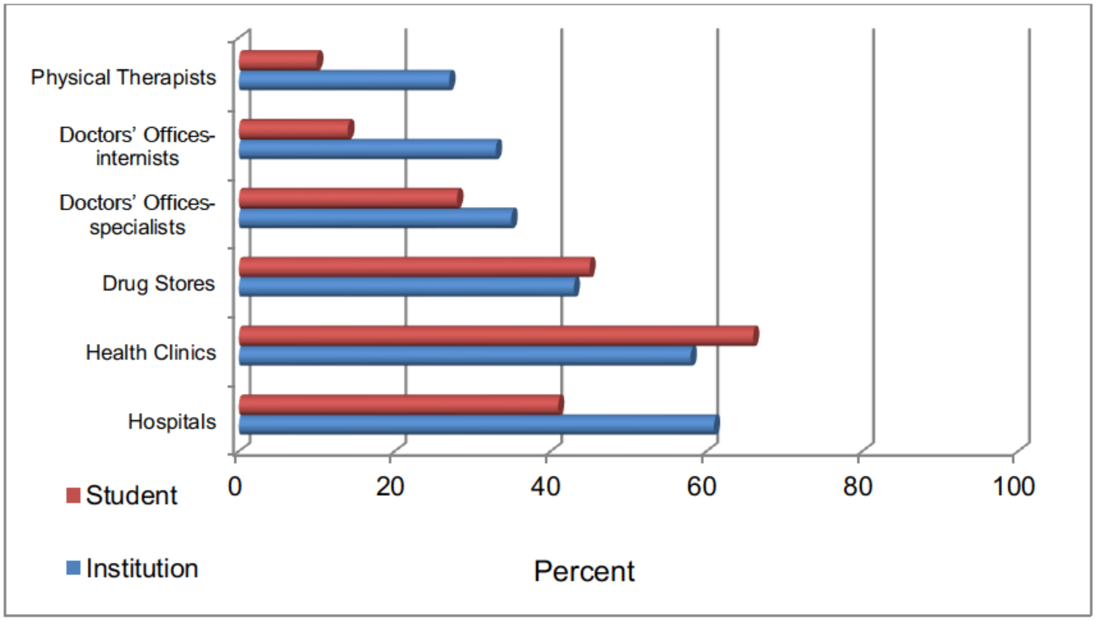
Communicating local community resources to students

Institutions were asked whether they provided information on local community resources such as hospitals, health clinics, drug stores, doctors' offices, and physical therapists. Students were asked whether they received information about these services. As seen in Figure 3, a higher percentage of institutions indicated they provided information on community services than students reported receiving in all areas except for health clinics and drug stores. Eleven institutional respondents stated in the open-ended section of this question that they provided information about their health services, referring students to the appropriate facility (I8, I24, I27, I54, I83, I64, I66, I114, I115, I131, & I136). Seven institutions indicated that they would only provide this information about community services if a student asked (I14, I28, I61, I86, I116, I123, & I127). Four institutions indicated that they provided none of this information to students (I50, I62, I82, & I137). One institution stated that they link students with other campus and community resources (I54). Three students specifically wrote that none of this information was provided (S6, S29, & S44).

Figure 3

Percent of institutions that communicate local community resources and

Percent of students who received such information



Encouragement of communication between students and faculty

Eighty-four percent of institutions encourage students to have a conversation with their faculty members even when healthy. However, many students only felt comfortable doing so depending on the situation, and therefore might not always have the conversation. The comments associated with this question from the respondents offered more insight into the actual practices that are in place. Students who self-disclose to the Disability Resource Office (or similar office) are the ones encouraged to initiate this conversation in various ways. Almost all Institutional respondents indicated that they coach or encourage students to talk with their faculty at the beginning of each semester so that the faculty members are more informed and understanding in case an "episode" occurs later on in the semester. "The better the students can discuss their needs and set up a plan of action, the smoother the process works and the better academic success the student has" (I15). "It helps faculty and the student to prepare for the needs ahead of time. Less stress for all when the need arises" (I79). Twenty-six institutions wrote that they have an accommodation form (of some variety) that can be used as the conversational starter or an "open door" (I84), especially if the student feels uncomfortable talking with the professor. One institution even provides "role-playing" before the student has the discussion with their faculty (I22). Another institutional respondent shared that "students are encouraged to self-disclose and self-advocate. They are not expected to provide details beyond their comfort level but ARE responsible for requesting authorized accommodations and otherwise maintaining communication as needed with their faculty" (I115). Another indicated that "students and instructors often differ on how they think this type [missing assignments, quizzes, or tests] of issue should be handled so this helps increase communication and decrease frustration later on in the semester" (I107). Two institutions (I49 and I80) indicate that a disability statement regarding accommodations is included in their course syllabi. Institution #45 specified that they encourage students to have a discussion with their faculty, but for students not to provide the details of their conditions due to misconceptions and misunderstandings that might occur. Another institution stressed that students with seizures explain to their faculty "how their medications make them zone out in class. They are paying attention and not hung-over or drunk" (I83). Some respondents indicated that even though they encourage the students to interact with their faculty and be pro-active about their condition, many students do not follow these suggestions. Another stated that it is best to educate students about the importance of sharing with faculty for their safety and others (I108). Institutional respondent #133 indicated that "some students hesitate to do this [discussions with faculty], but most report that they were glad that they did." When students were asked if it is easy to share their condition with faculty and administrators/staff, almost 70% stated that it depends on the situation, 12% only when they were sick, and 5% when they were not ill.

Training

Many institutions do not have sensitivity training for faculty on handling situations such as having students with disabilities in their classes. However, administrators feel this is an important topic to cover within in-service programs. Institutions were presented with a scenario of a student with cancer enrolled in a biology course that included cancer as a topic on the syllabus. They were asked if there was any training for the faculty to deal with such issues. Two common themes that emerged in the responses included the absence of training for faculty members (17) and Disabled Student Services' Coordinators' availability to talk with faculty one-on-one (12). One school is in the process of developing a "Disability 101 two-hour training session for faculty or staff to learn about students with all types of Disabilities" (I107). Another institution is working on a grant proposal that includes an educational training component (I38). Only nine wrote that they have the training, or it is incorporated into new faculty orientation (I46, I50) or department meetings (I75, I92). Another institution indicated that they participate in new faculty orientation and are on a Faculty Consultation Team that offers faculty and staff training (I49). Those that have training suggest that it is usually "preaching to the choir" but could enlighten others through these sessions (I22 & I41). It is essential to have such training with examples of how to teach subject matter that "hits close to home (I40)" with a student. One institution "trains faculty through diversity awareness and management programs and that this is an undesirable approach… as it is hard to reach adjunct instructors with any consistency. Each semester, I hear stories from the students about at least one teacher who blew it" (I79). As part of the question of what the disabled student services' offices would do to assist students with SWCI if they had an unlimited budget, the theme of absence of training was supported as fifteen would use the money to provide in-service programs for faculty and staff (I15, I22, I23, I26, I28, I37, I47, I61, I71, I79, I82, I86, I110, I112, &I134).

Specific examples of communication and training

While there was little evidence of sensitivity training or preparing faculty to have students with chronic illnesses in their classes, more institutions were prepared to support students with seizures. The following scenario was presented to respondents: If a faculty member teaches a class and a student starts having a seizure, what action should he/she take for the *student* and the *class*? What kind of training, if any, does your institution have to enlighten faculty on how to handle such situations? The theme of absence of training sessions appeared with 35 not having any sessions, or if they did, it was included in their first-aid sessions (13). Five specified actual having faculty training on what to do if a student has a seizure (I41, I90, I105, I128, & I129). One institution holds workshops, but usually, faculty only attend after an episode has occurred in their classroom (I41). One provides training for the faculty of students registered with DS who have a seizure disorder (I105). A theme where 29 specified that training for this situation would be covered under the institutions' emergency protocol surfaced. Most would involve public safety (or similar office) to make any medical decisions, but some have it included in a university emergency booklet or faculty handbooks. Information was usually provided to faculty from the DS office when students self-identified and included in their disclosure letter (38). Some will also include a seizure handout, a copy of the Epilepsy Foundation seizure first aid pages (I37); written instructions by the student usually whether or not the student would like an ambulance called; or encourage the student to talk with the faculty member as seizures affect each student differently. One institution had a specific seizure management plan that combines the student's wishes with the University policy on what to do when a student has a seizure (I27). In response to this question, a few indicated that this is something that is needed (I20, I125, & I138). Two (I46 & I47) revealed that they previously had sessions or discussions on this topic but had not lately, and this question served as a reminder to re-implement them. "Ignorance, by experience, causes the most adverse reactions in emergency situations" (I133).

Offering workshops/topics

Institutions were asked if they provided the workshops/topics listed in Table 5 and Figure 7 to students. Students were asked if they attended them. Both institutional and student respondents were asked if these workshops/topics were geared towards SWCI and if it was important to have these workshops geared towards SWCI. While most of the schools offered these to their students, less than 20% indicated that any of these were geared to SWCI. Two-thirds provided career guidance, time management, stress management, relaxation techniques, and coping workshops. Student participation in these workshops/topics ranged from 6% to 49%. Similar to the institutional responses, students indicated that less than 30% of these workshops/topics were geared towards SWCI. However, both institutional and student respondents believed that having these workshops geared to include the perspective of chronic illnesses was very important, with institutions ranging from 82% - 97% important and students ranging from 71% - 97% important. The top five workshops/topics that institutions thought were important to have geared towards SWCI were Balancing Health/School, Health Management, Coping, Career Guidance, Stress Management, and What to do in an Emergency. Students had most of the same topics but in a slightly different order of priority: Coping, Healthy Eating, Health Management, Social Adjustment, What to do in an Emergency, and Balancing Health/School.

Table 5

Workshops and topics that institutions offer, if they were geared towards SWCI, and their importance to institutions as well as students' perception of these workshops/topics

	I-Offered	I-Geared	I-Importance		S-Attended	S-Geared	S-Importance	
	%	%	$\overline{X}$	S.D.	%	%	M	S.D.
Career Guidance	93	17	1.65	0.571	49	22	1.74	0.759
Time Management	88	14	1.64	0.618	42	22	1.62	0.716
Stress Management	87	17	1.56	0.601	44	28	1.43	0.583
Relaxation Techniques	71	15	1.77	0.586	6	8	1.89	0.751
Coping	66	11	1.67	0.57	25	29	1.46	0.558
Balancing Health/School	62	14	1.61	0.553	19	21	1.47	0.687
Social Adjustment	62	11	1.84	0.624	16	6	1.66	0.67
Healthy Eating	62	10	1.76	0.57	34	22	1.47	0.625
What to do in an Emergency	57	18	1.58	0.608	22	15	1.6	0.695
Health Management	57	15	1.52	0.584	28	19	1.42	0.642
Managing Change	51	14	1.84	0.595	21	19	1.7	0.684
Spiritual Growth	45	9	1.93	0.66	22	12	1.94	0.802
Assertive Training	41	11	1.81	0.597	8	12	1.85	0.718

Peer-to-Peer Mentoring Programs

Seventy-five percent of the institutions responded that they do not have peer-to-peer mentoring for SWCI. Approximately 10% had peer-to-peer mentoring or an email group for this specific population or with other students with disabilities, similar to the

16% of the students who indicated that there was some similar activity for SWCI. Only six students indicated that they participated in such activities as either a mentor or mentee. The most popular activities offered by institutions for these groups were dinner/lunch meetings (46%), guest speakers (33%), social events (33%), focus groups (25%), and day trips (8%). Both institutions and students responded that students made the decisions about when and how frequently these activities would meet. Students felt that focus groups (82%) and guest speakers (81%) were important. In the qualitative answers, eight students mentioned explicitly suggesting institutions to have support/peer-peer groups. "I think it would be helpful if they were to offer a peer-to-peer program for incoming students where a student who had received disability services informed the incoming student about how to navigate the system" (S18). Another student wrote it "would have been nice to know that I am not alone [in facing a chronic illness]" (S21). Student #70 indicated that having a "peer to peer or focus group sessions for students and faculty members" could assist in the adjustment to college and follow-up with "check-point sessions" to ensure everything is going well and to hear comments and suggestions. On the other hand, four students indicated that they would not want to be a part of such activities due to the possibility of being "labeled" or compared to "other students." He/she just wanted to be treated equally as other students on campus.

Residence Facilities

For institutions with residence facilities (81%), almost all provide housing assignments appropriate for those with SWCI (91%). As with other students with disabilities, requests by SWCI are reviewed on a case-by-case basis, depending on the disability with documentation. Some examples provided by the respondents of how institutions serve SWCI in housing assignments in order of frequency included private rooms/bathrooms (26); single rooms (23); rooms on the ground floor (10); rooms with air conditioning/climate control for those with Asthma/respiratory conditions (9); rooms with a kitchen or additional refrigerators/microwaves for those with Celiac or other similar conditions (6); exclusion from the meal plan (5); rooms without carpeting (4); space for medical equipment/medicine/personal attendants (4); rooms with central campus location (3); limited use of cleaning products (3); and access to emergency assistance (2). One unique student-centered program was a 24/7 attendant (fellow students) service program for students with various physical impairments (I106).

Twenty-one percent of the students who responded lived in residence faculties. Of these, accommodations included the following: had their own refrigerator or microwave (6); single rooms (2); locks (2); a single room with private bath (1); or a double with air and private bath (1). Even though this was a small sample, many of the accommodations provided to students were the same as those indicated through the *Institution Survey*.

Summary

Communication, services, and training were themes that emerged from the questions asked about how Colleges and Universities serve SWCI. Administrators believe that they are serving SWCI; however, for the most part, the perception of SWCI is that they are not fully meeting their needs. Administrators use various means of communication (i.e., information conversations, e-mails) to disseminate information; however, SWCI indicated that they do not receive information. Institutions indicated that they collaborate and communicate between offices regarding serving SWCI and that members of their institutional communities are aware that specific services are available to this population. Institutions encourage SWCI to have conversations with their faculty. However, many students only felt comfortable doing so depending on the situation, and therefore might not always have the conversation. From the institutional perception, there is an absence of training for community members. If there was an unlimited budget, training was one of the items that money would be spent on. One instance where Institutions believe that they serve SWCI when it comes to residence facilities is offering various services on a case-by-case determination. Both Institutional and Student Respondents indicated that many useful workshop topics are offered at their institutions but are not geared to SWCI. Both believe having them would be very beneficial, especially the topics of Coping, Health Management, What to do in an Emergency, and Balancing Health/School.

Research Question #2: What policies and procedures are in place at colleges and universities for students with chronic illnesses?

The emerging themes of policies and procedures are individualized attention, communication, and collaboration, like the themes of research question one. Institutions indicated that a variety of procedures and policies are available to SWCI, including Universal Design. Students agree that these are available to them but to a lesser extent. Institutional respondents encouraged students to self-identify and to communicate their condition to faculty. They also created cross-campus collaboration processes and campus-wide teams to help support SWCI and students with disabilities.

Individualized Attention

When specifically asked how the Disability Resource Office assists students with chronic illnesses, there were many responses. Many institutions pride themselves in their ability to serve these students on a case-by-case basis, provide individual attention, and the appropriate accommodations based on documentation as they do with all students with every type of disability. A total of 61 respondents wrote about this major theme of treating each student as an individual. The good of the student is considered, and the most appropriate accommodations are put into place. One institution (I67) wrote that they are “constantly striving to meet the unique needs of each student without affecting the integrity of the academic program or course.” Another institution summed it up as “coming up with alternative and creative answers” (I23).

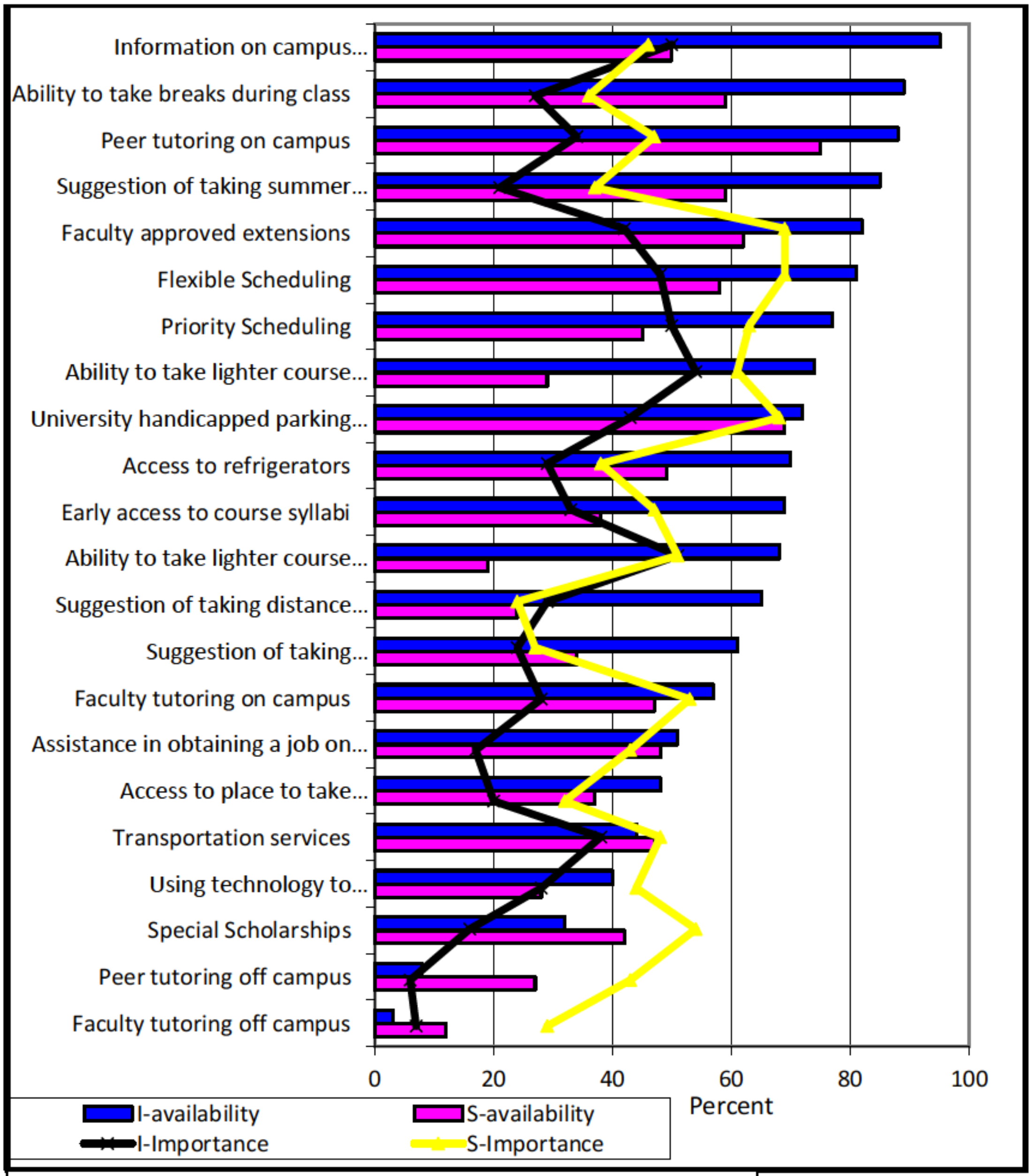
Available Policies and Procedures

As seen in the bar chart in Figure 4, many institutions have these policies and procedures in place. Over 80% of the institutions provide information on campus accessibility; ability to take breaks during class; peer tutoring on campus; suggestion of taking summer courses; faculty-approved extensions; and flexible scheduling. Students indicated that the top services available to them, ranging from 50% to 75%, were peer tutoring on campus, university accessible parking permits, faculty-approved extensions; suggestion of taking summer courses; ability to take breaks during class; flexible scheduling; and information on campus accessibility. Except for transportation services, special scholarships, and peer and faculty tutoring off-campus, students indicated that these services are not as available as the institutions indicated. A cross-tabulation analysis of the institutions that provided students with the ability to take a break from class revealed that 50% have a designated place for students to go and take this break. A similar analysis for students showed that 51% have a place to take this break. This was one of the few areas where both institutions and students had the same experience. The lines in Figure 4 indicate how important these policies and procedures are to students and institutions. For all items except for information on campus accessibility and the suggestion of taking distance-learning courses, students believe that these services were more important than the institutions. Differences are more clearly identified in Figure 4. Students' importance ratings ranged from 24% to suggest taking distance-learning course to 69% for flexible scheduling. Students rated faculty-approved extensions; flexible scheduling; university accessible parking permits; priority scheduling; and ability to take lighter course work one time as 60% or higher in importance. When it came to special scholarships for SWCI, faculty tutoring on campus, and using technology to view a class when absent; SWCI who consider having a disability considered these services significantly more important than SWCI who do not consider having a disability (Appendix K).

Institutions' importance ratings ranged from 6% for faculty tutoring off-campus to 54% for the ability to take a lighter course load one time. Ability to take a lighter course load one time; ability to take a lighter course load many times; priority scheduling and information on campus accessibility were all rated 50% or higher in importance for institutions. Forty percent has the technology available to assist students. Institutional #79 wrote the following additional comments: “I do not think the answer for every SWCI is distance education. I believe that to be part of a community benefits the student and the community through their presence.” In response to the open-ended question of what institutions could do, to help make the adjustment process easier for SWCI, four students suggested providing additional funding/special scholarships (S30, S47, S55, & S72).

Figure 4

Available policies and procedures to students and their importance to Institutions (I) and Students (S)



Importance based on Very Important

Other policies and procedures mentioned include the members of the disability services office assisting in educating other departments; having centralized services/contact person to assist with all aspects of their studies, especially when ill; being an advocate for students and training students to become self-advocates; working freshmen orientation for parents and students; counseling; coaching for life and academic skills; providing a disability coordinator who has expertise in medical disabilities; providing a one on one mentoring program upon request; and advisement.

Specific accommodations in practice by the Disability Resource Office include absent notices; authorizing letters of accommodations for faculty members; note-taking; test-taking; classroom modifications; creating and distributing seizure plans when appropriate; reduced course loads; medical withdrawals; opportunity to take breaks; provide referrals; permission to have food/drink for medicine; and late drop of semesters for medical emergencies. Eight institutions provided comments on a version of a modified attendance policy. The suspension of an attendance policy is something that "almost no other group of students with disabilities received" at this institution (I77). Institution #37 has "flexibility due to illness/disability policy" in place for faculty to determine how flexible they can be for a particular course.

Universal Design

Only 18% of the institutions indicated that their institution uses Universal design. The majority (49%) indicated that they use this sometimes, and 13% indicated their institution was in the planning stages of incorporating Universal Design at their institution. The responses were similar between private four-year institutions and public four-year institutions. Institutions felt that incorporating Universal Design was something they would include on their "wish list" if they had an unlimited budget (I67, I72, I73, I75, I80, & I135). Another institution (I66) indicated that this is another way that colleges and universities could serve SWCI.

Having Students Self-Identify

Institutions indicated that they have clear policies and procedures outlined on websites and in handbooks. Chronic illness is included in the description of students eligible for services through the Disability Resource Office in all materials regarding this office (I73). Many suggested that they could best help students when they register with their Disability Resource Office (13), and one even indicated that this is "rule number one" (I51). One stated that this is best so that they can "put a plan in place in case of an emergency and not have to operate in crisis mode" (I29). Four stated that they informed students about disability services at orientation (I54, I55, I86, & I92). Three mentioned a statement in all course syllabi is included about disability services (I54 & I72, I102). The services provided by the Disability Resource Office are advertised throughout the college's print and media resources (I110).

Referrals

Many Institutional Respondents indicated that students would know where to go for information. Respondents were presented with the following scenario: If a sophomore living in the residence facilities was just diagnosed with kidney failure and has been placed on dialysis, will need to modify his/her courses and obtain transportation to and from the dialysis center, does he/she know where to go to get assistance? Please explain this process at your institution. One central theme was that students would be referred to the Disability Resource Office/Health Services (44), with 18 stating that the housing staff would be the area on campus making the referral. Another theme, with 37 responses, was that students would know to come directly to the Disability Resource Office since it is provided at freshmen orientation, on websites, or in faculty syllabi. Institution #28 commented that this scenario did take place on their campus. Their students coordinate with Residence Life, Disability Resource Office, and Student Affairs assistance. A fellow student even volunteered to provide transportation. Fortunately, the student received a kidney transplant, took off a semester, and returned to school. Another institution was "not sure if there is a contingency plan for this" (I25). One institution responded with the following statements. "We can make the information available, but we certainly can't force a student to absorb this information. Information on resources is available on the university website and from a large number of professional staff. Of course, a student must seek this information and must not wait until someone senses his or her need for assistance. Too often, I find that this lack of self-advocacy is at the root of problems for students. Sadly, they are too often hesitant to ask for information or assistance" (I105).

Team Approach

Another theme was having "key persons" (I11) involved and using the "Team Approach" (I13) in supporting SWCI (18). Having "campus-wide commitment", (I114) is important to have in place. Institutional respondent #116 indicated that they try to develop a greater awareness and understanding by reviewing their campus to find ways to enable these students to function to their best capacity. One institution (I33) has a team in place to assist in policy changes. Another (I95) has a "disability support services committee" that meets weekly and can collaborate and handle any issues. Three specified that they used letters to communicate to faculty (I43, I92, & I131). Some also have training for the campus community (I46, I121, & I129).

Cross-Campus Collaboration

Regarding the theme of a team approach, many institutions have practices in place between departments that help to support SWCI. When an entering student indicates that he/she has a disability or a chronic illness, the Office of Admissions will collaboratively work with or refer the student to the Disability Resource Office to ensure proper paperwork is processed (39). One institution provides a disability information form as part of the acceptance package, which students may or may not complete (I88). Dean's offices/Academic advisors work collaboratively with the Offices of Disability Resource Office with the practice of referring students (52). Academic advisors would be responsible for assisting in facilitating independent study, making an appropriate schedule, planning reasonable goals for graduation, supporting students in "navigating" their degree, and advocating when necessary with a late withdrawal. The registrar's office would provide priority registrations (27), implementing reduced course loads, and assist with classroom location for students with needs. Financial aid offices have the practice to consider student appeals when students fall behind in course loads (12). Three schools would consider students' additional costs when calculating financial aid package (I34, I74, & I85). Two institutions have specific scholarships for those with disabilities, including chronic illness (I14 & I59). Many institutions have tutoring programs available to all students, including SWCI (81). Three institutions indicated that their tutors are trained in working with students with all types of disabilities and are sensitive to their conditions, special needs, and learning styles (I54, I120, & I133).

Another member of the team is the Office of Health Services. This Office assists in managing students' health issues (46). Examples of services include having a place for students to rest/take naps, providing referrals to outside specialists including pharmacies when necessary, parental consultation; space for self-care; assisting with transportation to off-campus appointments, offering information as needed/personal consultation, storing /monitoring medications, assisting with confirmation of students' documentation, and medical management expertise. They will work with the members of the Disability Resource Office and will refer students when necessary. It was interesting that some institutions provided no health services (9).

Public Safety works with Disabled Student Services in developing emergency plans (29). Some will create confidential emergency medical protocols for individual students so that public safety can respond appropriately in case of an emergency. One school encourages "students with specific dietary or medical needs to register with their emergency planning group to ensure that the university is prepared with supplies in a time of emergency" (I133). They will also create awareness training, provide transportation, parking, and assist when the student's behavior may be impacted by his/her illness and create a safety issue for other members of the school community.

As with other students with disabilities, the policy for assisting SWCI in residence halls is to review on a case-by-case basis depending on the disability with documentation (50). It is a collaborative effort between Residence Life and Disability Resource Office (24) for most institutions. Three institutions wrote that review is by committee (I7, I24, & I36). If the request is reasonable, it is then appropriately implemented. One institution indicated that what works for them (director of special services) is to take a tour with the student and director of Residence Life to review all the housing options to find the student's best fit (I132).

Other campus community areas also play a role in this team approach, including Information Technology, Career Center, Library, and Facilities. Information Technology (IT) in many schools has procedures in place to provide accessible and assistive technology as needed (39). Institutional respondent #47 stated that their IT would prioritize assistive technology problems as the highest priority to ensure equal access. One institution provides loaner laptops for students in long-term hospital treatment (I10). The Career Center also has practices and policies to assist SWCI (24) working with Disability Resource Office. In addition to Career Center services, SWCI can learn about workplace accommodations, how and if they should disclose during interviews, internship sites and websites that focus on companies/agencies that hire students with disabilities, and disability-specific job networking websites and organizations. One institution believes in "Working with the strengths of the student and finding the appropriate career path in light of their disabilities" (I32). Another institution has one counselor designated to disability issues (I47). Others hold workshops or panels regarding disabilities. Libraries also assist when needed. Examples of services include being accessible both physically and online, providing special software on computers, conversing with other departments on how to service this population, and having a specialized resource room. One institution state that "Librarians are great—they all aim to serve users and ask for guidance to deal with situations that are new to them" (I47). The Department of Facilities works with Disability Resource Office to ensure that reasonable and appropriate accommodations are met (35). At one institution (I133), disability specialists have input on new construction, and students receive emergency notifications, including when elevators are being repaired.

On-Going Support

Having on-going support (I45, I51, I125, & I133) is essential, as students never know when they need assistance. Two institutions have a policy of weekly meetings (I71, I78) as necessary in hopes that through these discussions, minor problems would not develop into larger ones. Another institution (I76) uses e-mail to monitor students formally and informally. Being a good listener and supporting the student is key to Institutional Respondent #48. In addition, helping the students with “accommodation with other aspects of Campus Life (e.g., Student Government, Athletics, Clubs, and Organizations)” (I49) is a good practice to have in place. One institution created a “Top Ten” handout to help students manage their chronic health issues and education (I107). Institution #78 is initiating student support groups.

Encouraging Students to Communicate Their Condition

The theme of encouraging and supporting students to talk with faculty was seen in nine responses. One institution had a procedure in place to coach/role play with students on how to speak with faculty about their accommodations (I22). This respondent believed that it could more likely lead the students to seek workplace accommodations after graduation. Another felt that one of their best procedures was to help students work with faculty, as they are the ones who best know their illness (I25). “We work with students to empower them to self-advocate but remain a resource should students have problems with faculty” (I54). “We encourage students to proactively communicate as “flare-ups” are common with chronic illnesses, and it is best that professors know this in advance so they will hopefully be more understanding and lenient with extensions if necessary" (I99). Another institution, I56, stated, "it is not the illness that is the issue as much as it is how well the student communicates with campus personnel about the situation at hand." This respondent believed that those students who maintain communication with their professors would receive the most support and fewer issues with their class work than those who do not.

Summary

The emerging themes of policies and procedures in place at colleges and universities for SWCI are individualized attention, communication, and collaboration, similar to the themes of research question one. Institutions pride themselves on treating each student with a chronic illness as an individual and providing specific accommodations on a case-by-case basis. Institutions indicated that a variety of procedures and policies are available to SWCI. Students agree that these are available to them but to a lesser extent. However, for most of these policies/procedures, students felt more important to have these than did the Institutions indicated. Communication was essential to the Institutional respondents seen by their encouragement of SWCI to self-identify and talk with their professors. This was also presented by administrators communicating through cross-campus collaboration and creating a Team Approach amongst their various departments such as Admissions, Academic Advisors, Health Services, Public Safety, and Residence Life to provide the appropriate services to SWCI.

Research Question #3: What experiences have institutions reported with students with chronic illnesses?

Institutional respondents had a wide range of experiences dealing with SWCI. Regardless of the situation, case-by-case accommodations in collaboration with campus community members is the "gold standard" in supporting these students.

Institutions were asked to write about their experiences with students with chronic illnesses. The illnesses identified most frequently were cancer (28), Epilepsy/seizures (19), IBS/Crohn's Disease (13), Diabetes (12), Kidney Disease/Transplant (12), Fibromyalgia (11), Lupus (8), Multiple Sclerosis and Neurological conditions (8), Chronic Fatigue (7), Chronic Pain (6), Heart Disease/Transplant (6), Cystic Fibrosis (5), Asthma (4), Celiac Disease (4), Arthritis (3), AIDS/HIV (3), Migraines (3), Traumatic Brain Injury (3), Allergies (2), Autoimmune Disease (2), Chemical Sensitivity (2), Chronic Vomiting (2), and Muscular Dystrophy (2). Individual Institutions also indicated working with students with Anhedonia, Anorexia, Dementia, Fabry Disease, Fainting, Liver disease, Lyme Disease, Post Traumatic Stress Disorder, Sickle Cell Anemia, Sleep Disorders, Spina Bifida, and Tourette Syndrome.

As Institutional respondent #24 stated, "Disability services are designed with individuals in mind." One theme that emerged, and that had surfaced in other questions, is that each student is unique and is served on a case-by-case basis (18). Many respondents shared the various services that they have provided. Another theme related to having a flexible attendance policy (18), since SWCI can be healthy for most of a semester and then fall ill unexpectedly. Institution #42 understands the need for a relaxed attendance policy but "emphasizes the need for the student to be able to tolerate the overall rigors of the course and to complete assignments, take tests, etc. as scheduled whenever possible." One institution allowed students to retake a course without penalty to make up the work (I125). Other accommodations include specific residential modifications (9); rescheduled or modified exam times (7); reduced course loads (6); incompletes (5); technology assistance of loaner laptops, videotaped classes, web cam (5); withdrawals (5); variations to the meal plan (3); breaks during class (2); air conditioning in dorm and classroom (1); eating in class (1); emergency plans (1); priority registration (1); and lighting (1). One of the institutions mentioned having modifications to the meal plan and obtained an area for a student with celiac disease to store and cook her food. "It was a challenge as we had to work around food service policies on campus" (I133).

One institution that has a student with a chronic condition that needs immediate assistance when ill has the student sign a release each year. This way, the administrators involved in assisting this student can inform each other of important information about the student (I32). Institution #54 uses internal resources to obtain a better understanding of any diagnosis that is identified. Another institution indicated that professors vary in their response to students (when sick) regarding finishing the course. "This is confusing to the student, who is already stressed because of their illness and may not have the energy or ability to work things out with each professor individually. We have handled these situations on a case-by-case basis so far, but we need a more unified approach" (I21). Another wrote that when they had a student with a chronic vomiting condition, a specific emergency plan was developed as the typical response of calling 911 was not appropriate and was distributed to faculty and staff in contact with this student (I48).

Institution respondent #105 wrote that some students manage their disability well, ask for assistance when needed, and do all the right things not to aggravate their condition. Others do quite the opposite, and no matter how much guidance is given, there is less chance for a positive outcome. Some respondents indicated that no matter how much they or the student tried, the student would have to drop out due to their illness (8). This can even occur with those students that are allowed to miss some classes as sometimes missing too many or not keeping up on the course work is just too much (I14). One institution suggested that there are times when it is best for students to take a break, concentrate on stabilizing their health, then come back, and focus on school (I102). Another respondent mentioned two instances where faculty did not understand and thought the students had an "unfair advantage" because of their accommodations (I82).

Institutional respondents also wrote about positive experiences their students have had in school. One administrator wrote how "a student with a chronic illness approached them to start a support group for this population. It was VERY well received" (I47). There were also two stories of students studying abroad. One (I71) involved a student with a seizure disorder. This student obtained doctor's clearance and planned by walking more and developing a way to combat the fatigue that would occur on the flights that may cause a seizure. At institution #79, a student had a congenital/genetic disorder that causes one's heart to stop. She needed to have access to a portable defibrillator. Long-term planning occurred with everyone in the institution and abroad, allowing this student to study abroad without any significant issues.

Summary

Overall, institutional respondents have had a wide range of experiences dealing with SWCI with various conditions. However, the idea that each student is unique and is served in a case-by-case situation is key. These administrators worked with their colleagues and the students to provide unique services and suggestions such as flexible attendance policies, residential modifications, or indications that a student might need to take a break from school to assist these students in their academic pursuits.

Research Question #4: How do students with chronic illnesses perceive that colleges and universities can assist them?

Almost half of the SWCI respondents do not consider themselves to have a disability. Many did not feel that their school was there to assist them with their chronic illness. They think that they can manage their medical condition, life, and school, even though they have side effects from medicine. They will share their condition with faculty and other campus community members, depending on the situation. Students shared various experiences with members of the campus community. Positive experiences expressed by students stemmed from the case-by-case practice indicated by institutions.

Many student respondents did not feel that their school was there to support them and their chronic illness. “There seems to be a plethora of systems in place for students with physical and learning disabilities, but less information and processes are targeted toward SWCI. I suppose I never really felt like I fit in with other disability groups. Maybe more targeted services and programs for those with chronic illnesses might have made me feel a more active participant in the disability services’ offerings” (S17). One student (S45) felt that her institution was “totally incompetent” in supporting this population. Student respondent #67 believes that “most schools have a long way to go.” Regarding receiving information from their institution about serving students with chronic illnesses, students stated the following: “they don’t” (S22); “have never seen information” (S14); or “no information at all” (S29).

Managing Their Medical Condition

Fifty-nine percent of the student respondents believe that they are managing their medical condition along with school and life. One student, who took a medical leave one semester, took CLEP credits and graduated on time with her classmates (S2). Student #3 tries “not to let it affect my daily life and carry on as a normal college student.” One student knows her limits and boundaries (S5). Student #6 looks at alternative ways to accomplish something if the illness gets in the way. One student did better once she realized that she did not want to jeopardize her future because of her illness (S15). Another was able to do better after surgery where life now involved more than just school, eat and work, but still has some bad days (S12). Student #16 believes she is doing as best as possible. “I’m just a bit unlucky to have this condition, so I do find myself frequently struggling, but I always find a way to stay tough and get by however I can” (S16). One student is managing by going part-time. She acknowledges, “it will take twice as long, but the fact that I will complete the program is a success and something I am very proud of” (S18). Student #71 considers herself to be “a survivor…I always succeed.” Another student (S70) took all the challenges of being diagnosed as a freshman and has accomplished many things, including raising money for Crohn’s disease, helping others who were depressed, and learning to take life one day/problem at a time and deal with each thing separately.

Twenty-three percent believe that they are only managing their life and their condition satisfactorily. Student #4 is muddling through. Student #11 says, “you learn to get as much done as possible when you feel well enough.” Three students (S14, S8, & S55) felt that they could do better. Student #30 felt that “sometimes it is difficult to manage. However, school is very important to me, so I try to toughen up and just deal.” Another student acknowledged that it is difficult to juggle school, life, and a condition and sometimes find it easier not to take care of the medical condition and therefore “fit in” more (S37).

Seventeen percent believed that they are not managing at all and had a hard time. Student #9 had a hard time maintaining the energy to succeed. Another (S26) acknowledges that life and school cannot coexist (S26). Student #28 believes it is a “revolving door” and very hard to stay on top of everything. Student #47 considers it a daily struggle and that they “haven’t mastered it yet.” Another student believes the combination of “going to the #1 ranked program in my field in the country” along with an illness-which can flare up because of stress “makes for a bad combination” (S48). Student #73 summarizes it by stating, “It is a struggle.”

For those who entered as freshmen, 34% believed that they had an excellent overall adjustment to college. There was no significant difference (-.98) on overall adjustment to college between SWCI who did not consider themselves as having a disability (2.29) and SWCI who do consider themselves as having a disability (2.08). The effect size Cohen’s d is approximately -.3, which is smaller than typical.

Side Effects Students Have

Seventy-four percent of students responded that they have multiple side effects from their medications that affect various aspects of their college life, as seen in Table 6. More than 50% stated that it affected their social life, involvement in extracurricular activities, and academic performance. Nineteen specified that their condition and medications make them tired and more challenging for them to go to class, complete homework, or participate in other school events. Seven said that they must create their schedules around the time that they take their medicine. Students also mentioned that it caused loss of concentration (6), mood swings (5), pain (4), nausea (3), forgetfulness (2), and not being able to drink with peers (2).

Table 6

Aspects of students' life affected by medications

Aspect	*f*	%
Social Life	39	71
Involvement in Extracurricular Activities	37	67
Academic Performance	35	64
Scheduling classes	20	36

Based on multiple responses

Ability to Share About Their Condition

When students were asked if it is easy to share their condition with faculty and administrators/staff, almost 70% stated that it depends on the situation. The following are experiences the students shared where they perceived that their conditions were not understood and that there was a lack of support from the institutional community members. Student #7 believes that "some faculty and staff seem disconnected from the subject and this feeling of it being 'a problem' makes me want to share if at all the problem-others are very nice about it." "In the past, I only shared my condition when I was ill and desperately needed help. I have learned that by doing so, I exacerbate my condition. Now I am much more open about it to avoid ending up feeling sick later on. However, I still feel embarrassed to share and admit I need special accommodations. I suppose it is good that I do, though, to help dissolve the stigma associated with epilepsy" (S16). "I told all of my professors and T.A's up front, in case something was to happen they would know I wasn't lying" (S28). Two others believe that the faculty thinks it is an excuse (S8 & S12). Student #29 believes that her teachers believe she "is taking advantage of the system because my disabilities cannot be seen." A student with migraines (S11) receives an attitude of "You get headaches, so what?" and believes that migraines are "debilitating and a lot of people don't understand that." One student, who has felt comfortable talking with peers and has not had to share with faculty, felt that "if I had to I would probably feel uncomfortable because I'm not sure if the teacher would care" (S21). Student #52 "felt it was very difficult to have the professors understand."

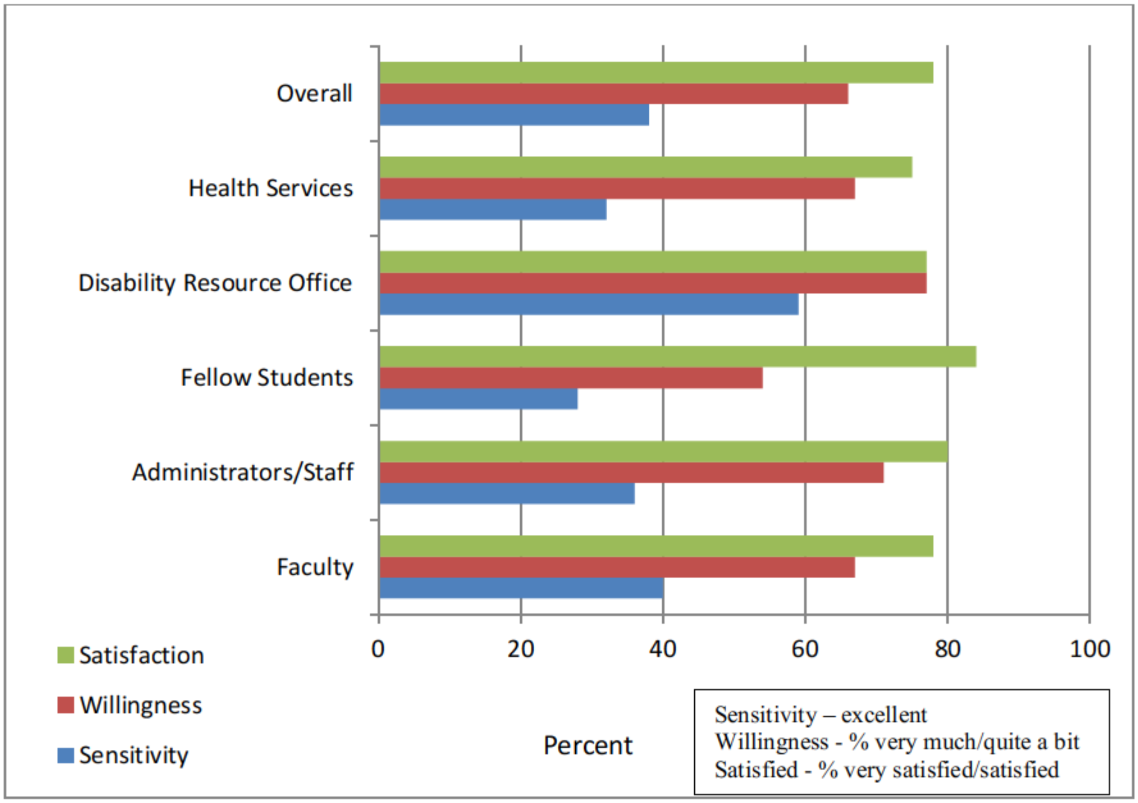
Students shared various reasons why they would not share about their condition. Examples include "there is a distrust of students getting accommodations" (S34); "viewed as weak or as a lesser individual…try to avoid looking vulnerable or needy' (S54); "reminds me that I am not 'normal'" (S59); "makes me stick out less if I don't bring it up" (S68); "do not want sympathy. I want a good full life without the pity" (S71, S40); "I feel like I'm being singled out and different from everyone else" (S73); and "Never wanted to be treated any differently" (S31, S49). Two students implied that it is more challenging in graduate school, and there is less support for graduate students (S8 and S47).

Student's Perception of Institutional Community

When students were asked how sensitive members of the institutional community were, only 40% indicated excellent. As seen in Figure 5, fellow students were the least sensitive, but students were most satisfied with their fellow students' understanding of their conditions. Only the Disability Resource Office had an excellent rating of over 50% for sensitivity. Willingness to help was significantly higher than sensitivity levels for each group, with willingness ranging from 54% to 67% and sensitivity from 28% to 40%. Students believed that only 40% of the faculty were sensitive, 67% willing, and were satisfied 78% of the time.

Figure 5

Students' perception of how sensitive and willing members of the university community are, along with their satisfaction with these populations



Perception of Faculty

Student Respondents perceived faculty as not always having a positive perception of them in their comments as well as indicating excellent in faculty sensitivity for only 40% of the time. Student #52 perceived that others, especially faculty, thought she was not intelligent since she spoke slowly when it was because of her chronic jaw joint pain where her jaw was closed and locked. One student's perception is that even if they converse with the faculty about their condition, "it does not stop the faculty from having a negative perception of me. One would not even write me a letter of recommendation after I missed three classes and I got an A in his class" (S8). Student #12 has had "teachers/administrators try to use my illness against me." One student believed that they had sent more information about scholarships and other resources on chronic illnesses to their institution than they had received (S44).

Positive Experiences

A few students perceived positive experiences with their institutions. "I think my college does a good job" (S10). Student #27 has felt supported by her institution in that they spoke with faculty and provided the appropriate housing accommodations. One student finds that "They are very understanding… They are very good about helping me to stress less. I think they like that I take the initiative, and they know I am a trustworthy student once I build up my reputation" (S70). Students #37 and #65 have had positive experiences where their institutions made them feel comfortable and supported. Student #37 also felt "that my institution has done a wonderful job in assisting to make the adjustment process as easy and smooth as possible." Another, student #54, believes that her institution does enough as SWCI only make up a small percentage of students. At a small institution, one student stated, “the way they take medical conditions case-by-case is nice (S62).” Students #39 and #59 had some issues but otherwise felt that their institutions did a good job supporting SWCI. Student #27 also had a positive experience but wished to have known that counseling services were available earlier. One student (S66) has a positive experience where food services provide a separate area for her food and constantly review food labels with her and identify those foods that are gluten-free. Her institution is trying to help her adjust to living with Celiac Disease.

Summary

Even though almost half of the students surveyed did not consider themselves to have a disability but whom the majority have side effects (tired, from the medications that they take that affect various aspects of their social life, involvement in extracurricular activities, and academic performance), more than half believe that they can manage their medical condition along with life and school. Only 34% who entered as first-time first-year students thought that they had an excellent overall adjustment to college. Students would share with faculty, administrators, and staff, depending on the situation. Even though almost 60% of the students felt that the university community was very much/quite a bit willing to assist them, only 40% indicated excellent in the institutional community being sensitive to their condition. The positive experiences shared by students seem to stem from the case-by-case practice indicated by institutions. Many felt that their institutions were not supportive enough of them and their condition.

Research Question #5. What services do students with chronic illnesses want and expect from an institution of higher education?

Students with chronic illnesses want to be informed of services specific to their needs and be encouraged to self-identify to benefit from these services and not encounter as many issues in knowing where to go for support and information. These students expect the appropriate communication from their institution and between members of the campus community. Students felt that having items such as workshops explicitly geared to SWCI is important, as well as having specific policies and processes in place for SWCI. This was essential as more than 50% encountered problems with certain services due to their chronic illness. Students experienced the most issues and are the least satisfied with knowing where to go for support and information and securing medical services. Institutions must use this as an opportunity to serve SWCI better.

Communication

Students wanted to know more about how their institution could assist them through wanting a comprehensive, consistent, transparent communication process that informs them about services specifically for SWCI and encourages them to identify. Students commented they would like more awareness of the available services, indicating that they are unfamiliar with them (20%). Less than 50% of the students responded that they received information by any of the means in Table 4 (from RQ#1). One student (S42) believes that institutions "can begin by recognizing that those with chronic illnesses exist…I do not know of the University having anything specifically designed to encourage those with chronic illnesses to come forward." "Make sure they let everyone know about their services and that they do exist for all illnesses, handicaps, and disabilities, not just educational or learning difficulties" (S5). Student #52 believed that she received advertisements on alternative lifestyles, but none for chronic illness, and wished to have seen more communication from her institution on their services to this population. Communication from the start - "the impact the health care center can have with SWCI is large, but could be bigger if students knew from the beginning" (S20). Another student suggested that when they mention the services of the Disability Resource Office at orientation to include specific examples of chronic illnesses so that if she had heard a particular illness like hers, she would listen and benefit from the services; otherwise, she would not have considered asking about services (S64). Two other students also believed that an explanation at orientation would be helpful (S6, S27). Ways to communicate included letters (S69 & S43), informational sessions (S15), handouts (S2), or a form to complete (S65 & S70). Student # 12 wants information available on how the school can support a student without the student "having to fight for everything that is mandated by federal and state governments." Another student is not aware of what their college does and believes "it is hard enough to go off to college but having to deal with Celiac Disease on my own is asking too much" (S59). One student only hears about services through the health center and no-where else (S48).

As seen in the following table, most of the students had some issues when asked how frequently they encountered problems with knowing where to go for support and information.

Table 7

Frequency and percent of students encountered problems of knowing where to go for support and information

Category	*f*	%
Very Often	15	23
Often	17	26
Sometimes	26	39
Never	8	12

One student who had signed up with Disability Resource Office for their learning disability "never knew the disability center helped with Chronic Fatigue Syndrome" (S31). Student #48 stated that "I never thought of disclosing my Crohn's disease to anyone at school besides my doctor," and Student #52 said, "I had no idea that there were specific services for someone with chronic head pain." Student #71 stated that she "did not know they helped those with Chronic Kidney Disease (CKD)." One student said, "I just wished I'd known I was eligible sooner" (S11).

Information Exchange Between Members of the Community

Students also indicated that there should be more communication between members of their institution to support them so that everyone involved understands the situation. That will help alleviate additional stresses to these students trying to navigate college with a chronic illness. Three students wanted more information provided to all areas of their universities as well as more communication between departments (S2, S5, &S22). This is important, as Student #2 believed not having this "makes a difficult time such as an illness even more stressful." This would also include maintenance staff, according to Student #7. Student #62 believes that the Disability Resource Office needs to have more staff members with "degrees of substance" to support SWCI and educate others. Educating faculty is vital to students. Students believed that if faculty were better informed about various chronic illnesses, they would be more understanding (S4, S28, & S36). Since these students have invisible diseases, their perception is that faculty think that they are taking advantage of the system or do not understand that other issues such as treatments and doctor's visits are part of their lives (S28, S29, & S52). Student #73 believes that faculty would be more sensitive if they were more informed on students "who don't have an outwardly visible physical disability, since the outside doesn't always reflect what's going on inside." Having faculty members understand students' condition is essential as some students will talk with their faculty when they miss a class, as seen in Table X. Seventy-nine percent of students would call or e-mail their professor when they missed a class. In Figure 6, most of the students communicated with their professor either before or at the next class in conjunction with contacting a fellow student. They rarely were dependent on classmates only.

Table 8

How students communicate when they miss a class due to their illness?

Category	*f*	%
Call or E-mail their professor	56	79
Talk to the professor next time I am in class	39	55
Call/e-mail "homework buddy"	30	43
Talk w/classmate next time in class	30	43

Based on multiple responses

Figure 6

Venn Diagram of how students obtain information about a class they missed

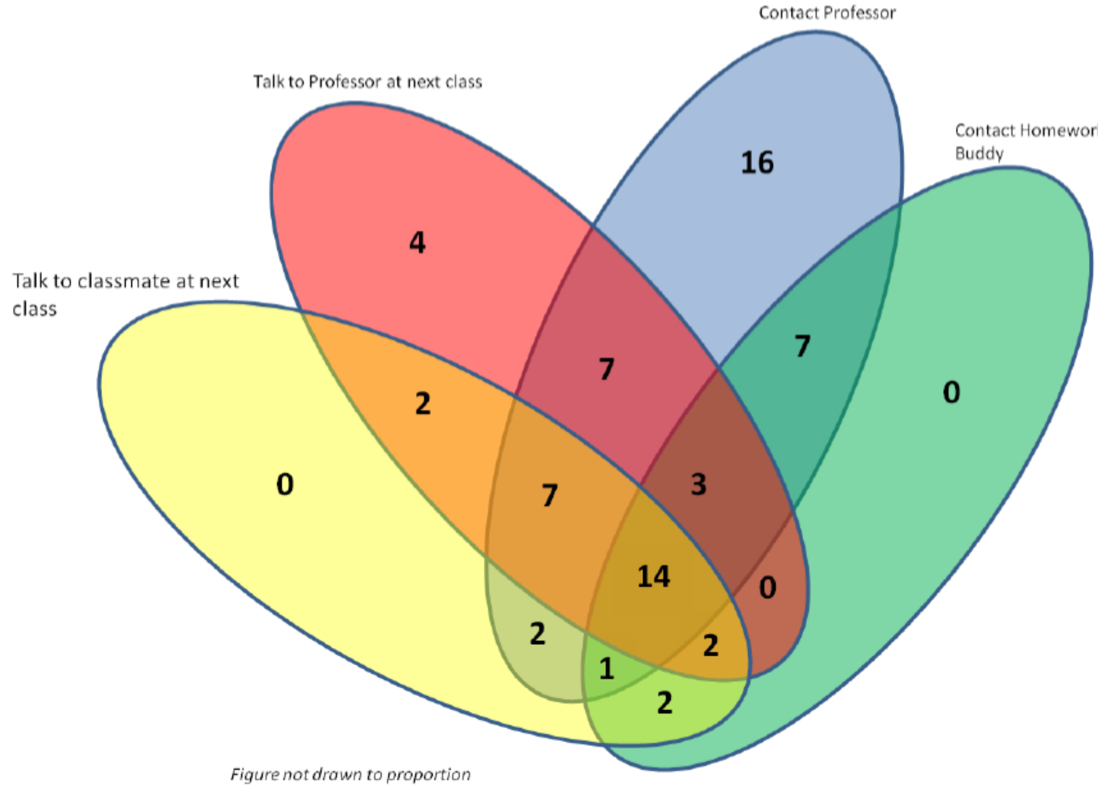


Figure not drawn to proportion

When students were presented with a scenario of exhibiting symptoms of their condition the day before the start of finals, slightly more than one-half would contact their professor or take their medication, contact their doctor, or talk with a family member about the occurrence with the hope that they could just get through it. Twenty-three percent would contact their dean or academic advisor. Only 12% would contact the Disability Resource Office. Student #18 said she would not contact Disability Resource Office because she had a similar experience and was told to take the test anyway. Eight students indicated that this was a good question or that they had experienced this (S4, S7, S18, S27, S43, S52, S55, & S72). Two said that they had no idea who they would contact (S42 &S44). Student #45 stated that "I always fear people will think I am lying because I am unprepared or something like that." A student with Celiac Disease (S63) knows that there are times where one must not only talk with faculty, but those above them since "Celiac Disease is still widely unknown and claiming you can't make final exams because of an illness that, for the uninformed, sounds like food poisoning, isn't a valid excuse."

Support Groups/Peer-to-Peer Mentoring

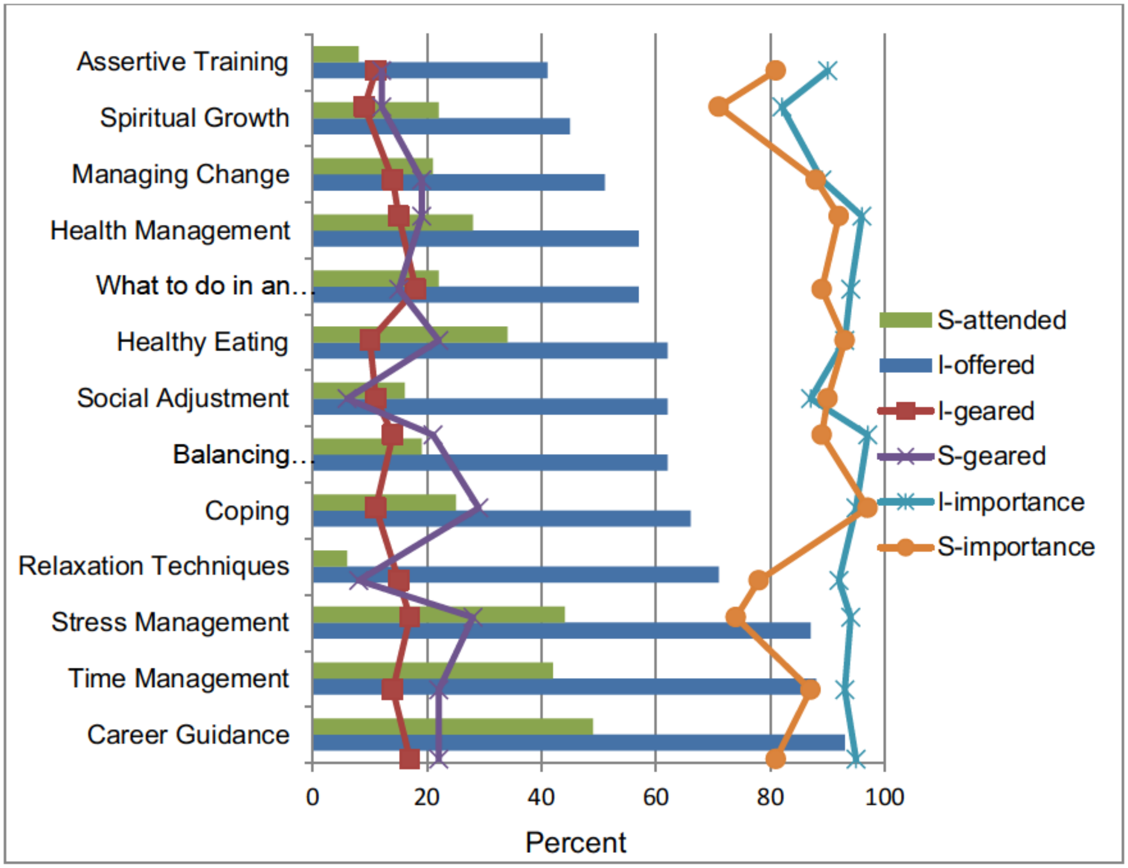
Almost all the students believed that focus groups were crucial to have for this population (82%). Appendix K shows that having focus groups was significantly more important to SWCI who consider themselves to have a disability (1.52) than those SWCI who do not consider themselves as having a disability (2.09), (p=.077). The effect size Cohen's d is approximately .8, larger than typical. A few specified support groups/peer mentoring (8), including those for the non-traditional older SWCI (S1) and incoming students (S18 & S44). Student #18 and #44 thought it would help incoming students learn from others on how to "navigate the system." Student #21 felt it would allow students not to feel as though they are the only ones facing such issues in life. Student #67 believes in the ability to network. She thinks that institutions could initiate the initial meetings between SWCI, and they would "play an important and integral" role in doing so, and then the students would take it from there. Students also felt that having guest speakers come and speak with SWCI is essential (81%).

Workshops

As seen in Figure 7 and Table 5, many students believe that having workshops geared towards SWCI is important, ranging from 71% - 97%. Institutional respondents also agreed that having these workshops geared towards SWCI is important, ranging from 82% to 97%. Coping, healthy eating, health management, social adjustment all received 90% or higher importance rating by students. Balancing health/school; health management; coping; career guidance; stress management; what to do in an emergency; time management; healthy eating; relaxation techniques; and assertive training all received 90% or higher importance by institutional respondents. Even though the workshops were not specifically geared towards this population, less than 30% indicated by both students and institutional respondents, many students, still attended such sessions at their institution ranging from 6% - 49%. SWCI, who consider themselves to have a disability, believed workshops on social adjustment, time management, stress management, managing change, and career guidance were significantly more important than SWCI, who do not consider themselves to have a disability (Appendix K).

Figure 7

Workshops and topics that institutions offer, those attended by SWCI; if they are geared towards SWCI (from institutional and student perspectives); and their importance (from institutional and student perspectives)



Policies and Procedures

Students stated that having specific policies and procedures available to SWCI is important. Sixty percent or more of the student respondents felt it was important to have faculty-approved extensions, flexible scheduling, university accessible parking permits, priority scheduling, and the ability to take a lighter course work one time (Figure 4).

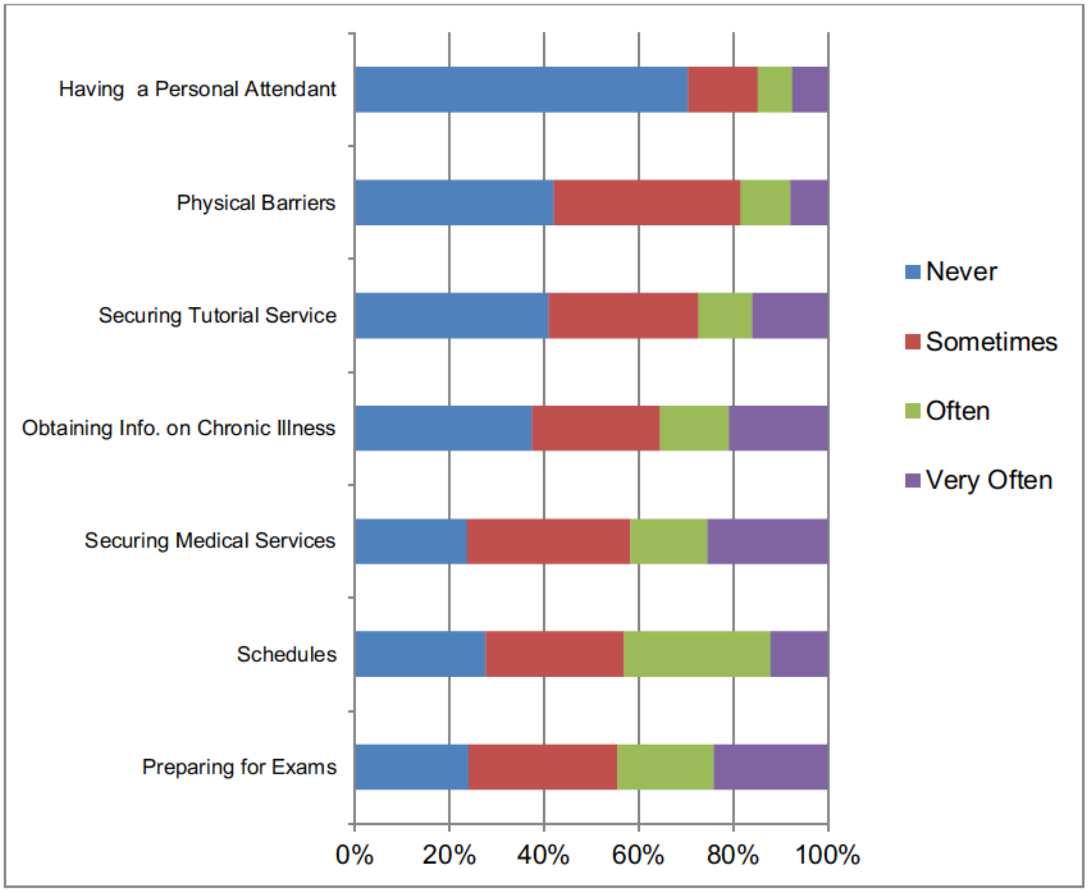
Fifty percent or more of the student respondents felt that special scholarships, faculty tutoring on campus, and the ability to take a lighter course load many times were important as well. In addition to specific scholarships, more awareness of financial aid is necessary (S30, S47, S55, S72). Specific services mentioned include housing accommodations (S15) such as private rooms with private bathrooms; provide more information available on dining services and having better dining plans and more food options (S7, S15, S57, & S63); serving students with food allergies or providing a separate area for students with food intolerances (S39); assisting students when they are studying abroad (S62); having the option of taking classes at their own pace, within reason (S72); having more counseling services available (S15); knowing that these services were available (S27); having more support and ideas on balancing life and school from the institutions (S2); and having better accommodations for service animals (S55).

Issues with Certain Services

Students indicated that they encountered problems with certain services because of their chronic conditions. More than 50% of the students had an issue some of the time with securing medical services, preparing for exams, their schedules, obtaining information on their chronic illness, securing tutoring services, and physical barriers. Having a personal attendant was not an issue for the majority of the students. Students had more issues with preparing for exams, their schedules, and securing medical services, with more than 40% occurring often or very often. These results are presented in Figure 8. As seen in Appendix K, there were significantly more problems for SWCI who consider themselves having a disability than those SWCI who did not consider having a disability in the areas of physical barriers, schedules, securing tutoring services, and preparing for exams. Appendix L maps students' satisfaction with the frequency that they have encountered issues. Students have experienced the most problems and are the least satisfied with knowing where to go for support and information and securing medical services. Therefore, institutions must use this as an opportunity to improve these areas to serve students with chronic illnesses better. Students had frequent issues with preparing for exams and their schedules but were the most satisfied with these items, and therefore, institutions must continue supporting SWCI in these two areas.

Figure 8

Percentage of students encountering issues with services

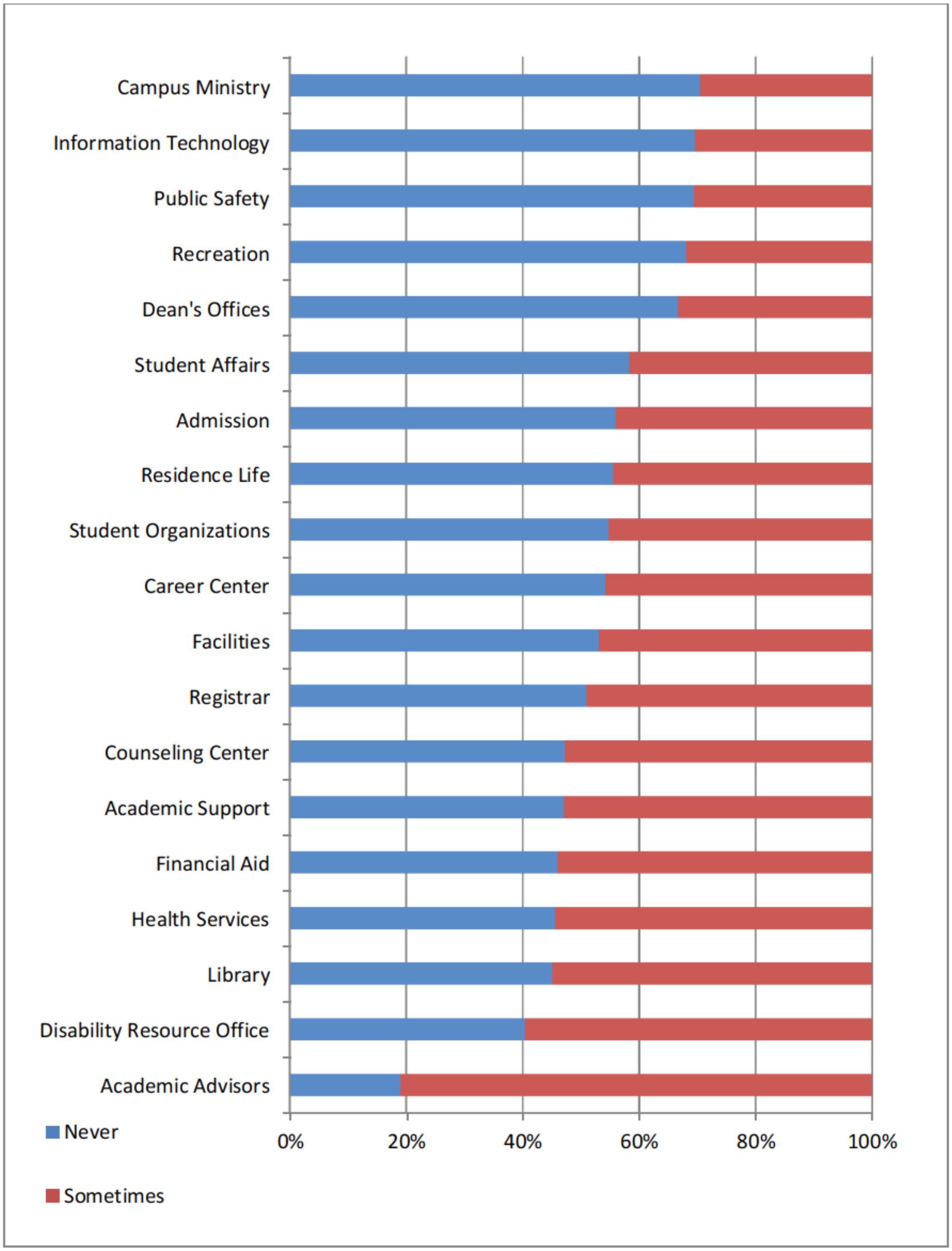


Departments Across Campuses Students Visited for Assistance

Students visited various departments across campus to obtain specific assistance or services concerning their chronic illness (Figure 9). Students mostly went to their Academic Advisors, Disability Resource Office, Library, Health Services, Financial Aid, Academic Support, and Counseling Center. They least visited Campus Ministry, Information Technology, Public Safety, Recreation, and the Dean's Offices. Students with chronic illnesses who consider having a disability significantly frequented more the Disability Resource Office; Academic Advisors; Public Safety; Academic Support; Registrar; Admissions; Human Resources (student employment); Financial Aid; Career Center; Facilities; Athletics; and Marketing and Communications than SWCI who did not consider themselves as having a disability (Appendix K).

Figure 9

Students' frequency in visiting departments across campus



Summary

Communication is key from the student's perspective. They want to be informed of the services specifically for SWCI and be encouraged to self-identify to benefit from these services and not encounter as many issues in knowing where to go for support and information throughout their academic career. Communication was important, but students felt that communication to all areas of an institution, especially faculty, needed to be disseminated regarding serving and understanding SWCI. Students felt that there were many services necessary for institutions to have for SWCI. This included focus groups; guest speakers on the topic of SWCI; workshops geared towards SWCI on coping, healthy eating, health management, and social adjustment; and having specific policies and processes in place for SWCI. This was important as more than 50% encountered problems with certain services due to their chronic illness. Students experienced the most issues and are the least satisfied with knowing where to go for support and information and securing medical services. Institutions must use this as an opportunity to serve SWCI better. Students had frequent issues with preparing for exams and their schedules but were the most satisfied with these items, and therefore, institutions must continue to support SWCI in these two areas.

Research Question #6. How satisfied are students with chronic illness in how colleges and universities are serving their needs?

Students' satisfaction was not as high as their rating of importance in all categories surveyed. One-on-one conversations were among the categories of obtaining information that students were the most satisfied with and rated it as one of the most important categories. This is similar to the institutional belief of providing services in a case-by-case situation. Areas of Institutional Policies and Services are areas that had high importance and low satisfaction with students and are opportunities for institutions to improve their services to SWCI. Students were still dissatisfied with the resolution for issues relating to physical barriers, obtaining information on chronic illness, and securing medical services.

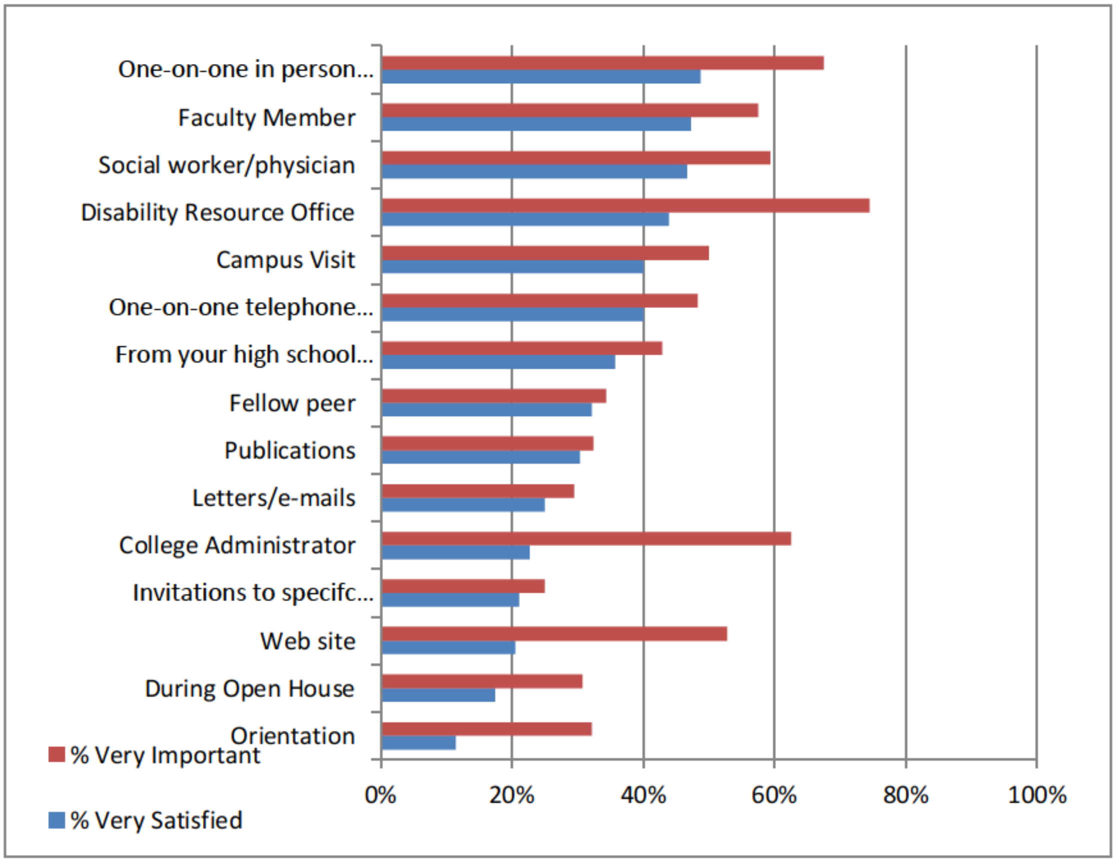
Obtaining Information

Students were asked to indicate importance and satisfaction with fifteen different ways of obtaining information about how their institutions serve SWCI (Figure 10). The percent of students who thought these means of communications were very important ranged from 25% to 74% compared to a range of 11% to 49% who were very satisfied. For all categories, students' satisfaction was not as high as their rating of importance. The largest gaps, 30% or more, between satisfaction and importance were college administrators, websites, and the Disability Resource Office. They were the most satisfied with one-on-one in-person conversations and the least satisfied with orientation. Over 40% were very satisfied with one-on-one in-person conversations, faculty members, social workers/physicians, and Disability Resource Office. Sixty percent of students felt that obtaining information from the Disability Resource Office, college administrators, and one-on-one conversations were the most important, with invitations to special presentations, the least important. Publications and fellow students had the smallest difference between satisfaction and importance. SWCI who did not consider themselves as having a disability were significantly more satisfied with obtaining information from their fellow peers than SWCI who consider themselves having a disability (Appendix K).

Using the matrix in Appendix M, the forms of communication with college administrators and through websites were of high importance but low satisfaction to students and are areas in which institutions need to improve. The forms of communication with social workers/physicians, one-on-one personal meetings, meeting with faculty members, Disability Resource Office, and the campus visit are of high importance and high satisfaction and, therefore, areas in which the institutions should maintain this level of service.

Figure 10

Student satisfaction and importance on ways in which they obtained information about services to SWCI



For those who identified their condition during the admission process, 30% considered that overall assistance and support was excellent during this process. It should be noted that 36% of the student respondents had not informed their institutions during the admission process. Approximately 80% of the students were satisfied with how fellow students, administrators/staff, faculty, Disability Resource Office, Health Services understood and were sensitive to their chronic illness. This is seen in Figure 5. Even though they were satisfied, students' perception of their sensitivity or willingness was not as high as their satisfaction.

Available Services

In addition to services available (Figure 4), students indicated their satisfaction with these services, as seen in Figure 11 and Table 7. Students were satisfied for the most part. Students were the most satisfied/very satisfied with access to refrigerators; recommendations to take summer class; faculty-approved extensions; faculty tutoring on campus; and the ability to take a break during class with 70% or more satisfied. More than 50% of students were dissatisfied/very dissatisfied with the ability to take a lighter course load multiple times, the use of technology, special scholarships, the ability to take a lighter course load one time, and peer tutoring off-campus.

Appendix N is a matrix of student's importance and satisfaction with these services. The areas of Accessibility of Campus include information on campus accessibility and parking permits and the area of Academic Support of flexible scheduling; faculty extensions; and faculty tutoring on campus were of high satisfaction and high importance to students. Institutions must maintain these levels of services. The areas of Institutional Policies of priority scheduling, lighter course loads one-time, lighter course loads multiple times, and special scholarships and the area of Institutional Services of transportation and using technology to view class when absent have high importance but low satisfaction with students. Therefore, these areas are opportunities for institutions to review their policies and improve these services to students with chronic illnesses.

Figure 11

Students' satisfaction with available services

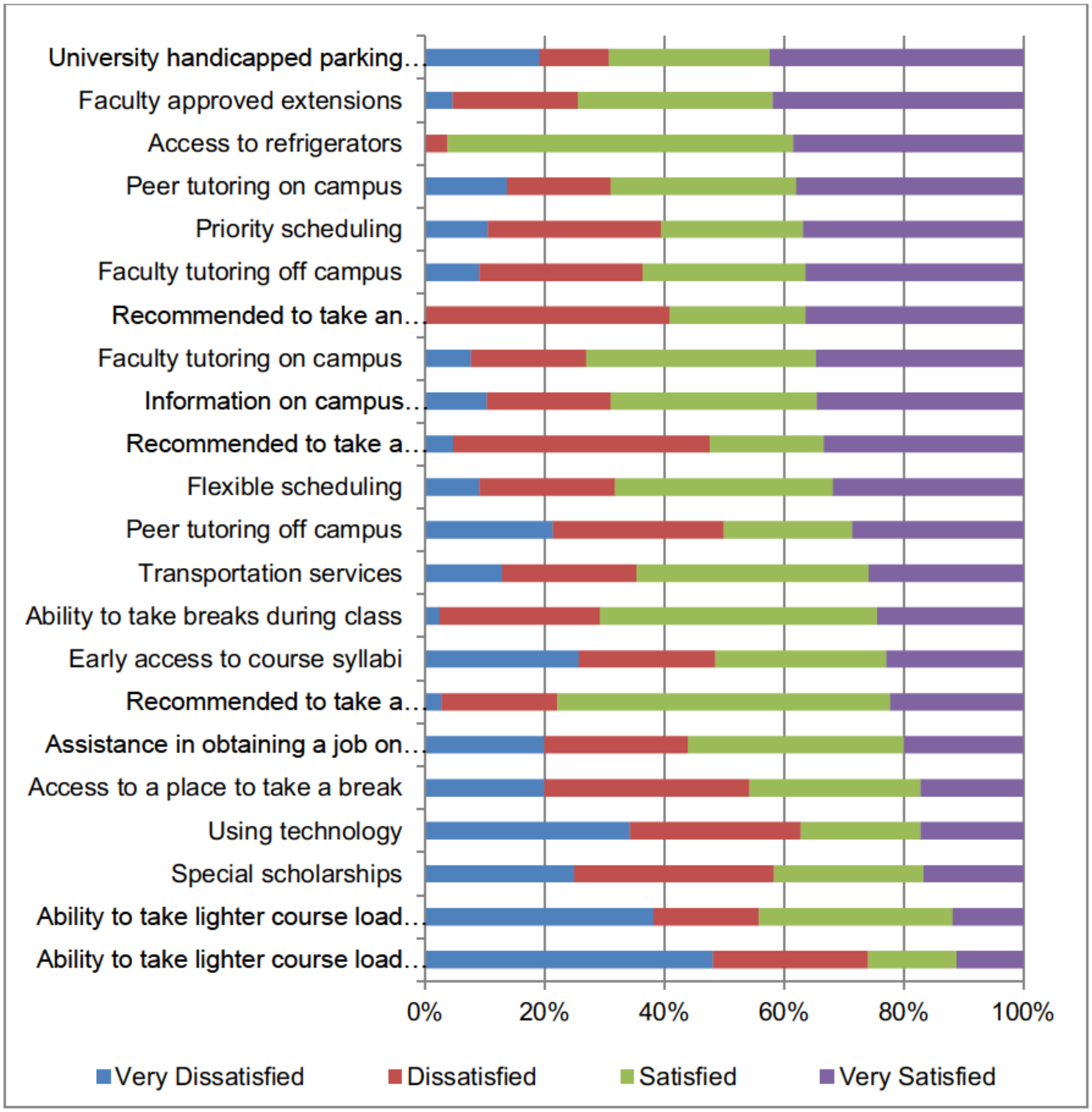


Table 9

Students' satisfaction and importance with available services

	Satisfaction		Importance	
Services	M	S.D.	M	S.D.
Ability to take lighter course load many times	3.11	1.050	1.54	.600
Ability to take lighter course load 1 time	2.82	1.086	1.42	.545
using technology to communicate course to student	2.80	1.106	1.63	.610
Special Scholarships	2.67	1.042	1.56	.681
Access to place to take breaks/naps	2.57	1.008	1.77	.605
Early access to course syllabi	2.51	1.121	1.66	.700
Assistance in obtaining a job on campus	2.44	1.044	1.76	.760
Peer tutoring off campus	2.43	1.158	1.86	.848
Transportation services	2.23	0.990	1.60	.632
Suggestion of taking distance learning courses	2.19	0.981	1.94	.649
Priority Scheduling	2.13	1.044	1.47	.674
Faculty tutoring off campus	2.09	1.044	1.96	.751
Flexible Scheduling	2.09	0.96	1.37	.592
University accessible parking permits	2.08	1.164	1.41	.657
Peer tutoring on campus	2.07	1.067	1.72	.772
Information on campus accessibility	2.07	0.998	1.57	.555
Ability to take breaks during class	2.07	0.787	1.78	.679
Suggestion of taking independent study courses	2.05	0.899	1.88	.640
Suggestion of taking summer courses	2.03	0.736	1.74	.658
Faculty tutoring on campus	2.00	0.938	1.96	.751
Faculty approved extensions	1.88	0.905	1.33	.519
Access to refrigerators	1.65	0.562	1.95	.837

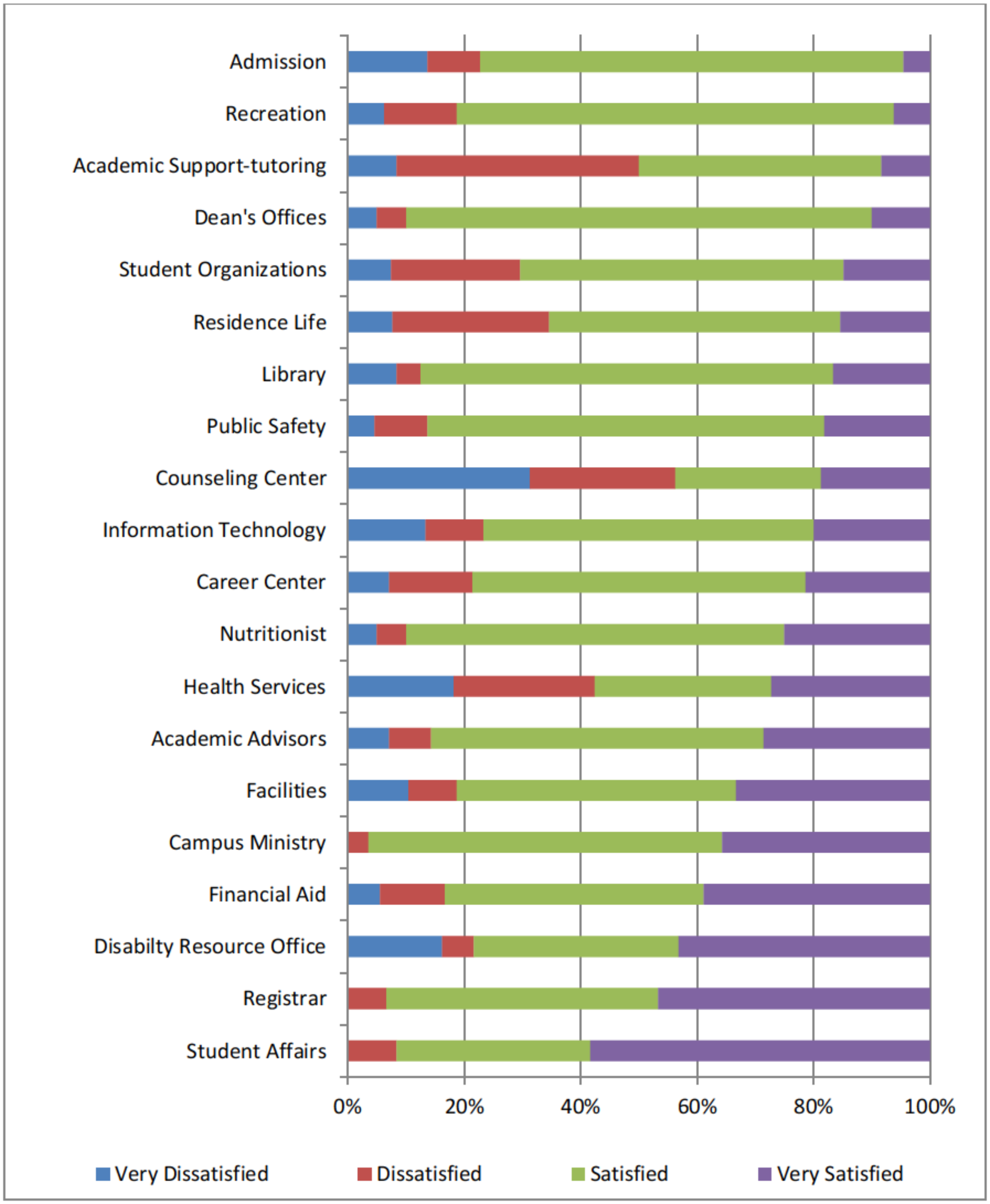
Specific Campus Departments

Students were satisfied with many of the departments on their campuses when they went to them for specific assistance regarding their chronic illness. More than 90% were satisfied with Campus Ministry, the Library, Information Technology, Student Affairs, and Admissions. Students were the most dissatisfied with Residence Life, Nutritionist, and Health Services, with more than 40% dissatisfied. Some students indicated that they were denied resident accommodations. One student indicated that she did not reside on campus, as “they wouldn’t accommodate me with a private room” (S40). Another said that she “tried to get a single for privacy reasons (administering insulin, testing supplies)” but was denied (S15).

Using the quadrant analysis in Appendix O, students were the most satisfied with and frequented the most the departments of Academic Advisors; Disability Resource Office; Facilities; Library; Dean’s Offices; Student Organizations; Student Affairs; and Admissions. Institutions must maintain this level of satisfaction. The departments of Health Services, Financial Aid, Academic Support, Counseling, Registrar, and Residence Life were areas that students frequented. The students had the least satisfaction, and therefore institutions must improve these departments' services to students with chronic illnesses.

Figure 12

Students' satisfaction with campus departments and their assistance with issues relating to their chronic illness



Resolution of Issues with Services

Even though more than 50% of the students had an issue some of the time with specific services, as seen in Figure 13, most were satisfied with the resolution (Figure 14). Students were still dissatisfied with the resolution for issues relating to physical barriers, obtaining information on chronic illness, and securing medical services, with 50% or more dissatisfied.

Figure 13

Students' frequency in encountering problems due to their chronic illness

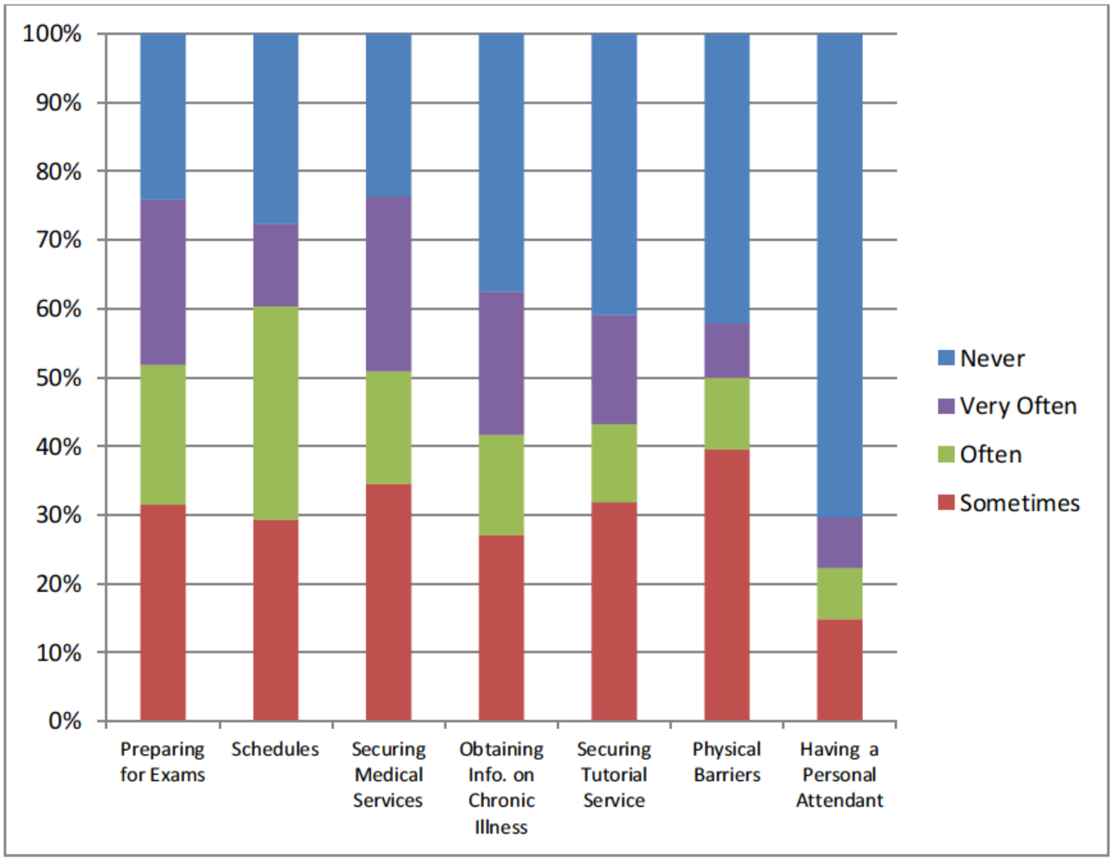
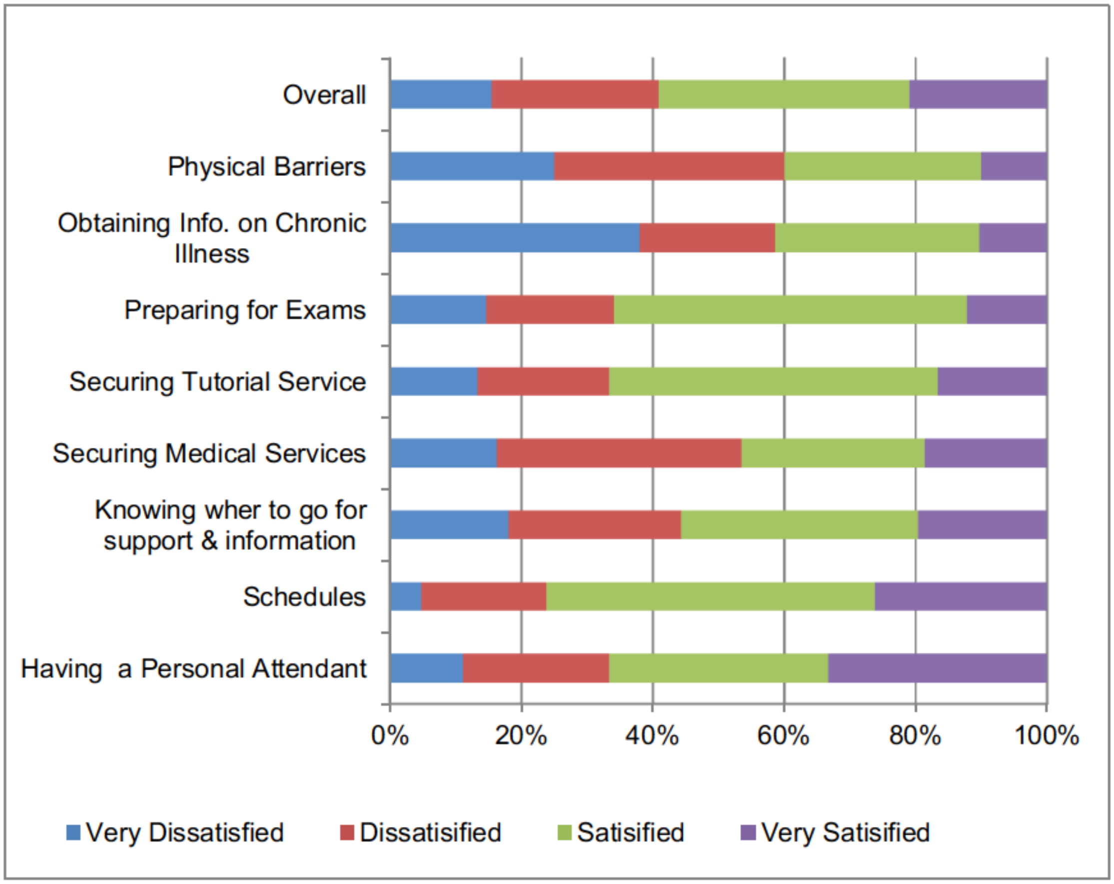


Figure 14

Students' satisfaction with the resolution of certain issues when related to their chronic illness



Participation in Activities for Students with Chronic Illnesses

Only a few students indicated that they participated in activities for students with chronic illnesses and were not satisfied with them. One student shared the idea that they would like to have "check-point sessions to see how we are doing and take comments and suggestions" (S70). Two students indicated that their friends are more important than participating in a support group (S34 & S68). Others indicated that they did not want to participate in activities that would treat them special (S4 & S54); they wanted to be treated like everyone else.

Looking at Institutional Websites

To provide additional insight, the researcher reviewed 100 institutional websites for content analysis in 2012, sometime after the federal law went into effect to provide information on disabled student services on the web. This analysis looked for the words chronic illness or medical conditions on a school's website for Disability Resource Office. The researcher selected these institutions based on their location and type of institution to try to mirror the characteristics of those institutions that participated in this research. Eighty-six percent of these schools used the word "Disability" in the name of the department. Three institutions did not have a specific page/department to serve students with disabilities. Twenty-five percent of the schools did not provide examples of any particular disabilities on their web page. As seen in Table 8, Learning Disabilities were the most frequently viewed on these websites, and Visual Disabilities were the least viewed. Chronic illness/health/medical conditions/systematic conditions were seen 52% on the websites, with six of these institutions using the terminology of systematic. Some of these were not listed on the initial webpage but buried within links from the main Disabilities webpage. Some institutions explained the words of chronic illness by providing specific examples such as AIDS and diabetes. Most were generic and did not provide additional clarification when using the terms chronic illness, health-related illnesses, or systematic conditions. As mentioned before, Student #64 recommended that specific examples of chronic illnesses would be beneficial, as she would most likely not believe that these services were applicable to her without further explanation.

Table 10

Types of Disabilities represented on institutional web sites

Type of Disability	% represented
Learning Disabilities	67%
Physical/Mobility	63%
Psychological/mental	60%
Chronic Illness/health/systematic	52%
Hearing/Deaf	50%
Visual	49%

Summary

Regarding obtaining information about how institutions serve SWCI, students' satisfaction was not as high as their rating of importance in all categories. One-on-one conversations were among the categories of obtaining information that students were the most satisfied with and rated one of the most important categories. This is similar to the institutional belief of providing services on a case by case. Students with chronic illnesses were satisfied with how the individuals they interact with on-campus understood and were sensitive to their condition. However, SWCI's perception of how these individuals are sensitive or willing to assist was not as high as their satisfaction. Students were, for the most part, satisfied with available services on campus. Areas of Institutional Policies and Institutional Services have high importance and low satisfaction with students and are opportunities for institutions to improve their services to SWCI. Students were still dissatisfied with the resolution for issues relating to physical barriers, obtaining information on chronic illnesses, and securing medical services.

CHAPTER 5: DISCUSSION

This chapter summarizes the findings in response to the research questions on how colleges and universities serve students with chronic illnesses through the lens of both institutions and students. The purpose of this study was to obtain a better understanding of serving SWCI and provide an opportunity to increase awareness of this underserved population and their unique situations. If colleges and universities are to serve as the foundation for students' continued success, they must be effective in serving all students, including those with chronic illnesses. This study helped to fill the research gap by identifying the services provided to this population and how these students want to be served. The research will disseminate this information, highlight the exemplary practices already in place by institutions, and provide means to enhance future innovations to support SWCI.

Interpretation of Results

This exploratory study used the following two instruments: *College and Universities Serving Students with Chronic Illnesses Survey* and *College Students with Chronic Illnesses Survey*. The findings in Chapter 4 were presented in accordance with the research questions. Those findings are now summarized according to the themes that were revealed. Some of the themes were consistent with prior research in the field. The themed headings are as follows: communication, training, mentoring and other support services, institutional support, and lack of support.

Overall Communication

Through the data analysis of these surveys, communication was the key element underpinning the response, whether it was communicating information to students, training faculty, or providing workshops. Administrators perceived that they are providing the information as they indicated that 50% or more of faculty, administrators, and students of their institutions are aware of the specific services available to SWCI. They noted that they have clear policies and procedures outlined on websites and in handbooks. When responding to the scenario question of a student just diagnosed with kidney failure to know where to go for assistance, institutions responded that the student would know to contact the Disability Resource Office or be referred there. However, most students responded that they only sometimes/never knew where to obtain information about being a SWCI. Students also commented that they had no idea how information on SWCI was provided to the university community. Students also indicated that they did not receive information on community services such as local hospitals in the area compared to the percentage of institutions that stated they provided this information. Students want to be more aware of the services that are available to SWCI. Almost all surveyed students indicated having issues with obtaining support and information.

It is critical for institutions to inform constituents of the available services to students with chronic illnesses. Not only is communication important in sharing with the students and their families in their decision to come to an institution, but it is also important to share with the institutional community so that all can refer students to the appropriate area or able to know what to do in case of an emergency. Since almost half of the respondents did not consider themselves as having a disability, communication needs to be different to ensure that they understand that there are resources for them. Communication is also beneficial to the institutional community if there is an understanding of students with chronic illnesses and their challenges living with such conditions.

Training

Training is another essential aspect of communication. Many institutions indicated the absence of training for faculty and believed having this is important. Students also stated this importance. Some students' perception is that faculty thinks they are taking "advantage" of the system since their conditions are invisible. Institutional Respondent #67 indicated that it would be good "to instruct/educate faculty and staff about the kinds of symptoms they might expect to see with certain disorders/illness." Institutions included training for faculty and workshops for students on coping on their "wish list." Training can also take the form of workshops that educate the student on topics such as stress management, health management, coping, or what to do in an emergency. Both institutional and student respondents believed that having these workshops in place, specifically geared to include the perspective of chronic illnesses was very important.

Mentoring and Other Support Services

Communication can also include peer-to-peer mentoring, which the majority of institutions did not specifically have for SWCI. Institutions indicated that having peer counseling/mentoring was on their "wish list." Students indicated that having programs such as focus groups and guest speakers were important. Student Respondent #44 believes that many of the services mentioned in the survey would be wonderful to have at their institution.

Institutional Support

When it came to policies and procedures, many institutions pride themselves in their ability to serve these students on a case-by-case basis, providing individual attention, and the appropriate accommodations based on documentation as they do with all students with disabilities. Institutions indicated that they had experiences with various conditions of chronic illnesses, including cancer, epilepsy/seizures, diabetes, kidney disease/transplant, IBS/Crohn's Disease, Fibromyalgia, and many others. Some institutions provided continual communication with students to minimize issues arising. Institutions also indicated having cross-institutional committees/teams to collaborate and find ways to improve their support of SWCI. Following this approach, many institutions have practices in place between departments to assist SWCI. This includes Admissions when a student immediately indicates he/she has a disability/chronic illness; working with Dean's offices/Academic advisors with referrals; Registrar's office; Financial Aid offices; tutoring; Health Services; Public Safety in creating emergency plans; Residence Facilities in providing the appropriate room accommodations; Information Technology with assistive technology as needed; Career Center with job preparation in light of their unique situations; and Libraries in providing accessible resources. One specific accommodation provided to SWCI is a flexible attendance policy. However, except for transportation services, special scholarships, and peer and faculty tutoring off-campus, students indicated that specific services are not as available as the institutions indicated. Most of the institutions indicated that they use Universal Design sometimes at their institution and an additional group indicated that they would implement this if they had an unlimited budget.

Lack of Support

Almost half of the student respondents do not consider themselves to have a disability. For those who did inform their institution of their status, only 44% did during their first year at their institution. Only depending on the situation would students feel comfortable about sharing their condition with faculty and administrators. Students believe that there is a stigma as it is an invisible disability (S18 and S19). Some students do not want to draw attention to their condition and would like to be known for who they are without the label of having a particular condition (S5 & S7). Students perceived that their conditions were not understood and that there was a lack of support from the institutional community members through various examples shared. One student (I82) shared that “I find people, in general, are less understanding of ‘invisible’ disabilities... wheelchairs scream ‘I am disabled,’ but lots look to be typical when they have special needs.” Only 40% of students responded that faculty, administrators, and fellow students were sensitive to their condition as excellent. Still, they felt these individuals were very much/quite a bit more willing to assist them and were very satisfied/satisfied with the members of the university community understanding and sensitivity of their condition. Many institutional respondents indicated that they treat all students with disabilities the same. Still, there are different accommodations that SWCI need and different communication forms necessary for these students to feel supported. SWCI feel abandoned as support offices tend to focus more on other disabilities that can be assisted with tools already in place while their needs are misinterpreted or overlooked (Royster &

Marshall, 2008). However, some Institutional respondents did indicate that more needs to be done. One institution (I125) stated that they thought, “ongoing campus education and support groups would be very important to develop as we have neither.” Another (I20) wrote that “this is an area that we are not as developed as I think we should be, simply because we haven’t talked about our service plan for this particular group,” and another said that we “still have a long way to go” (I82). One of Giroux et al. (2016) recommendations was to increase faculty knowledge through training opportunities specifically on chronic illnesses.

Students Self-identify

Institutions indicated that it is best for students to register so that schools can provide the appropriate support during the student’s academic career. They believe that they have clear policies and procedures outlined for students to self-identify. While as, students wanted to know more about how their institutions could assist them by wanting a comprehensive, consistent, transparent communication process that informs them about services specifically for SWCI and encourages them to identify. They felt that if they did receive communication, they thought it was not relevant to their situation. Since these students do not consider themselves to have a disability, the information they received might not have been specific enough for them to identify with. Many students indicated that they encountered problems of knowing where to go for support and information. Institutions indicated that they would have more publicity for SWCI on their “wish list.”

Adjustment to College

Only 34% believed that they had an excellent overall adjustment to college for those students who entered as freshmen. Seventy-four percent of students responded that they have multiple side effects from their medications that affect various aspects of their college life.

Relationship Between Results and Prior Research

Since most students who participated in this research had issues with adjustment to college and had side effects from medications that affect their college experience, Colleges should be aware of the increased challenges faced by SWCI. This is especially true of first-year students and includes medical transition issues (Adler et al., 2008; Hoffman et al., 2019) and lower Health-Related Quality of Life scores (Fedele et al., 2009; Molzon et al., 2013). All professionals working with SWCI must increase the awareness, use, and availability of needed health and social support services to facilitate the smooth transition to college (Giroux et al., 2016; Herts et al., 2014).

Since institutions indicated that they pride themselves in assisting students case by case, they are still operating under the Medical Model of Disability. This model identifies the disability of the individual and needs a form of treatment to make that person become "normal" (Mitra, 2006). It is also, where the student needs to self-identify with the appropriate documentation to request services. Since almost half of the student respondents do not consider having a disability, they may not always recognize the requirement to provide documentation or even have the necessity to visit the Disability Resource Office.

Therefore, it is beneficial to institutions to incorporate the Social Model of Disability, which sees disability as a social construct (Haegele & Hodge, 2016; Howard, 2003; Mitra, 2006). It is also, where it is up to society to remove the barriers (Howard, 2003). It moves from a view that individuals with disabilities are a problem that needs to be fixed to individuals that are a valuable part of society who have something to contribute. Students come to colleges and universities to become even more contributing citizens of the world, and it should not be a place of barriers for them. Student respondents felt that communication to all areas of an institution, especially faculty, needed to be disseminated regarding serving and understanding SWCI. This is something that institutions can do under the Social Model of Disability umbrella and begin to break down barriers for SWCI. This is important as more than 50% encountered problems with certain services due to their chronic illness. Students experienced the most issues and are the least satisfied with knowing where to go for support and information and securing medical services.

One aspect of the Social Model of Disability is to create access through Universal Design. As indicated in this study, Universal Design was used by institutions some of the time, and that it was on their "wish list." This supports the literature where if it is fully incorporated into the curriculum, students with disabilities no longer need to identify and "ask" for accommodations. These accommodations would already be included in the course material (Silver et al., 1998). Students indicated in this research that they might not always self-identify like the research of Herts et al. (2014). Almost half did not identify to having a disability supports one of the principles of Perfect et al. (2017), which was for institutions to work within the social model of disability to reduce barriers and create inclusive campuses. In contrast, the institutions in this research showed that it would be best for students to self-identify to provide the appropriate services similar to the literature where it is believed best to mandate SWCI to identify (Adler et al., 2008; Hoffman et al. 2019). Students wanted to know more about how their institutions could assist them specifically and encourage them to identify. Institutions should reach out to SWCI before they attend in a way that does not shame them and builds a lasting relationship of support (Hamlet et al., 2011; Herts et al., 2014; Lemly et al., 2014).

Having workshops on coping for students was similar to the findings in the literature (Fedele et al., 2009; Firmin et al., 2011; Herts et al., 2014; Hoffman et al., 2019; Molzon et al., 2013; Ravert et al., 2017; Scheese, 2018; Wodka & Barakat, 2007). Training for faculty and members of the university was also similar to the findings in the literature (Abdullah, 2015; Cantrell & Conte, 2016).

Limitations

The present study's findings can potentially benefit university administrators as they advise and support students with chronic illnesses. They can also be helpful to students who are seeking support within university settings. However, some cautions are indicated when interpreting the results.

There are no previous benchmarks with which to compare the findings of the present study. Since the survey methodology permitted only a convenience sample of students and institutions, extrapolating these findings beyond these groups is very limited.

Internal Validity

The possibility of Selection Bias was a threat to internal validity. College administrators of the surveyed institutions who were not providing services could have chosen to ignore this survey. Only those administrators more familiar with assisting these students or with solid programs in existence might have been more committed to completing such a survey. These administrators could also have chosen to share or not to share with their students to participate in the Student Survey for the same reasons. In addition, since forty-eight percent of the student respondents were twenty-five years or older, it is possible that age or growth stimulated by other experiences influenced maturity.

To obtain some student feedback, the researcher was dependent on finding students to survey only with administrators' assistance at surveyed schools, through chronic illness organizations, and word of mouth. At the institutions, only those who self-identified could be asked. In addition, it was dependent on the administrator to share, as mentioned above. Specific social networks, listservs, e-mails, and discussion/message boards were also used. Limitations to using these avenues included low participation rates on these groups of college-aged students with chronic illnesses and possible confusion that the survey was spam or a solicitation. Therefore, another threat to internal validity is attrition. Since only the data of those who completed the survey were included, one does not know if there are any differences between those who completed the surveys and those who did not.

There may have been an instrumentation threat to validity, as the researcher constructed the instrument. Although several validation strategies were implemented (expert panel review, peer testing), this study is the first time the instruments have been used on a large scale. Since both instruments were self-reported, “satisficing” was also a limitation to the survey. Satisficing is the process where individuals respond to a question by selecting an answer that makes them feel they have provided a good enough response (Smyth et al., 2005). This typically makes answers that are listed first to be picked over those listed last. The design of the questions within the surveys tried to reduce this effect as much as possible.

External Validity

External validity refers to the extent to which the study results can be generalized beyond the sample. Timing was a threat to external validity as the survey was distributed during the end of the spring semester and the beginning of the summer. This was also the time when an administrator might have left his/her position. Since many disabled student coordinators are one-person offices, this may have led to an administrator not completing the survey. Regarding the students, they may have been distracted with finals and end-of-the-semester events or moved on to their summer plans. Since this research included on-line surveys, the response rate was a limitation. Typically, on-line surveys have a lower response rate than paper surveys (Couper et al., 1999; Solomon, 2001).

As mentioned above, the researcher was dependent on university administrators and college-aged students to complete the respected surveys by being invited through numerous listservs, other college administrators, and organizations. Therefore, since these various avenues are not comprehensive in their membership, they may not represent all university administrators serving students with disabilities. It may not be representative of all students with chronic illnesses who attend colleges and universities. Despite the limitations, this research does add to the literature and provides a model for future research.

Implications for Future Research

If colleges and universities are to serve as the foundation for students' continued success, they must serve all students, including those with chronic illnesses. They must understand these students’ needs and understand how to meet these desires. This study has provided a step in better understanding how colleges currently serve these students' needs. However, it was limited to the responses from those institutions and students who participated in the surveys, which came from a convenience sample of students and institutions. Therefore, extrapolating these findings beyond these groups was not appropriate. It does add to the literature and provide a model for future research.

Case Study

An additional way to expand this survey would be to work with a specific group of institutions to implement these survey findings as case studies and review the results. This would be a controlled way of seeing if implementing specific policies and procedures for SWCI would provide the services students with chronic illnesses want and expect from their institutions.

Expansion of this study - Additional educational facilities

Future research would also include expanding this survey. One way would be to survey more institutions and to have their students participate as well. By incorporating more institutions, it would allow the ability to generalize the findings from this study. Having the students complete the survey from the same institutions completing the institutions survey would allow for an even better comparison between the students' beliefs and those of the institutions. This is similar to the suggestions that Wodka & Barakat (2007) made of expanding their research to include large samples and expand to multiple sites across the country.

Expansion of the study - Working with health facilities

Another way would be to work with specific health institutions with large populations of individuals with chronic illnesses, specifically within the age range of eighteen years of age through twenty-five years of age. This would enable more of these students to provide their opinions and have their voices heard. It would be a very involved process to obtain the necessary approvals to work with these patients through health institutions, but well worth it. It would also show these students that individuals are interested in their success. This would also provide access to large numbers of students with similar conditions. In some of these institutions, they have hospital schools, which could be a means of communicating with the students.

In addition to obtaining their opinion, this study could be expanded so that students are followed and tracked on their academic progress while these health institutions follow students from the medical perspective. One institution, Memorial Sloan-Kettering Cancer Center, has a Pediatric Convocation for those students graduating high school and going to college, and each year the number of participants is growing. It would be great to partner with such institutions and programs to follow these students' progress when they enter college and the issues they may or may not have during their college careers. This would enable trends to be created and see if the students succeed and graduate from college. Having a collaborative effort between the health team and the institution through this research could provide additional support and guidance to these students and hopefully bridge the transition from pediatric to adult units (Cantrell & Conte, 2016; Lemly et al., 2014).

Analyzing subpopulations

Since the number of students per chronic condition in this study was small, not much analysis was done by disease. If large enough samples were obtained for each of the various chronic illnesses such as Cancer, Crohn's Disease, Diabetes, Celiac Disease, Arthritis, Migraines, and Asthma, it would be helpful to administer separate analyses for each of these conditions to see if there were issues specific to one condition than another. Similar analysis should also be done by gender and type of institution attended. Additional research could also be conducted on students with greater self-efficacy who do not identify as having a disability.

Sharing this research

Part of supporting future research is sharing the knowledge learned in this study. As indicated, this population is growing. Colleges and universities need to be able to support this population. Therefore, sharing this research is essential. The researcher will summarize the findings and share them with the AHEAD organization as part of the initial agreement of having the support and collaboration of the AHEAD organization in distributing the *Colleges and Universities Serving Students with Chronic Illnesses Survey* to institutions. She will also submit proposals to present to the AHEAD membership at their annual meeting. This will allow opportunities to share the findings and hopefully encourage others to implement recommendations regarding policies and procedures that support SWCI.

While distributing the instrument to both groups, the researcher received positive support for pursuing this topic. She received many independent e-mails stating that the participants were interested in receiving a copy of the results. Written comments both from these e-mails and from the results of the surveys included that “this is valuable information;” “develop a format to share your findings – consider presenting at AHEAD Conference;” “thank you for doing this topic-thank you for helping pave the ways and understandings for those with chronic illnesses;” “I REALLY want to see the results of your study, thanks for undertaking it;” and “this is perfect timing due to the changes in the ADA regulations.” The present study raises awareness of the needs of individuals with chronic illnesses within the university community so that institutions can advocate for needed resources with informed administrators, faculty, staff, and peers.

Implications for Future Practice

Higher education institutions are and will be seeing an increase in the number of students with chronic illnesses based on the increases in chronic illness in children and young adults such as Obesity, Asthma, Diabetes, Celiac Disease, and an increased in Childhood Cancer Survivors. One school considered a “hospital hub/medical” center indicated that they see more and more students with chronic illnesses each year (I79). Another stated that “it is a rapidly growing group of students, who do not necessarily consider themselves disabled or avail themselves of the protection/resources available via ADA” (I133). This study's findings are valuable to coordinators of Disability Resource Offices, admission advisors, and educators who want to assist students with chronic illnesses in coming to college and succeeding. The results suggest that the perceptions of students and college administrators are not the same.

Since the perceptions are not the same and SWCI do not always identify with their institution but still need support, schools need to move towards a culture of Universal Design within the concept of the Social Model of Disability. Since almost half of those surveyed do not consider themselves as having a disability and may not identify with a Disability Resource Center's services, they most likely will not seek out services on their own. This would be beneficial for students by providing an inclusive environment where all students are and feel welcomed. Students support this mentality with their comments. One student (S56) stated, “Be kind and respectful to all people you come into contact with, for no one knows what another goes through, and it could be shocking if they say and/or do something hurtful!” Another indicated that all “be treated equally” (S58). Institutions stated that this would be something they would incorporate if they had an unlimited budget (I66, I72, I75, I80, & I135).

This would take time and much effort, but worthwhile. “There are some students who don’t want special treatment and therefore will only accept minimal assistance. There are other students who require a lot of assistance and receive special living arrangements, academic arrangements, and counseling” (I117). No one who is sick wants to jump through hoops to prove that they are actually ill (I2). Whether or not a student with chronic illness self-identifies or whenever they become sick, they will all have the resources in place to succeed. Even though there is a lack of agreement on best practices for the inclusion of SWCI (Perfect et al., 2017), Universal Design would be a good starting place.

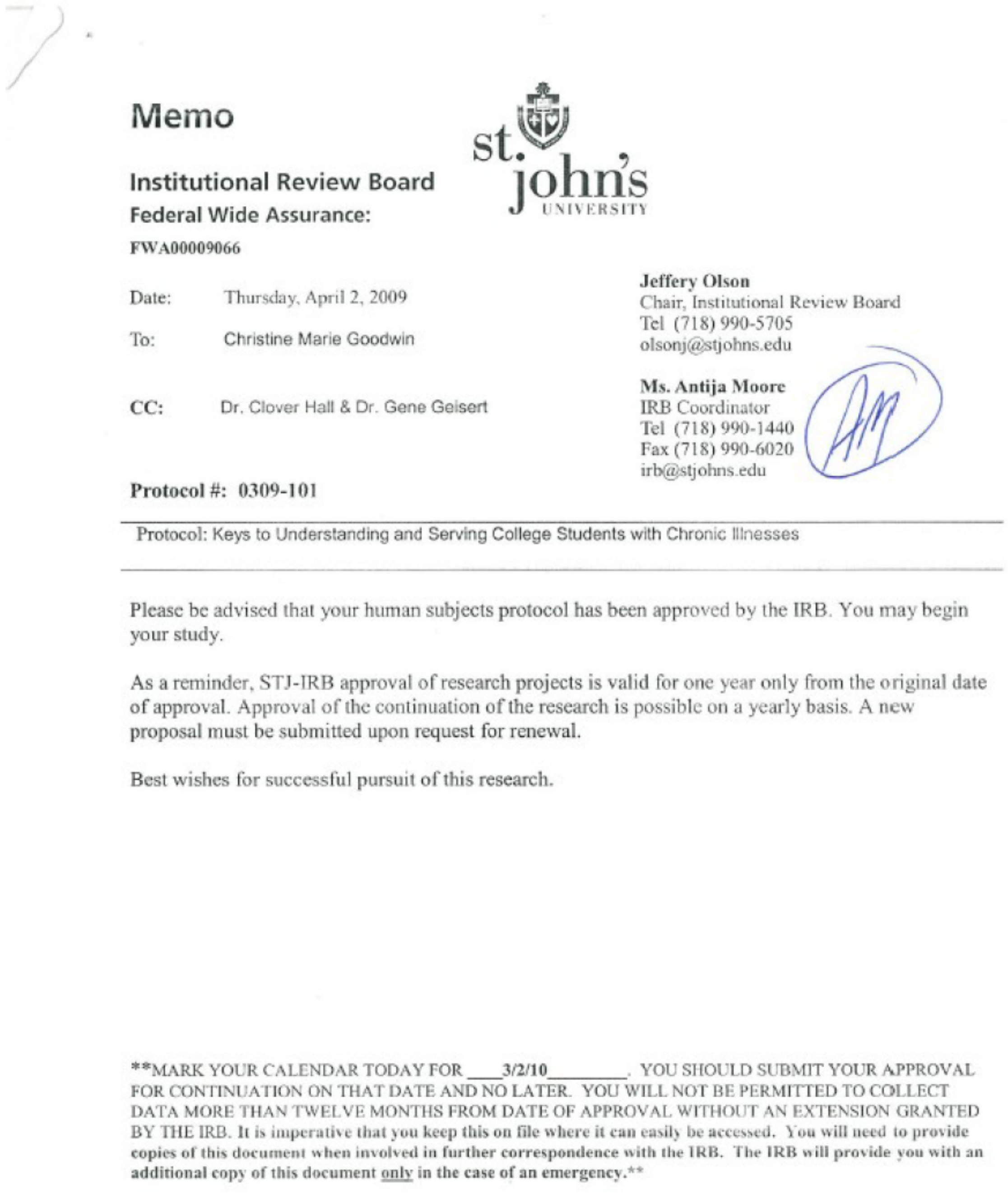
Institutions should provide training, orientation sessions, professional development workshops, and guidance to all community members to understand these students within an inclusive environment. This way, they will be more understanding of the issues and challenges that these students face and know what resources are available on campus, in order to support these students through graduation. This will also support better communication with SWCI. Institutional respondents believed they were communicating appropriately. However, SWCI indicated they did not receive the information – or did not feel it was relevant to their situation. Since almost half of the respondents did not consider themselves as having a disability, communication needs to be different to ensure that they understand that there are resources for them. Students want to be informed of the services specifically for SWCI and be encouraged to self-identify to benefit from these services and not encounter as many issues in knowing where to go for support and information throughout their academic career. This is important as more than 50% surveyed encountered problems with certain services due to their chronic illness. Students have faced the most issues and are the least satisfied with knowing where to go for support and information and securing medical services. Depending on the situation, SWCI would discuss items with their faculty members. If faculty and other institution members were trained and more knowledgeable on the topic of chronic illnesses, SWCI would be more comfortable having discussions with faculty members and most likely have a better academic outcome in the end. Even having a "check-off" list for the Disability Resource Office members could be a starting point. They can ask the appropriate questions to students as some student respondents indicated they had no idea that the Disability Resource Office would support issues associated with their chronic illness in addition to "traditional" services already provided.

Training can also take the form of workshops that educate the student on topics such as stress management, health management, coping, or what to do in an emergency. Both institutional and student respondents believed that having these workshops specifically geared to include the perspective of chronic illnesses was very important to have.

As more and more attention is placed on retention, graduation rates, and career outcomes, colleges and universities need to ensure that all students, including those with chronic illness, complete their degrees. One of the fundamental purposes of colleges and universities is serving all students and helping them succeed and graduate.

APPENDIX A:

Institutional Review Board Approval Memorandum



Memo

st. john's
UNIVERSITY

Institutional Review Board
Federal Wide Assurance:
FWA00009066

Date: Thursday, April 2, 2009

To: Christine Marie Goodwin

CC: Dr. Clover Hall & Dr. Gene Geisert

Jeffery Olson
Chair, Institutional Review Board
Tel (718) 990-5705
olsonj@stjohns.edu

Ms. Antija Moore
IRB Coordinator
Tel (718) 990-1440
Fax (718) 990-6020
irb@stjohns.edu

Protocol #: 0309-101

Protocol: Keys to Understanding and Serving College Students with Chronic Illnesses

Please be advised that your human subjects protocol has been approved by the IRB. You may begin your study.

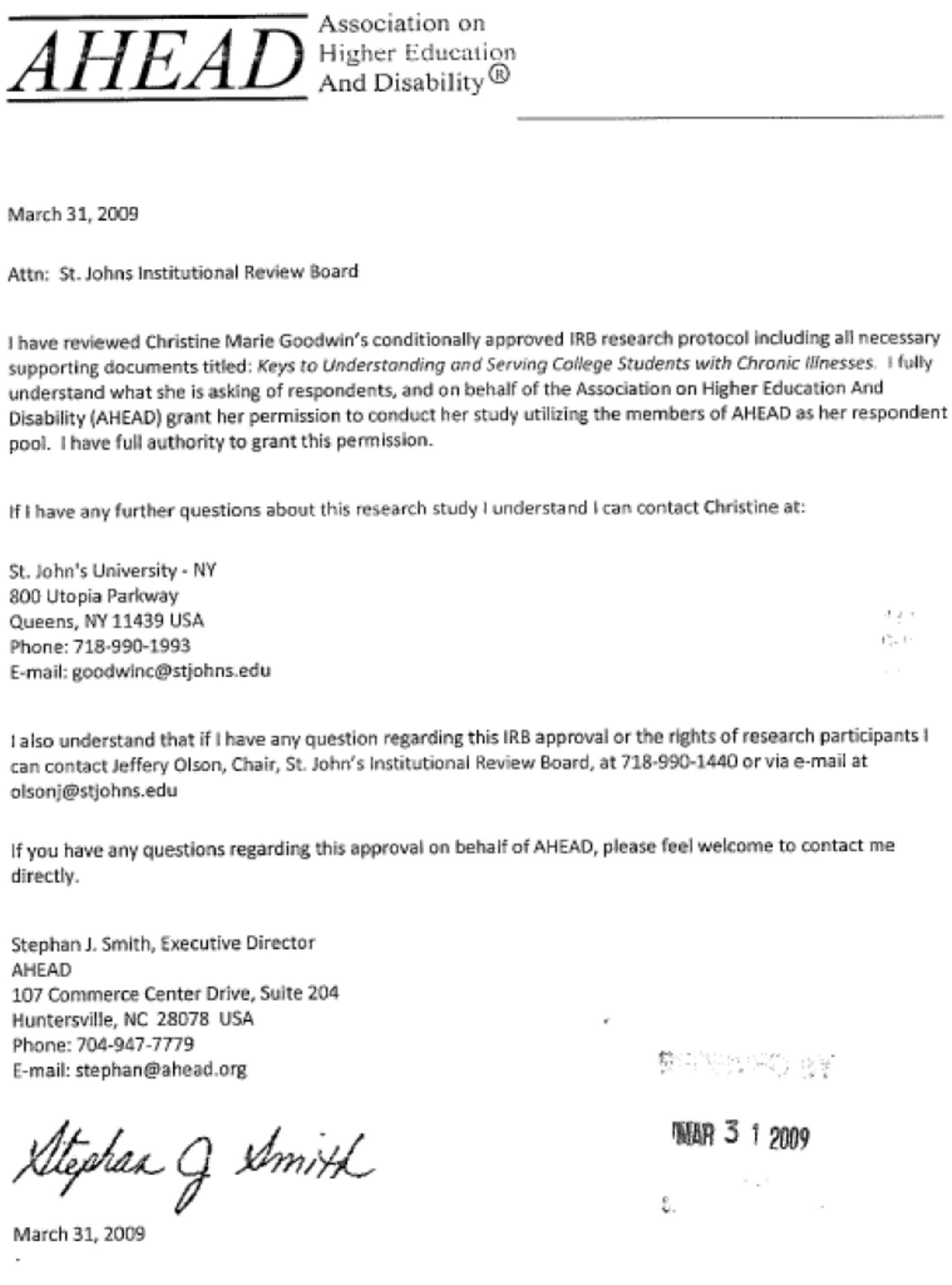
As a reminder, STJ-IRB approval of research projects is valid for one year only from the original date of approval. Approval of the continuation of the research is possible on a yearly basis. A new proposal must be submitted upon request for renewal.

Best wishes for successful pursuit of this research.

MARK YOUR CALENDAR TODAY FOR ____3/2/10**________. YOU SHOULD SUBMIT YOUR APPROVAL FOR CONTINUATION ON THAT DATE AND NO LATER. YOU WILL NOT BE PERMITTED TO COLLECT DATA MORE THAN TWELVE MONTHS FROM DATE OF APPROVAL WITHOUT AN EXTENSION GRANTED BY THE IRB. **It is imperative that you keep this on file where it can easily be accessed. You will need to provide copies of this document when involved in further correspondence with the IRB. The IRB will provide you with an additional copy of this document <u>only</u> in the case of an emergency.****

APPENDIX B:

AHEAD Approval



AHEAD Association on Higher Education And Disability®

March 31, 2009

Attn: St. Johns Institutional Review Board

I have reviewed Christine Marie Goodwin's conditionally approved IRB research protocol including all necessary supporting documents titled: *Keys to Understanding and Serving College Students with Chronic Illnesses.* I fully understand what she is asking of respondents, and on behalf of the Association on Higher Education And Disability (AHEAD) grant her permission to conduct her study utilizing the members of AHEAD as her respondent pool. I have full authority to grant this permission.

If I have any further questions about this research study I understand I can contact Christine at:

St. John's University - NY
800 Utopia Parkway
Queens, NY 11439 USA
Phone: 718-990-1993
E-mail: goodwinc@stjohns.edu

I also understand that if I have any question regarding this IRB approval or the rights of research participants I can contact Jeffery Olson, Chair, St. John's Institutional Review Board, at 718-990-1440 or via e-mail at olsonj@stjohns.edu

If you have any questions regarding this approval on behalf of AHEAD, please feel welcome to contact me directly.

Stephan J. Smith, Executive Director
AHEAD
107 Commerce Center Drive, Suite 204
Huntersville, NC 28078 USA
Phone: 704-947-7779
E-mail: stephan@ahead.org

[illegible] BY
MAR 3 1 2009

Stephan J. Smith

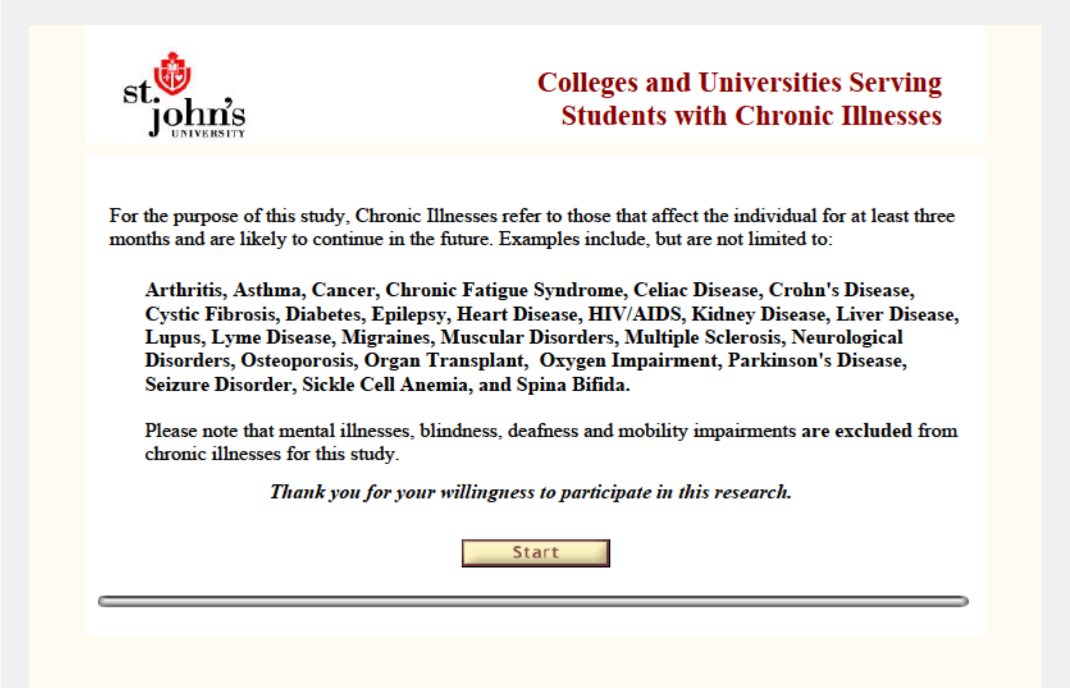
March 31, 2009

107 Commerce Centre Drive, Suite 204, Huntersville, North Carolina USA
(v/t) 704-947-7779 (fax) 704-948-7779 e-mail: ahead@ahead.org www.ahead.org

APENDIX C:

Instrument -- Colleges and Universities Serving Students with Chronic Illnesses

Web Page 1:



Colleges and Universities Serving Students with Chronic Illnesses

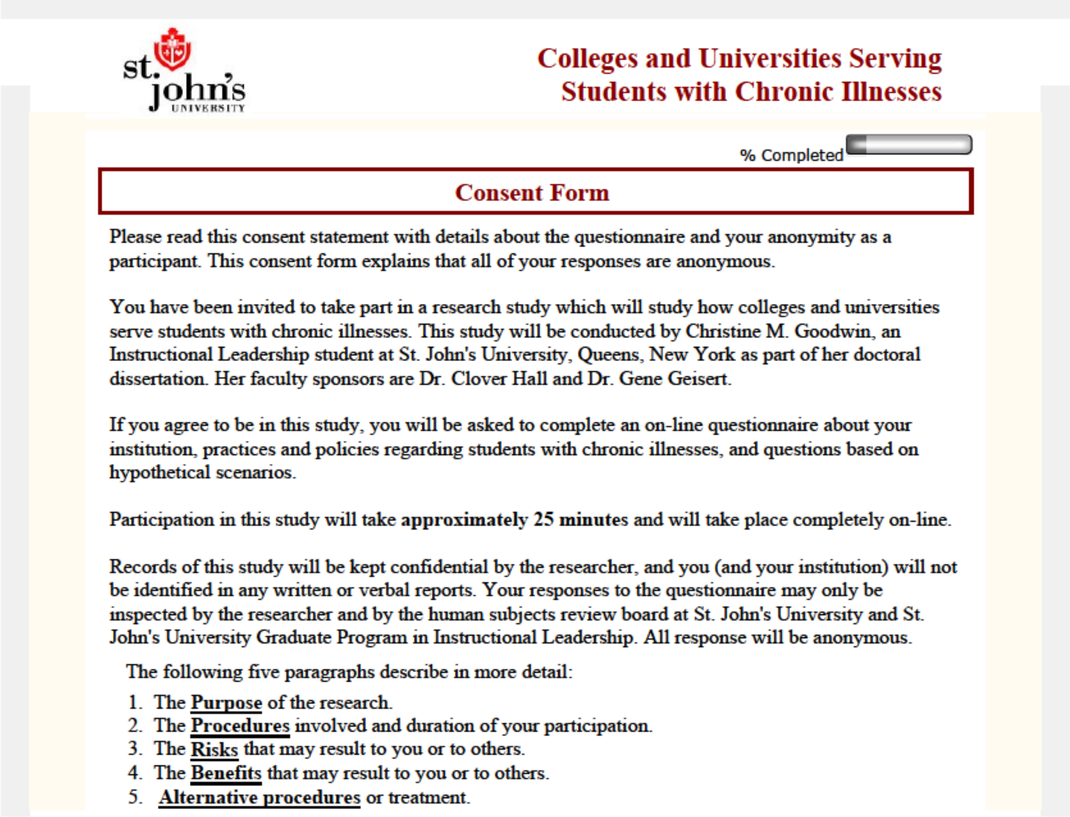
For the purpose of this study, Chronic Illnesses refer to those that affect the individual for at least three months and are likely to continue in the future. Examples include, but are not limited to:

Arthritis, Asthma, Cancer, Chronic Fatigue Syndrome, Celiac Disease, Crohn's Disease, Cystic Fibrosis, Diabetes, Epilepsy, Heart Disease, HIV/AIDS, Kidney Disease, Liver Disease, Lupus, Lyme Disease, Migraines, Muscular Disorders, Multiple Sclerosis, Neurological Disorders, Osteoporosis, Organ Transplant, Oxygen Impairment, Parkinson's Disease, Seizure Disorder, Sickle Cell Anemia, and Spina Bifida.

Please note that mental illnesses, blindness, deafness and mobility impairments are **excluded** from chronic illnesses for this study.

Thank you for your willingness to participate in this research.

Web Page 2 Consent:



Colleges and Universities Serving Students with Chronic Illnesses

Consent Form

Please read this consent statement with details about the questionnaire and your anonymity as a participant. This consent form explains that all of your responses are anonymous.

You have been invited to take part in a research study which will study how colleges and universities serve students with chronic illnesses. This study will be conducted by Christine M. Goodwin, an Instructional Leadership student at St. John's University, Queens, New York as part of her doctoral dissertation. Her faculty sponsors are Dr. Clover Hall and Dr. Gene Geisert.

If you agree to be in this study, you will be asked to complete an on-line questionnaire about your institution, practices and policies regarding students with chronic illnesses, and questions based on hypothetical scenarios.

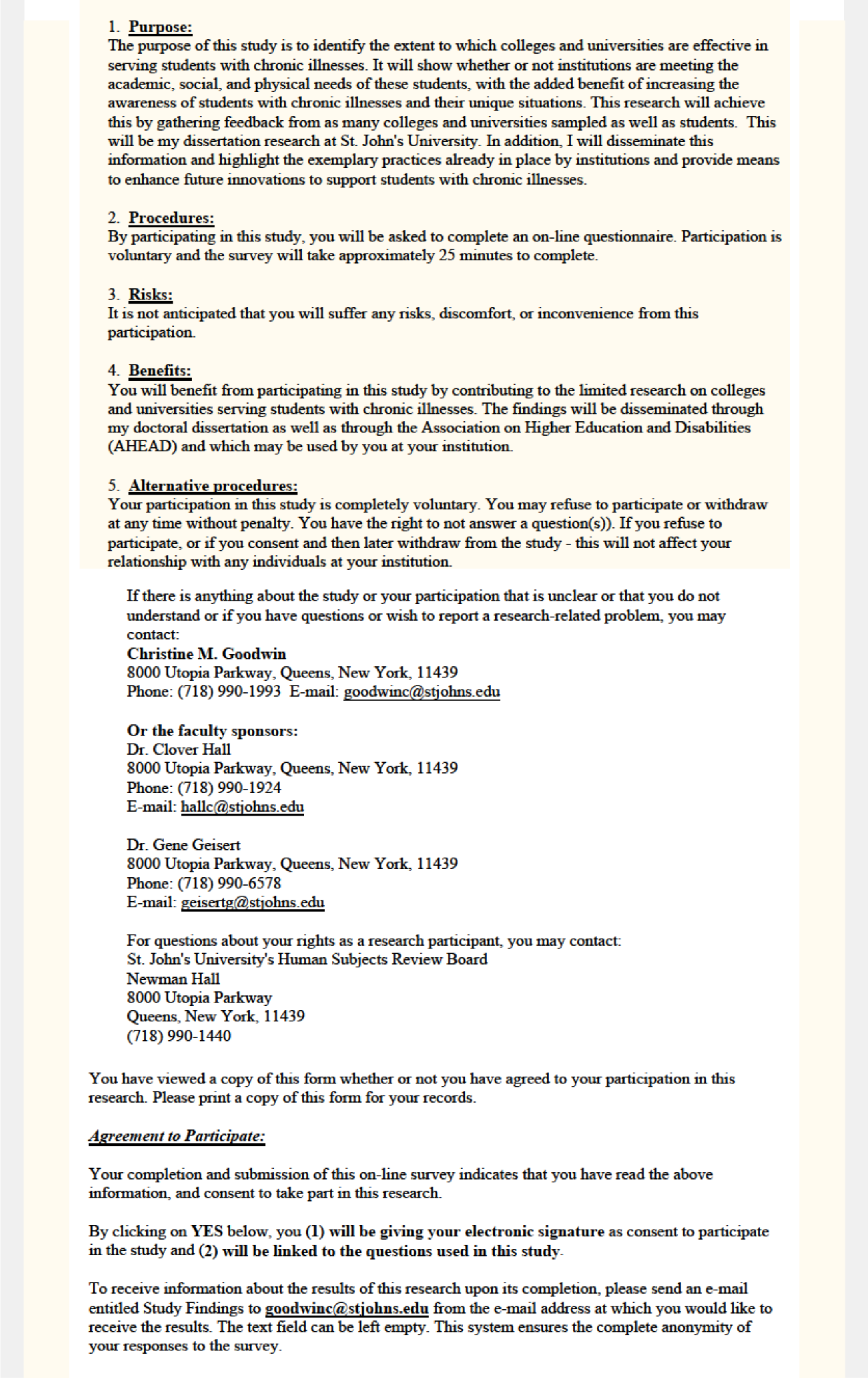
Participation in this study will take **approximately 25 minutes** and will take place completely on-line.

Records of this study will be kept confidential by the researcher, and you (and your institution) will not be identified in any written or verbal reports. Your responses to the questionnaire may only be inspected by the researcher and by the human subjects review board at St. John's University and St. John's University Graduate Program in Instructional Leadership. All response will be anonymous.

The following five paragraphs describe in more detail:

1. The **Purpose** of the research.
2. The **Procedures** involved and duration of your participation.
3. The **Risks** that may result to you or to others.
4. The **Benefits** that may result to you or to others.
5. **Alternative procedures** or treatment.

Web Page 2 Consent -- continued:



1. **Purpose:**
The purpose of this study is to identify the extent to which colleges and universities are effective in serving students with chronic illnesses. It will show whether or not institutions are meeting the academic, social, and physical needs of these students, with the added benefit of increasing the awareness of students with chronic illnesses and their unique situations. This research will achieve this by gathering feedback from as many colleges and universities sampled as well as students. This will be my dissertation research at St. John's University. In addition, I will disseminate this information and highlight the exemplary practices already in place by institutions and provide means to enhance future innovations to support students with chronic illnesses.

2. **Procedures:**
By participating in this study, you will be asked to complete an on-line questionnaire. Participation is voluntary and the survey will take approximately 25 minutes to complete.

3. **Risks:**
It is not anticipated that you will suffer any risks, discomfort, or inconvenience from this participation.

4. **Benefits:**
You will benefit from participating in this study by contributing to the limited research on colleges and universities serving students with chronic illnesses. The findings will be disseminated through my doctoral dissertation as well as through the Association on Higher Education and Disabilities (AHEAD) and which may be used by you at your institution.

5. **Alternative procedures:**
Your participation in this study is completely voluntary. You may refuse to participate or withdraw at any time without penalty. You have the right to not answer a question(s)). If you refuse to participate, or if you consent and then later withdraw from the study - this will not affect your relationship with any individuals at your institution.

If there is anything about the study or your participation that is unclear or that you do not understand or if you have questions or wish to report a research-related problem, you may contact:
Christine M. Goodwin
8000 Utopia Parkway, Queens, New York, 11439
Phone: (718) 990-1993 E-mail: goodwinc@stjohns.edu

Or the faculty sponsors:
Dr. Clover Hall
8000 Utopia Parkway, Queens, New York, 11439
Phone: (718) 990-1924
E-mail: hallc@stjohns.edu

Dr. Gene Geisert
8000 Utopia Parkway, Queens, New York, 11439
Phone: (718) 990-6578
E-mail: geisertg@stjohns.edu

For questions about your rights as a research participant, you may contact:
St. John's University's Human Subjects Review Board
Newman Hall
8000 Utopia Parkway
Queens, New York, 11439
(718) 990-1440

You have viewed a copy of this form whether or not you have agreed to your participation in this research. Please print a copy of this form for your records.

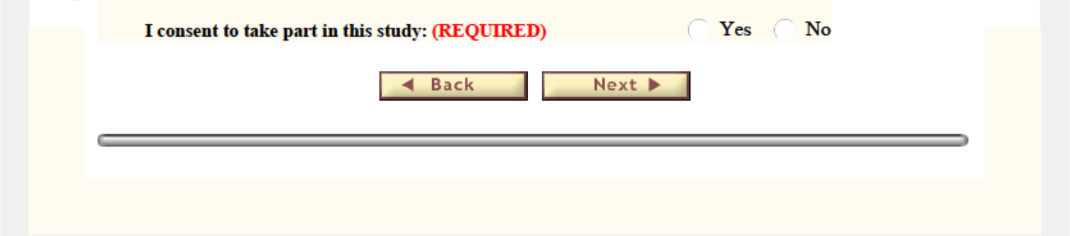
Agreement to Participate:

Your completion and submission of this on-line survey indicates that you have read the above information, and consent to take part in this research.

By clicking on YES below, you **(1) will be giving your electronic signature** as consent to participate in the study and **(2) will be linked to the questions used in this study**.

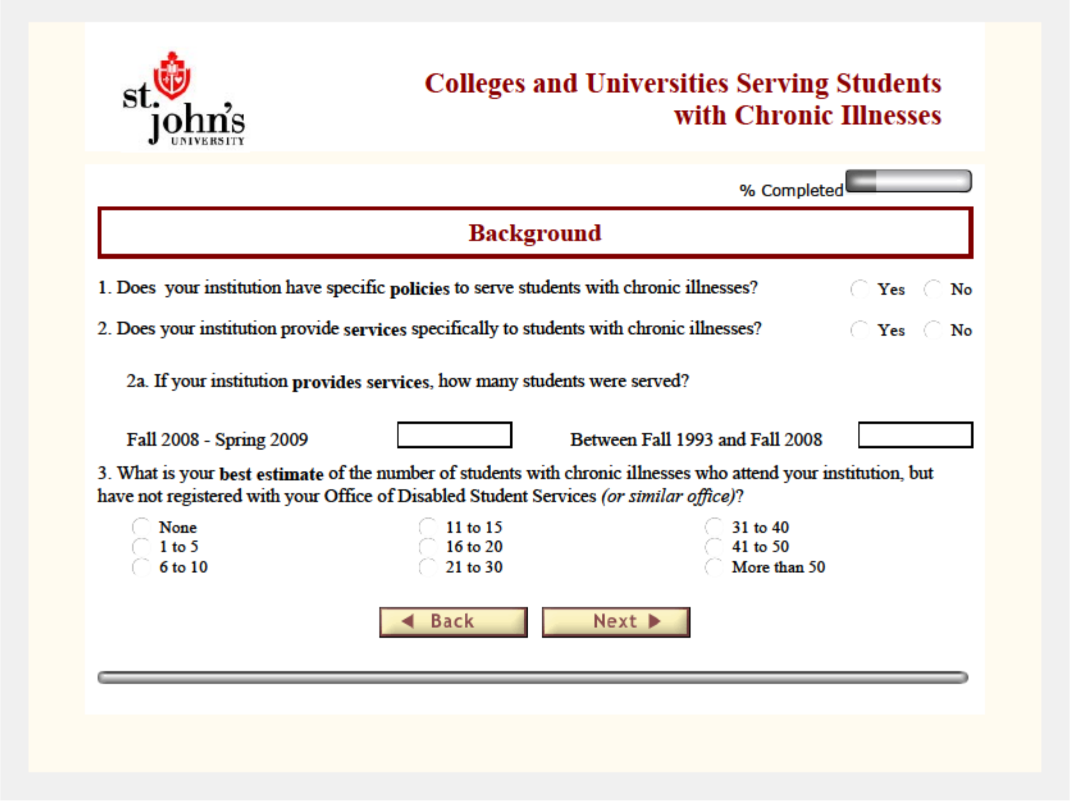
To receive information about the results of this research upon its completion, please send an e-mail entitled Study Findings to **goodwinc@stjohns.edu** from the e-mail address at which you would like to receive the results. The text field can be left empty. This system ensures the complete anonymity of your responses to the survey.

Web Page 2 Consent -- continued:



I consent to take part in this study: (REQUIRED) ○ Yes ○ No

Web Page 3:



Colleges and Universities Serving Students with Chronic Illnesses

Background

1. Does your institution have specific **policies** to serve students with chronic illnesses? ○ Yes ○ No

2. Does your institution provide **services** specifically to students with chronic illnesses? ○ Yes ○ No

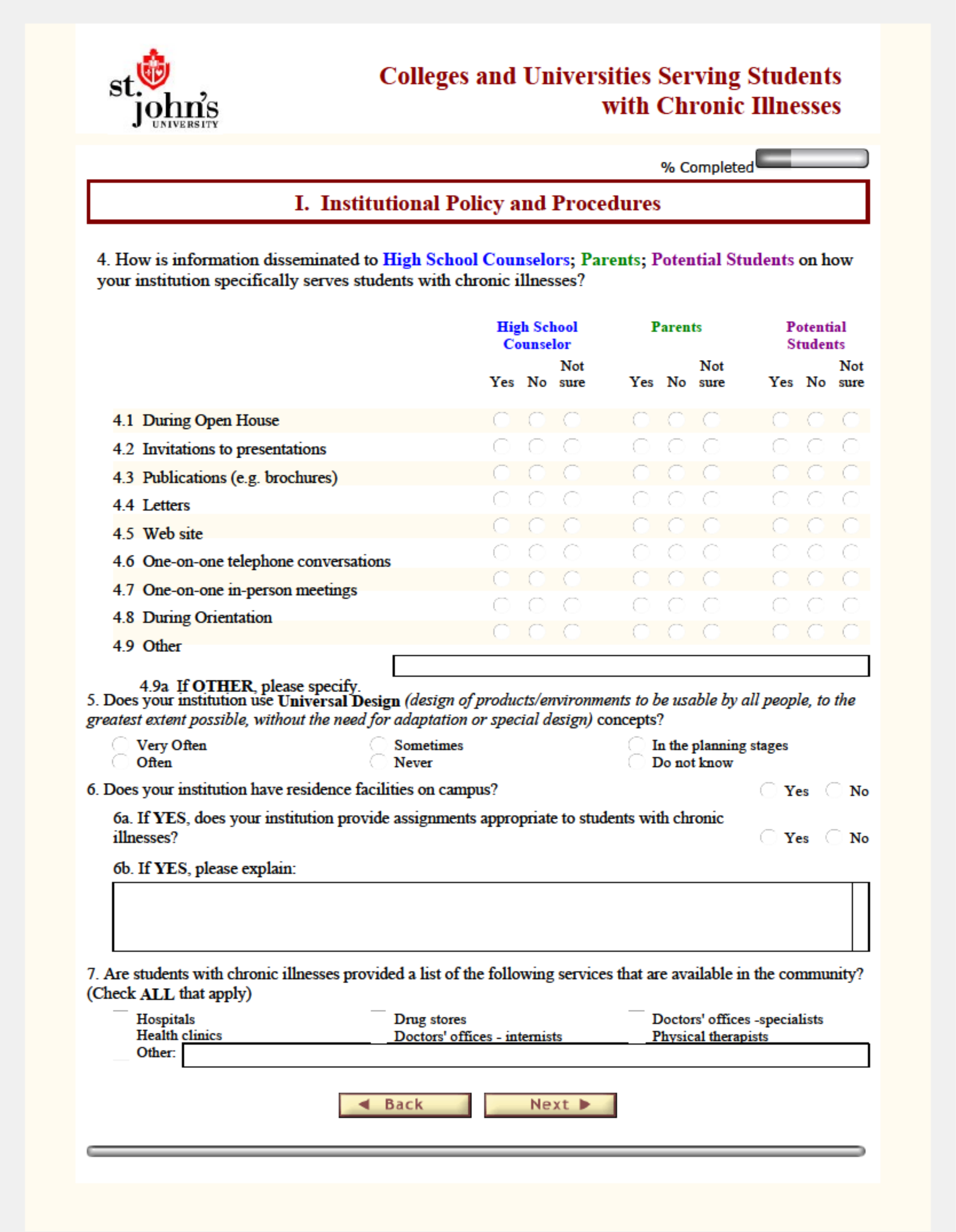
2a. If your institution **provides services**, how many students were served?

Fall 2008 - Spring 2009 ☐ Between Fall 1993 and Fall 2008 ☐

3. What is your **best estimate** of the number of students with chronic illnesses who attend your institution, but have not registered with your Office of Disabled Student Services *(or similar office)*?

○ None
○ 1 to 5
○ 6 to 10
○ 11 to 15
○ 16 to 20
○ 21 to 30
○ 31 to 40
○ 41 to 50
○ More than 50

Web Page 4:



Colleges and Universities Serving Students with Chronic Illnesses

I. Institutional Policy and Procedures

4. How is information disseminated to **High School Counselors**; **Parents**; **Potential Students** on how your institution specifically serves students with chronic illnesses?

	High School Counselor			Parents			Potential Students		
	Yes	No	Not sure	Yes	No	Not sure	Yes	No	Not sure
4.1 During Open House	○	○	○	○	○	○	○	○	○
4.2 Invitations to presentations	○	○	○	○	○	○	○	○	○
4.3 Publications (e.g. brochures)	○	○	○	○	○	○	○	○	○
4.4 Letters	○	○	○	○	○	○	○	○	○
4.5 Web site	○	○	○	○	○	○	○	○	○
4.6 One-on-one telephone conversations	○	○	○	○	○	○	○	○	○
4.7 One-on-one in-person meetings	○	○	○	○	○	○	○	○	○
4.8 During Orientation	○	○	○	○	○	○	○	○	○
4.9 Other	○	○	○	○	○	○	○	○	○

4.9a If **OTHER**, please specify.

5. Does your institution use **Universal Design** *(design of products/environments to be usable by all people, to the greatest extent possible, without the need for adaptation or special design)* concepts?

○ Very Often
○ Often
○ Sometimes
○ Never
○ In the planning stages
○ Do not know

6. Does your institution have residence facilities on campus? ○ Yes ○ No

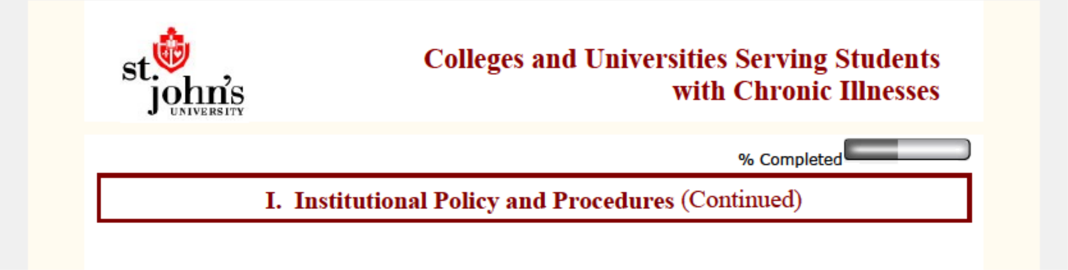
6a. If **YES**, does your institution provide assignments appropriate to students with chronic illnesses? ○ Yes ○ No

6b. If **YES**, please explain:

7. Are students with chronic illnesses provided a list of the following services that are available in the community? (Check **ALL** that apply)

☐ Hospitals
☐ Health clinics
☐ Other:
☐ Drug stores
☐ Doctors' offices - internists
☐ Doctors' offices -specialists
☐ Physical therapists

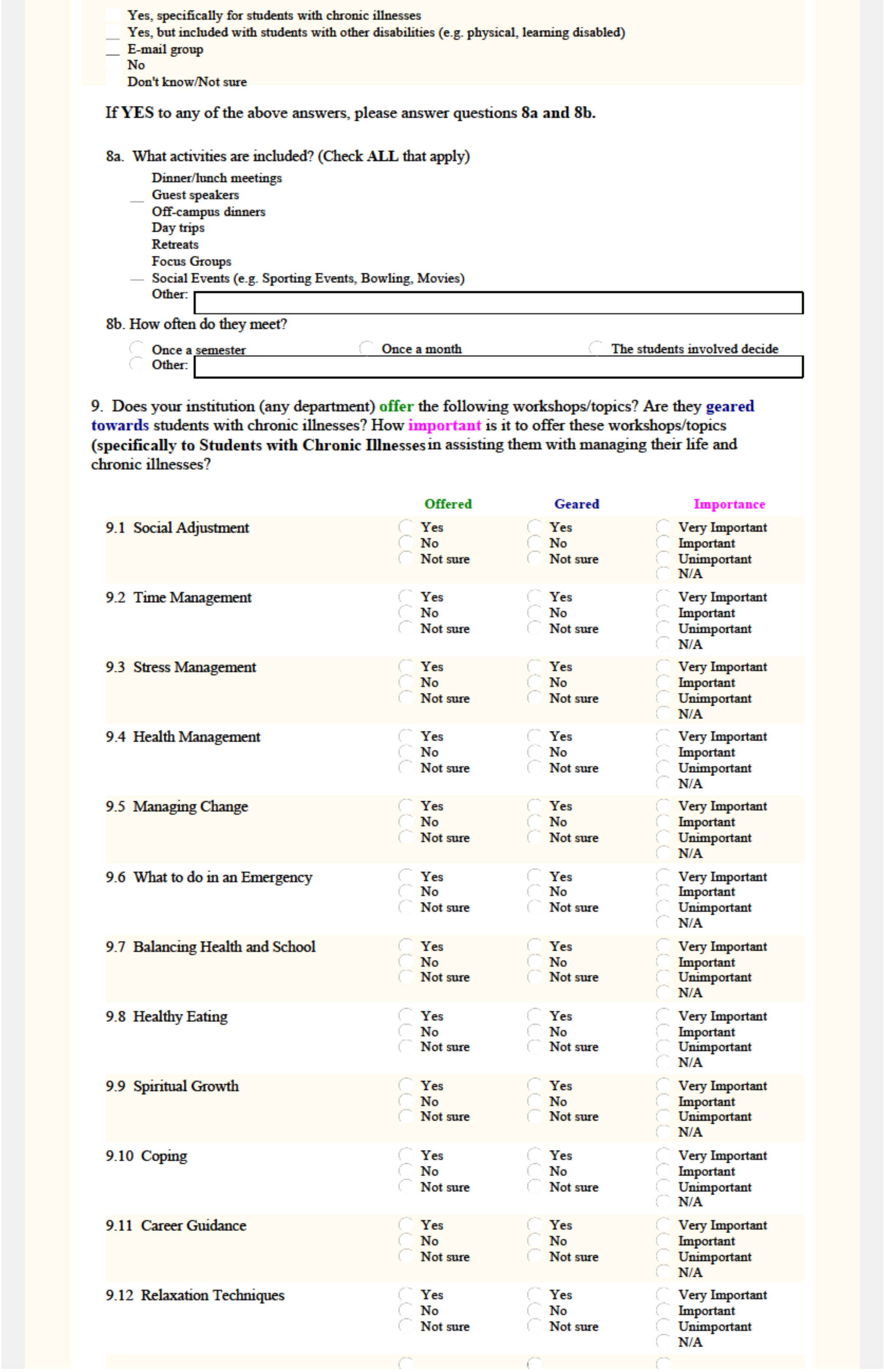
Web Page 5:



Colleges and Universities Serving Students with Chronic Illnesses

I. Institutional Policy and Procedures (Continued)

Web Page 5 -- continued:



8. Does your institution offer peer-to-peer mentoring to students with chronic illnesses? (Check **ALL** that apply)

☐ Yes, specifically for students with chronic illnesses
☐ Yes, but included with students with other disabilities (e.g. physical, learning disabled)
☐ E-mail group
☐ No
☐ Don't know/Not sure

If **YES** to any of the above answers, please answer questions **8a and 8b.**

8a. What activities are included? (Check **ALL** that apply)

☐ Dinner/lunch meetings
☐ Guest speakers
☐ Off-campus dinners
☐ Day trips
☐ Retreats
☐ Focus Groups
☐ Social Events (e.g. Sporting Events, Bowling, Movies)
Other: ____________________

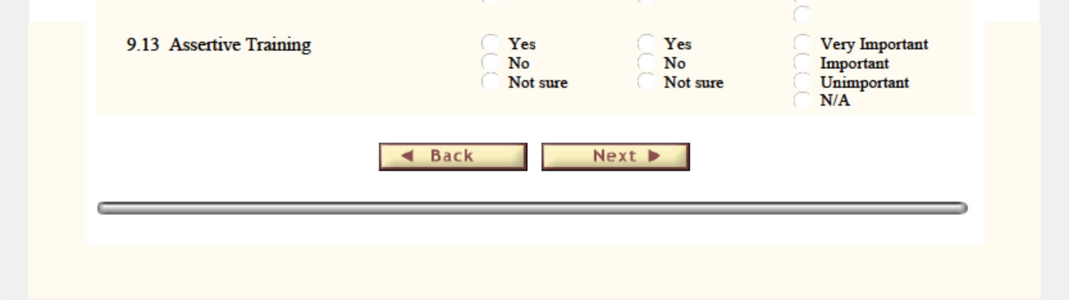
8b. How often do they meet?

○ Once a semester ○ Once a month ○ The students involved decide
○ Other: ____________________

9. Does your institution (any department) offer the following workshops/topics? Are they geared towards students with chronic illnesses? How important is it to offer these workshops/topics (**specifically to Students with Chronic Illnesses** in assisting them with managing their life and chronic illnesses?

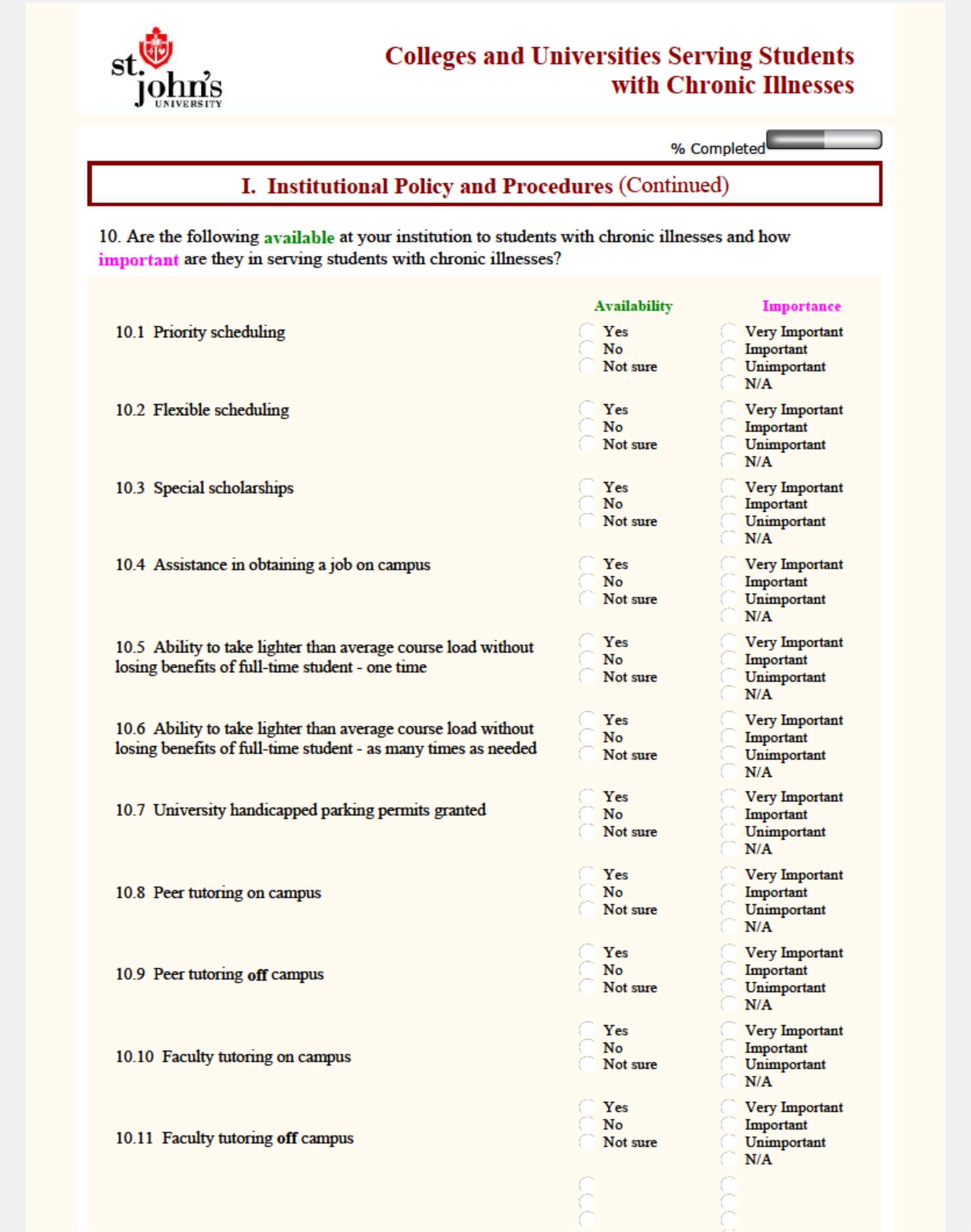
	Offered	Geared	Importance
9.1 Social Adjustment	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.2 Time Management	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.3 Stress Management	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.4 Health Management	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.5 Managing Change	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.6 What to do in an Emergency	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.7 Balancing Health and School	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.8 Healthy Eating	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.9 Spiritual Growth	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.10 Coping	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.11 Career Guidance	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
9.12 Relaxation Techniques	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
	○	○	○

Web Page 5 -- continued:



9.13 Assertive Training	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A

Web Page 6:



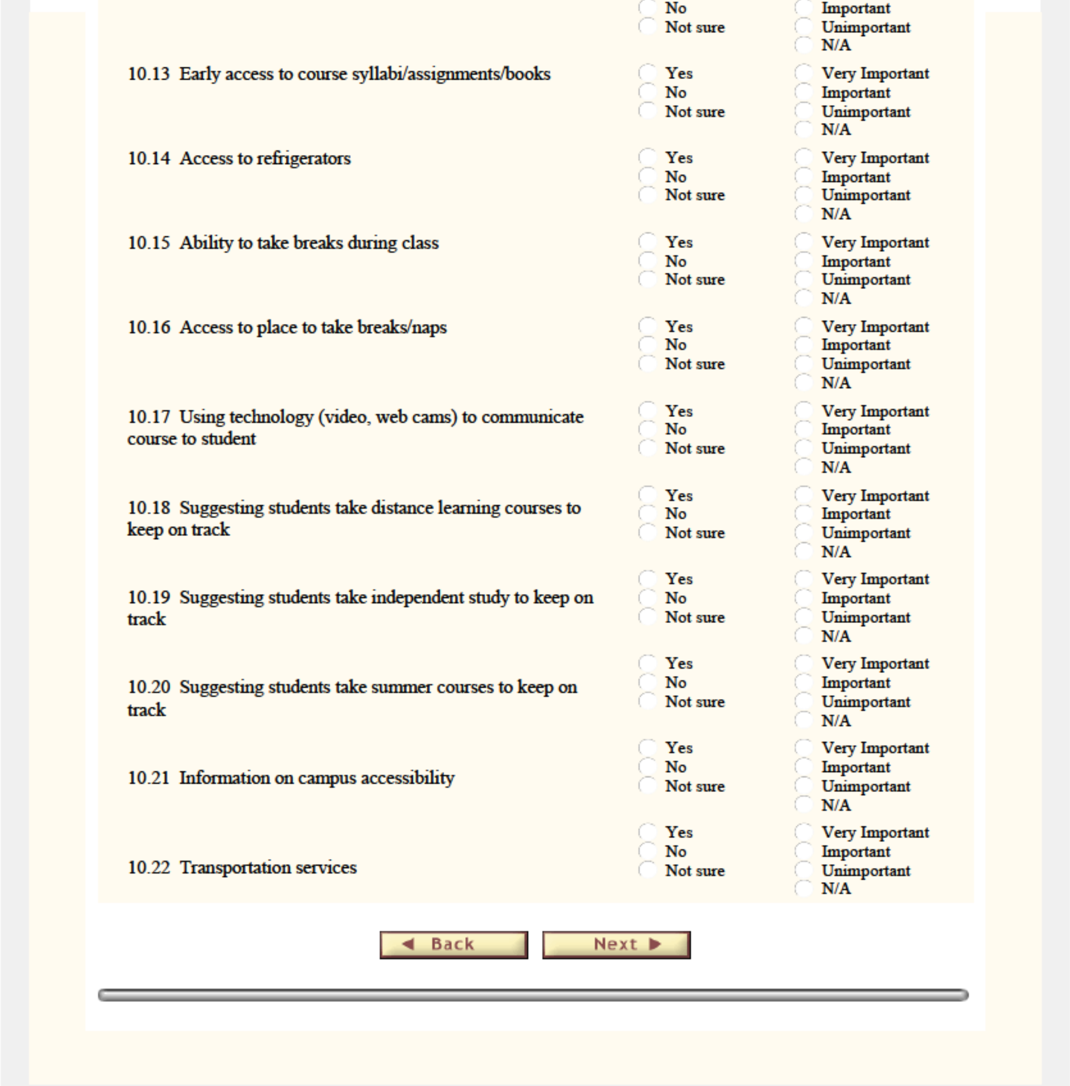
Colleges and Universities Serving Students with Chronic Illnesses

I. Institutional Policy and Procedures (Continued)

10. Are the following available at your institution to students with chronic illnesses and how important are they in serving students with chronic illnesses?

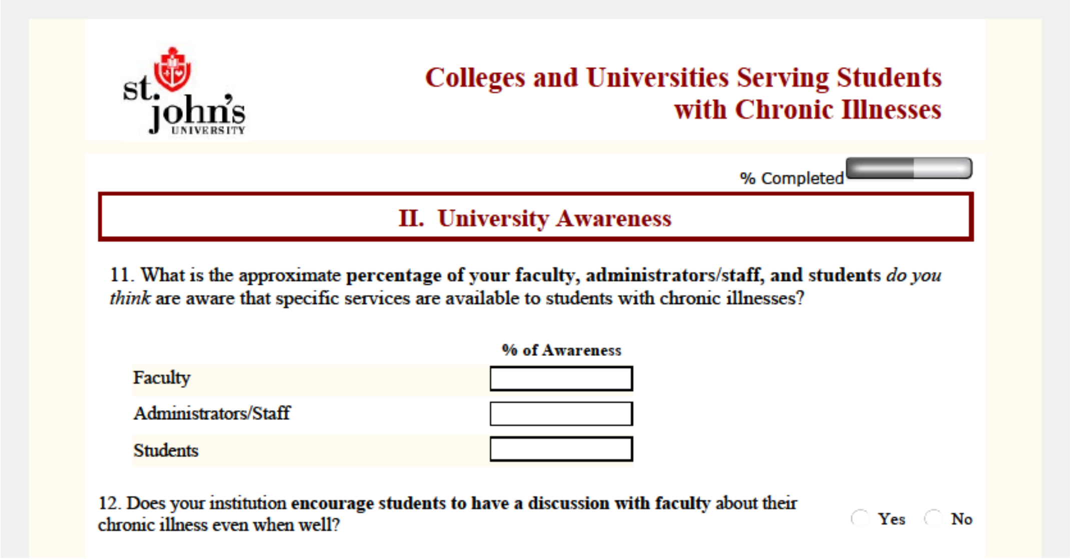
	Availability	Importance
10.1 Priority scheduling	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.2 Flexible scheduling	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.3 Special scholarships	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.4 Assistance in obtaining a job on campus	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.5 Ability to take lighter than average course load without losing benefits of full-time student - one time	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.6 Ability to take lighter than average course load without losing benefits of full-time student - as many times as needed	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.7 University handicapped parking permits granted	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.8 Peer tutoring on campus	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.9 Peer tutoring **off** campus	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.10 Faculty tutoring on campus	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.11 Faculty tutoring **off** campus	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A

Web Page 6 -- continued:



10.12 Faculty approved extensions on deadlines	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.13 Early access to course syllabi/assignments/books	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.14 Access to refrigerators	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.15 Ability to take breaks during class	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.16 Access to place to take breaks/naps	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.17 Using technology (video, web cams) to communicate course to student	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.18 Suggesting students take distance learning courses to keep on track	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.19 Suggesting students take independent study to keep on track	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.20 Suggesting students take summer courses to keep on track	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.21 Information on campus accessibility	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A
10.22 Transportation services	○ Yes ○ No ○ Not sure	○ Very Important ○ Important ○ Unimportant ○ N/A

Web Page 7:



Colleges and Universities Serving Students with Chronic Illnesses

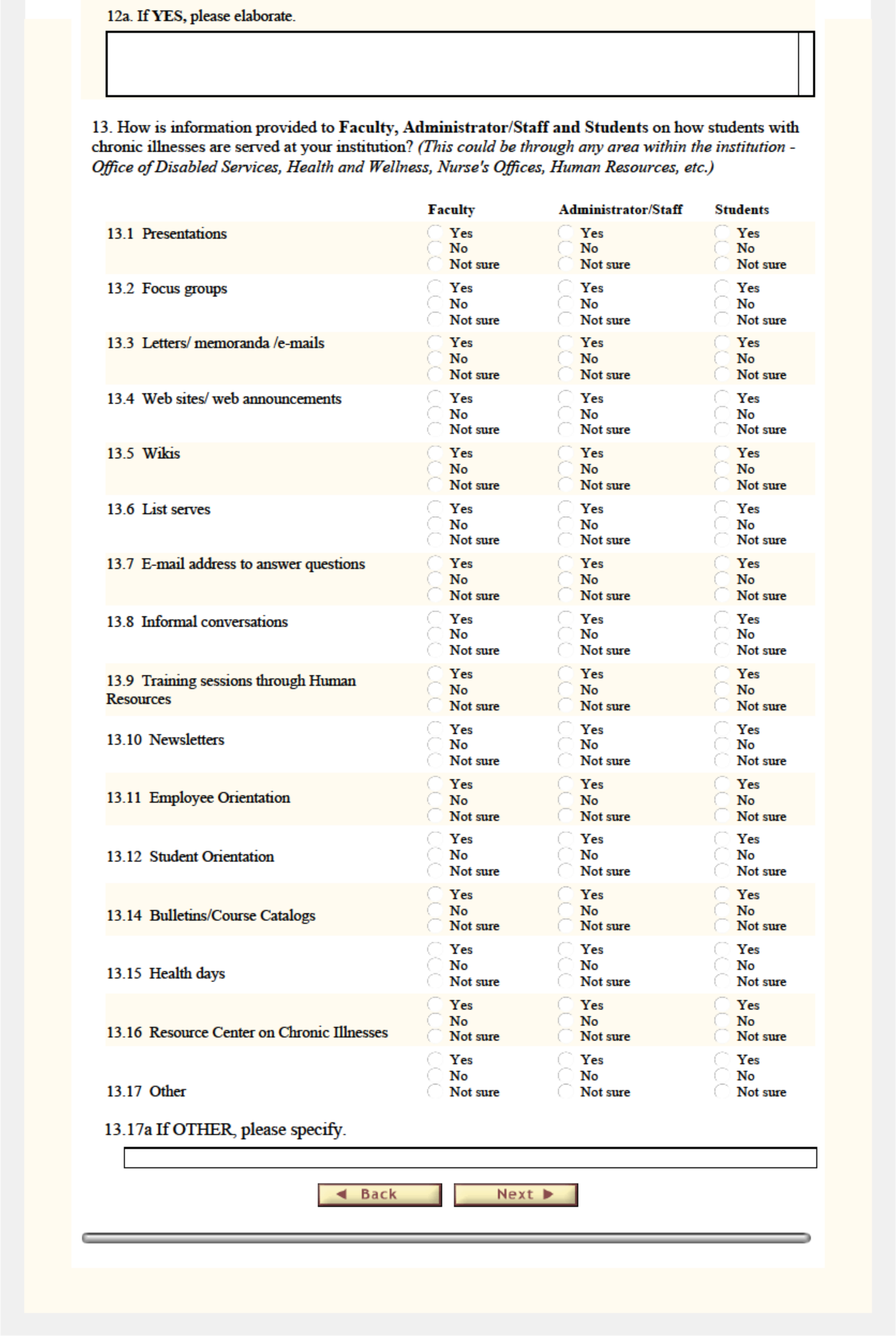
II. University Awareness

11. What is the approximate percentage of your **faculty, administrators/staff, and students** *do you think* are aware that specific services are available to students with chronic illnesses?

	% of Awareness
Faculty	
Administrators/Staff	
Students	

12. Does your institution **encourage students to have a discussion with faculty** about their chronic illness even when well? ○ Yes ○ No

Web Page 7 -- continued:



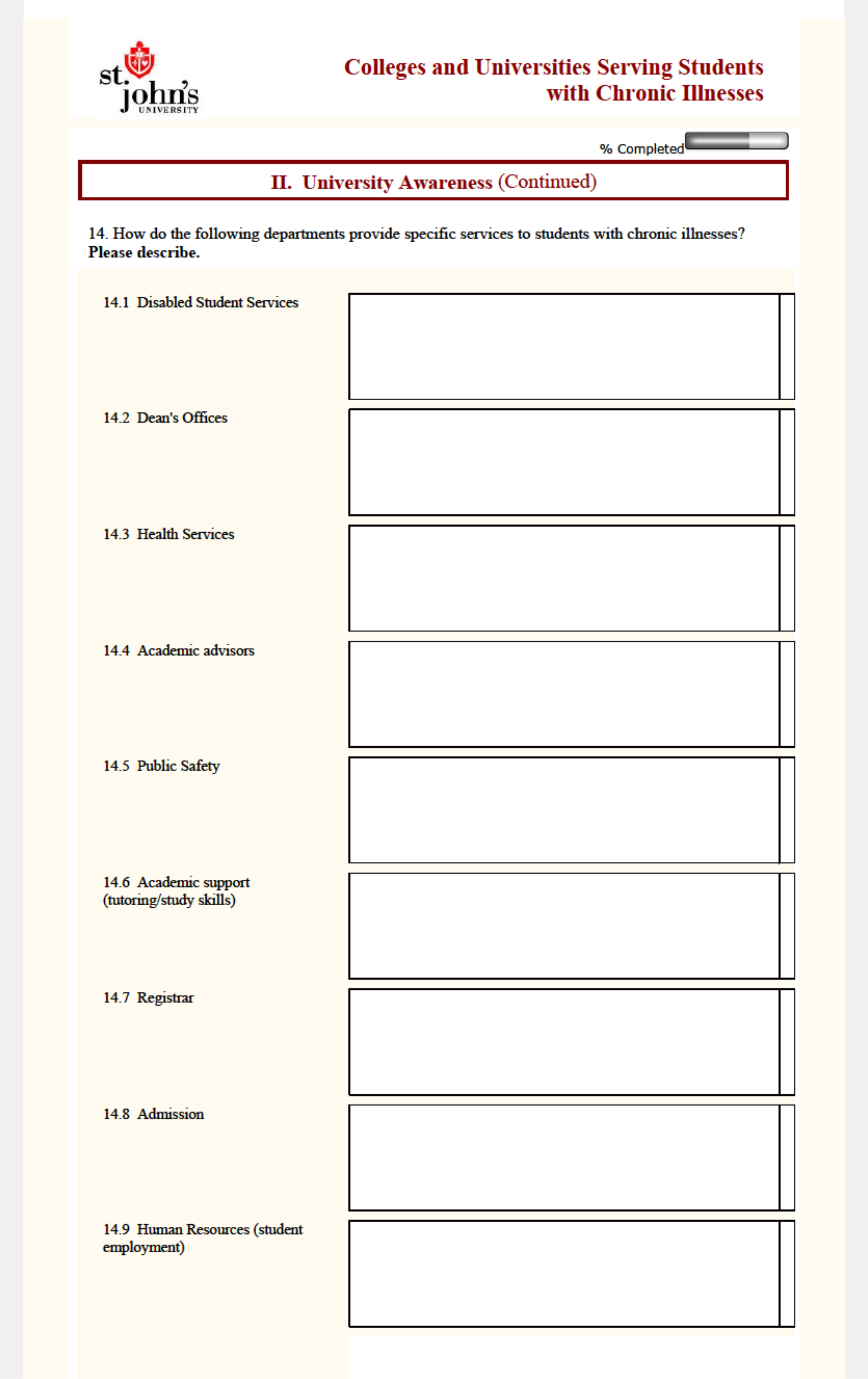
12a. If **YES**, please elaborate.

13. How is information provided to **Faculty, Administrator/Staff and Students** on how students with chronic illnesses are served at your institution? *(This could be through any area within the institution - Office of Disabled Services, Health and Wellness, Nurse's Offices, Human Resources, etc.)*

	Faculty	**Administrator/Staff**	**Students**
13.1 Presentations	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.2 Focus groups	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.3 Letters/ memoranda /e-mails	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.4 Web sites/ web announcements	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.5 Wikis	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.6 List serves	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.7 E-mail address to answer questions	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.8 Informal conversations	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.9 Training sessions through Human Resources	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.10 Newsletters	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.11 Employee Orientation	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.12 Student Orientation	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.14 Bulletins/Course Catalogs	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.15 Health days	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.16 Resource Center on Chronic Illnesses	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure
13.17 Other	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure	○ Yes ○ No ○ Not sure

13.17a If OTHER, please specify.

Web Page 8 -- continued:



st. john's UNIVERSITY

Colleges and Universities Serving Students with Chronic Illnesses

II. University Awareness (Continued)

14. How do the following departments provide specific services to students with chronic illnesses? **Please describe.**

14.1 Disabled Student Services

14.2 Dean's Offices

14.3 Health Services

14.4 Academic advisors

14.5 Public Safety

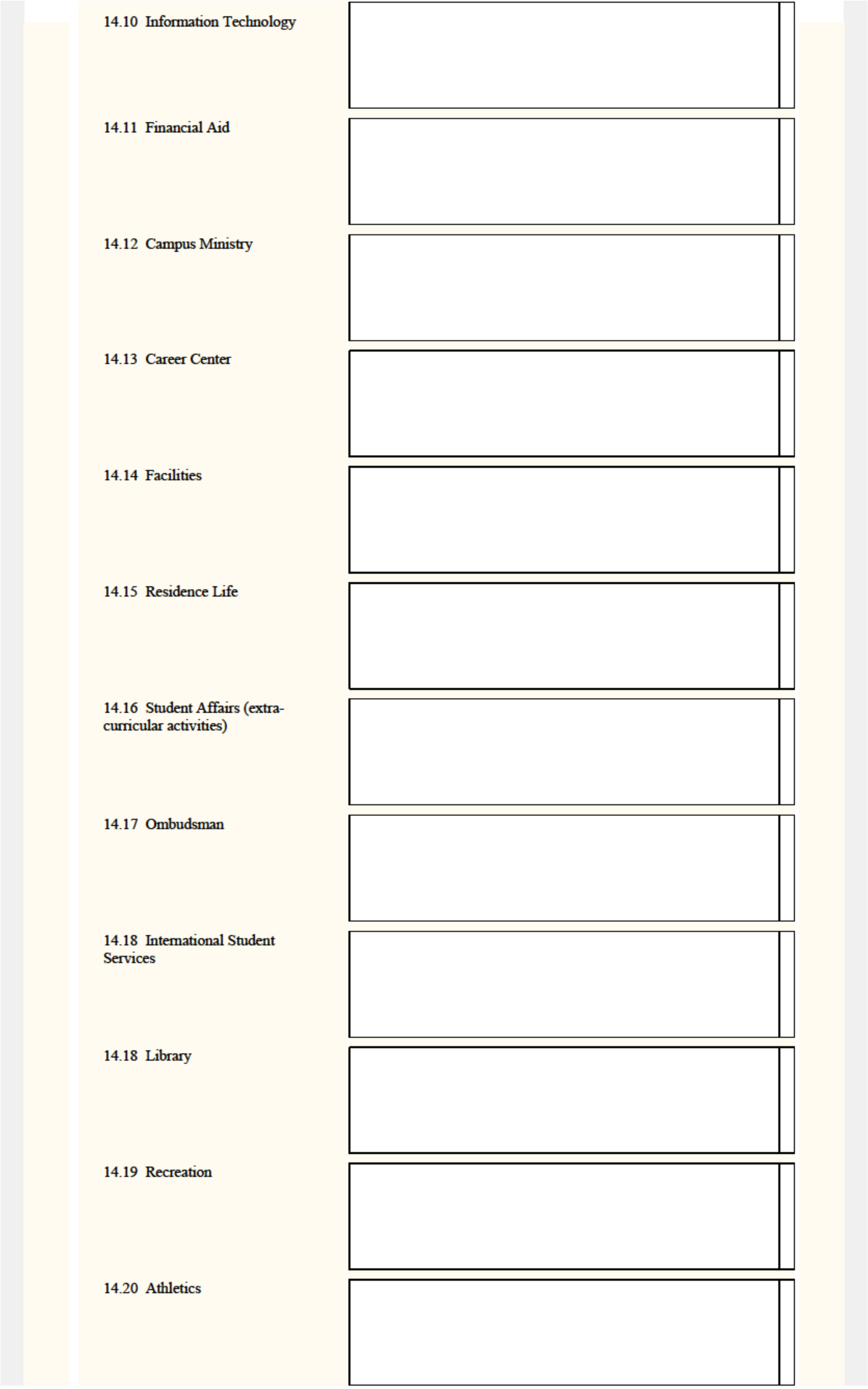
14.6 Academic support (tutoring/study skills)

14.7 Registrar

14.8 Admission

14.9 Human Resources (student employment)

Web Page 8 -- continued:



14.10 Information Technology

14.11 Financial Aid

14.12 Campus Ministry

14.13 Career Center

14.14 Facilities

14.15 Residence Life

14.16 Student Affairs (extra-curricular activities)

14.17 Ombudsman

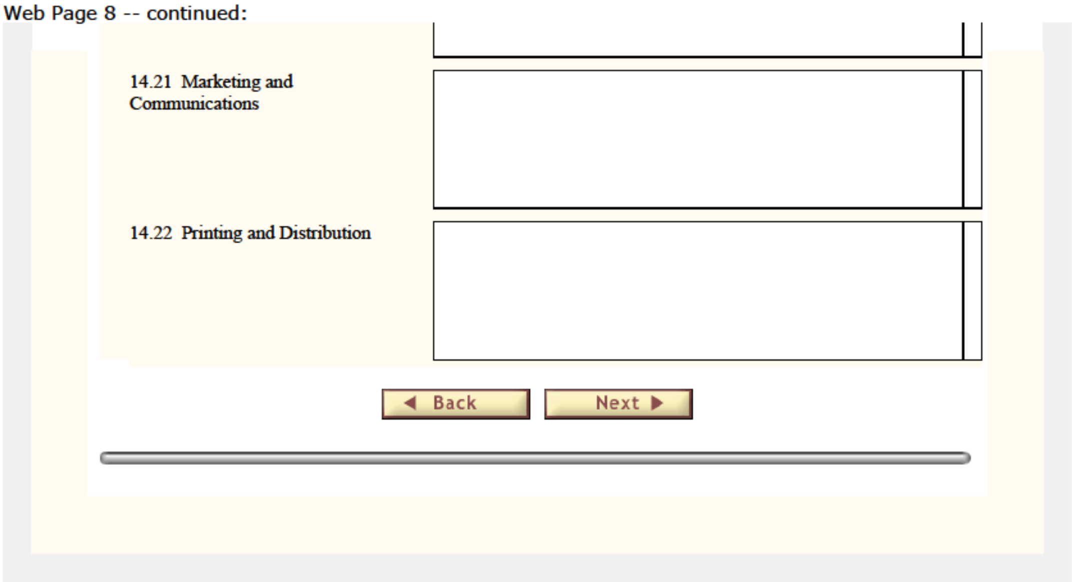
14.18 International Student Services

14.18 Library

14.19 Recreation

14.20 Athletics

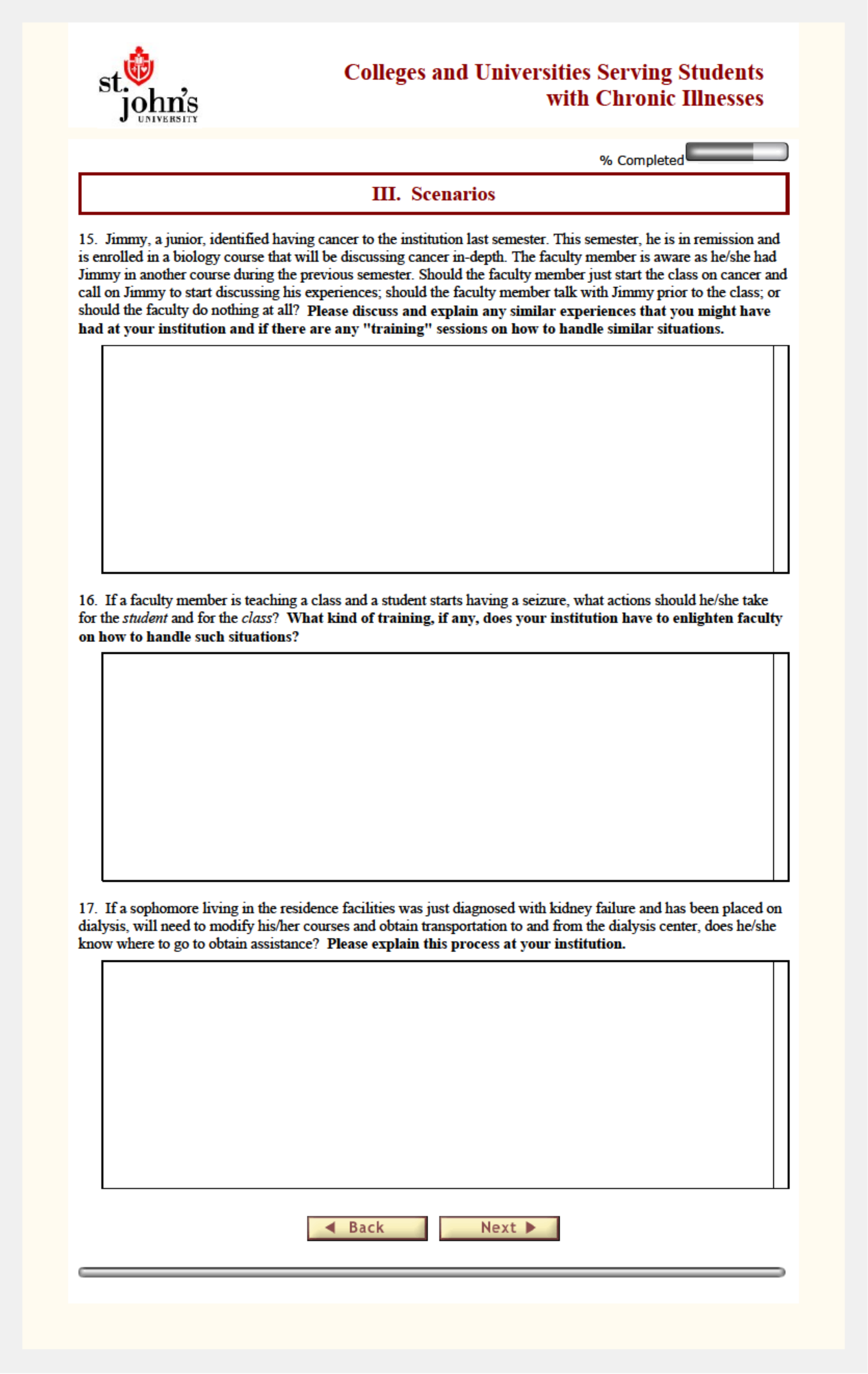
Web Page 8 -- continued:



14.21 Marketing and Communications

14.22 Printing and Distribution

Web Page 9:



Colleges and Universities Serving Students with Chronic Illnesses

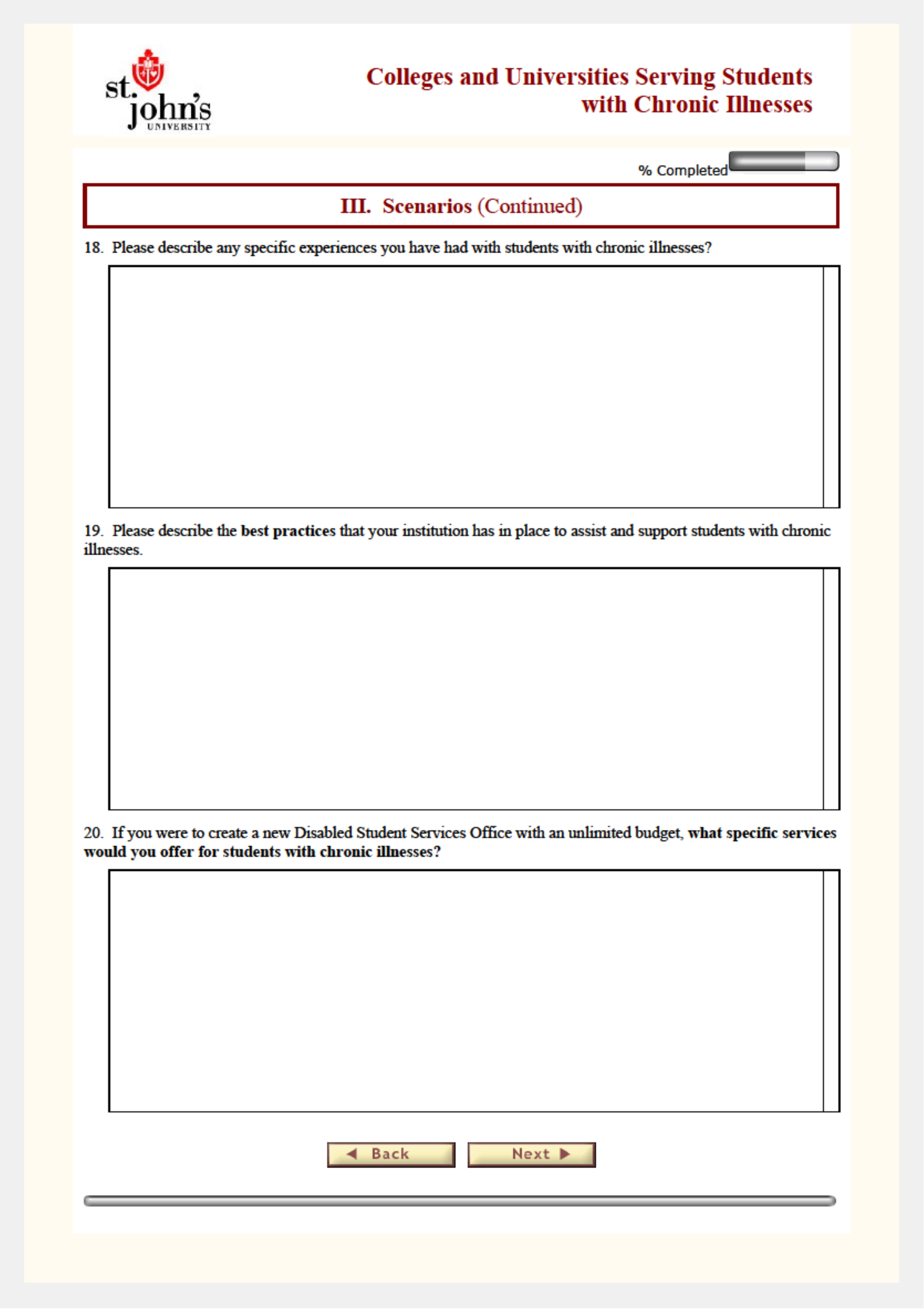
III. Scenarios

15. Jimmy, a junior, identified having cancer to the institution last semester. This semester, he is in remission and is enrolled in a biology course that will be discussing cancer in-depth. The faculty member is aware as he/she had Jimmy in another course during the previous semester. Should the faculty member just start the class on cancer and call on Jimmy to start discussing his experiences; should the faculty member talk with Jimmy prior to the class; or should the faculty do nothing at all? **Please discuss and explain any similar experiences that you might have had at your institution and if there are any "training" sessions on how to handle similar situations.**

16. If a faculty member is teaching a class and a student starts having a seizure, what actions should he/she take for the *student* and for the *class*? **What kind of training, if any, does your institution have to enlighten faculty on how to handle such situations?**

17. If a sophomore living in the residence facilities was just diagnosed with kidney failure and has been placed on dialysis, will need to modify his/her courses and obtain transportation to and from the dialysis center, does he/she know where to go to obtain assistance? **Please explain this process at your institution.**

Web Page 10:



Colleges and Universities Serving Students with Chronic Illnesses

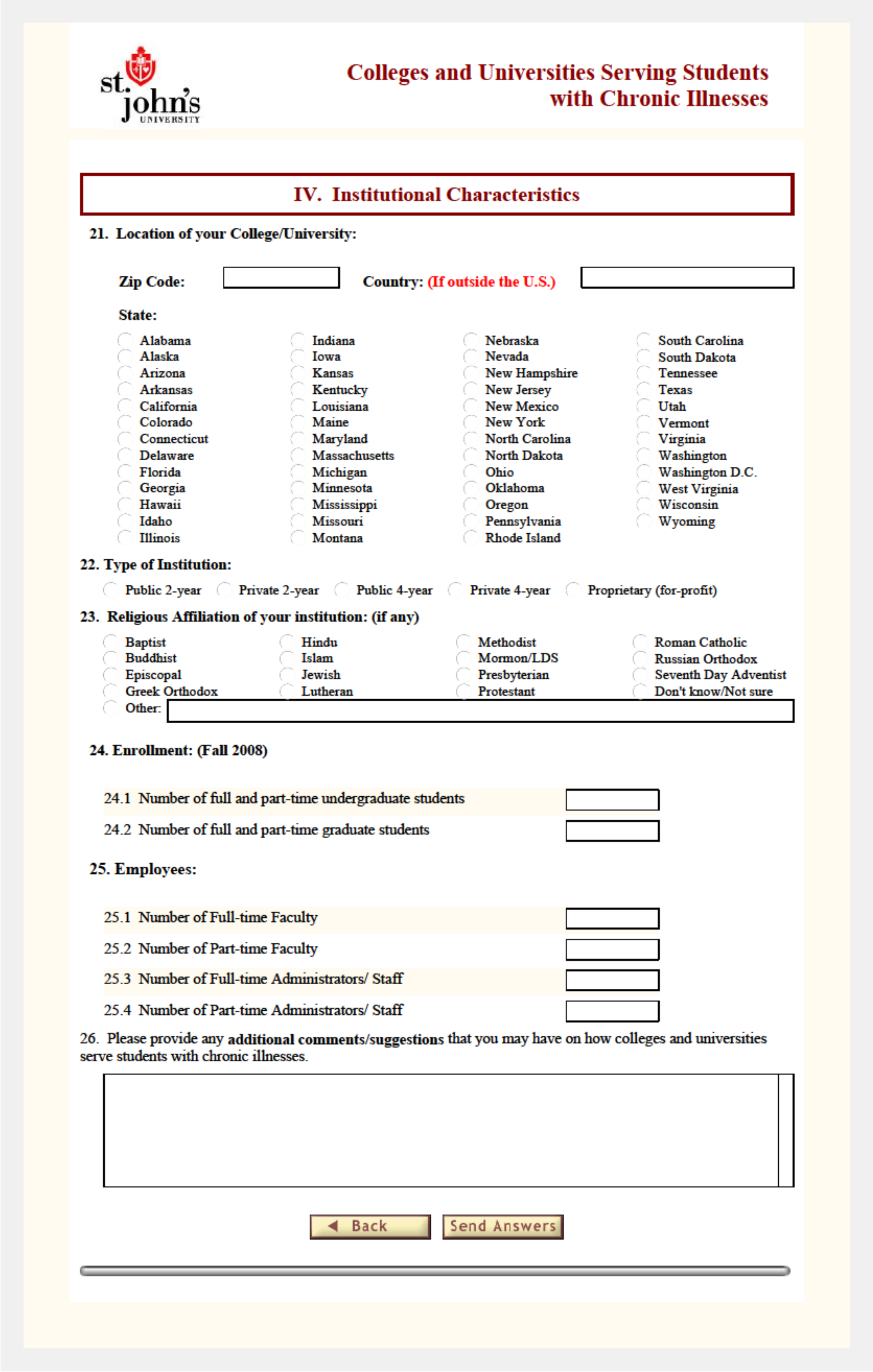
III. Scenarios (Continued)

18. Please describe any specific experiences you have had with students with chronic illnesses?

19. Please describe the **best practices** that your institution has in place to assist and support students with chronic illnesses.

20. If you were to create a new Disabled Student Services Office with an unlimited budget, **what specific services would you offer for students with chronic illnesses?**

Web Page 11:



Colleges and Universities Serving Students with Chronic Illnesses

IV. Institutional Characteristics

21. Location of your College/University:

Zip Code: ☐ **Country:** (If outside the U.S.) ☐

State:

○ Alabama
○ Alaska
○ Arizona
○ Arkansas
○ California
○ Colorado
○ Connecticut
○ Delaware
○ Florida
○ Georgia
○ Hawaii
○ Idaho
○ Illinois
○ Indiana
○ Iowa
○ Kansas
○ Kentucky
○ Louisiana
○ Maine
○ Maryland
○ Massachusetts
○ Michigan
○ Minnesota
○ Mississippi
○ Missouri
○ Montana
○ Nebraska
○ Nevada
○ New Hampshire
○ New Jersey
○ New Mexico
○ New York
○ North Carolina
○ North Dakota
○ Ohio
○ Oklahoma
○ Oregon
○ Pennsylvania
○ Rhode Island
○ South Carolina
○ South Dakota
○ Tennessee
○ Texas
○ Utah
○ Vermont
○ Virginia
○ Washington
○ Washington D.C.
○ West Virginia
○ Wisconsin
○ Wyoming

22. Type of Institution:

○ Public 2-year ○ Private 2-year ○ Public 4-year ○ Private 4-year ○ Proprietary (for-profit)

23. Religious Affiliation of your institution: (if any)

○ Baptist
○ Buddhist
○ Episcopal
○ Greek Orthodox
○ Hindu
○ Islam
○ Jewish
○ Lutheran
○ Methodist
○ Mormon/LDS
○ Presbyterian
○ Protestant
○ Roman Catholic
○ Russian Orthodox
○ Seventh Day Adventist
○ Don't know/Not sure
○ Other: ☐

24. Enrollment: (Fall 2008)

24.1 Number of full and part-time undergraduate students ☐
24.2 Number of full and part-time graduate students ☐

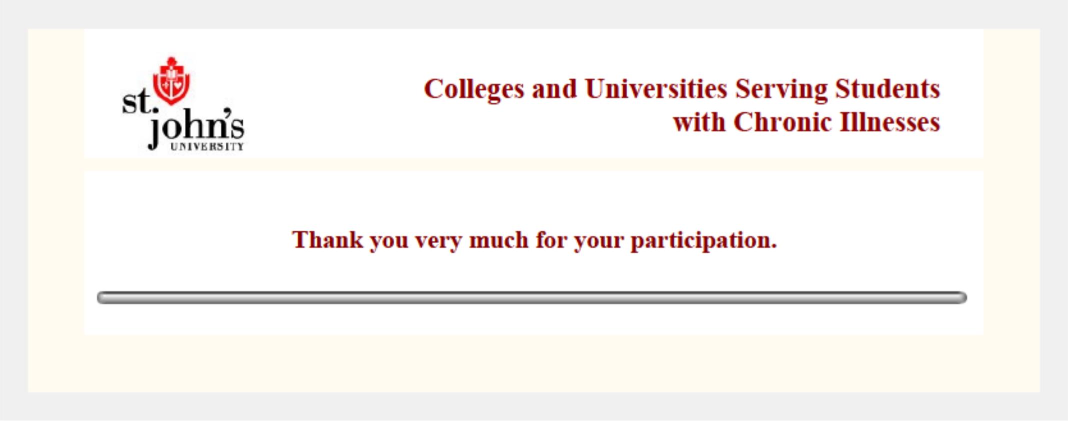
25. Employees:

25.1 Number of Full-time Faculty ☐
25.2 Number of Part-time Faculty ☐
25.3 Number of Full-time Administrators/ Staff ☐
25.4 Number of Part-time Administrators/ Staff ☐

26. Please provide any **additional comments/suggestions** that you may have on how colleges and universities serve students with chronic illnesses.

☐

Web Page 12 Thanks:



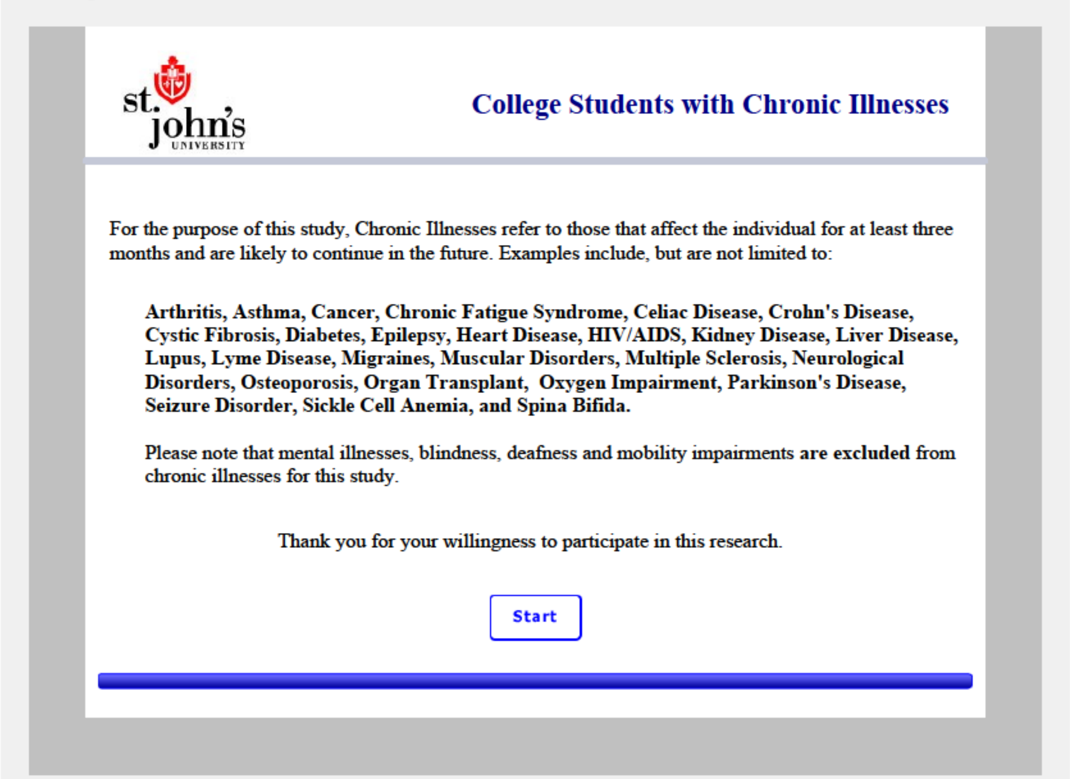
Colleges and Universities Serving Students with Chronic Illnesses

Thank you very much for your participation.

APPENDIX D:

Instrument - College Students with Chronic Illnesses Survey

Web Page 1:



College Students with Chronic Illnesses

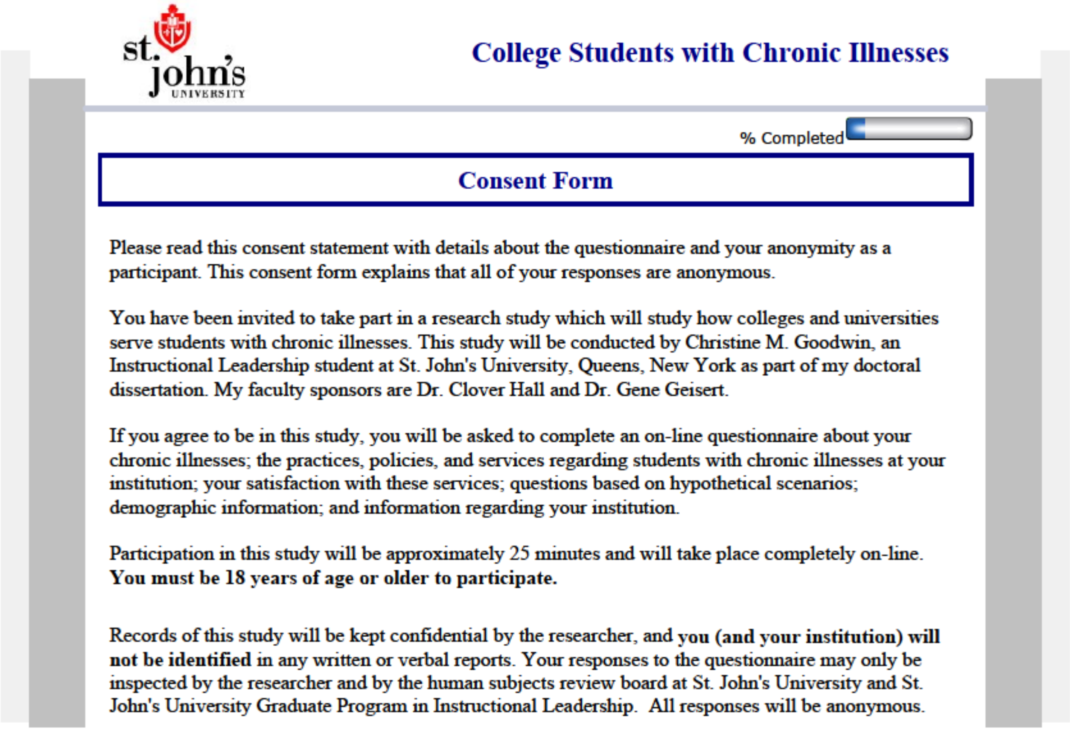
For the purpose of this study, Chronic Illnesses refer to those that affect the individual for at least three months and are likely to continue in the future. Examples include, but are not limited to:

Arthritis, Asthma, Cancer, Chronic Fatigue Syndrome, Celiac Disease, Crohn's Disease, Cystic Fibrosis, Diabetes, Epilepsy, Heart Disease, HIV/AIDS, Kidney Disease, Liver Disease, Lupus, Lyme Disease, Migraines, Muscular Disorders, Multiple Sclerosis, Neurological Disorders, Osteoporosis, Organ Transplant, Oxygen Impairment, Parkinson's Disease, Seizure Disorder, Sickle Cell Anemia, and Spina Bifida.

Please note that mental illnesses, blindness, deafness and mobility impairments **are excluded** from chronic illnesses for this study.

Thank you for your willingness to participate in this research.

Web Page 2 Consent:



College Students with Chronic Illnesses

Consent Form

Please read this consent statement with details about the questionnaire and your anonymity as a participant. This consent form explains that all of your responses are anonymous.

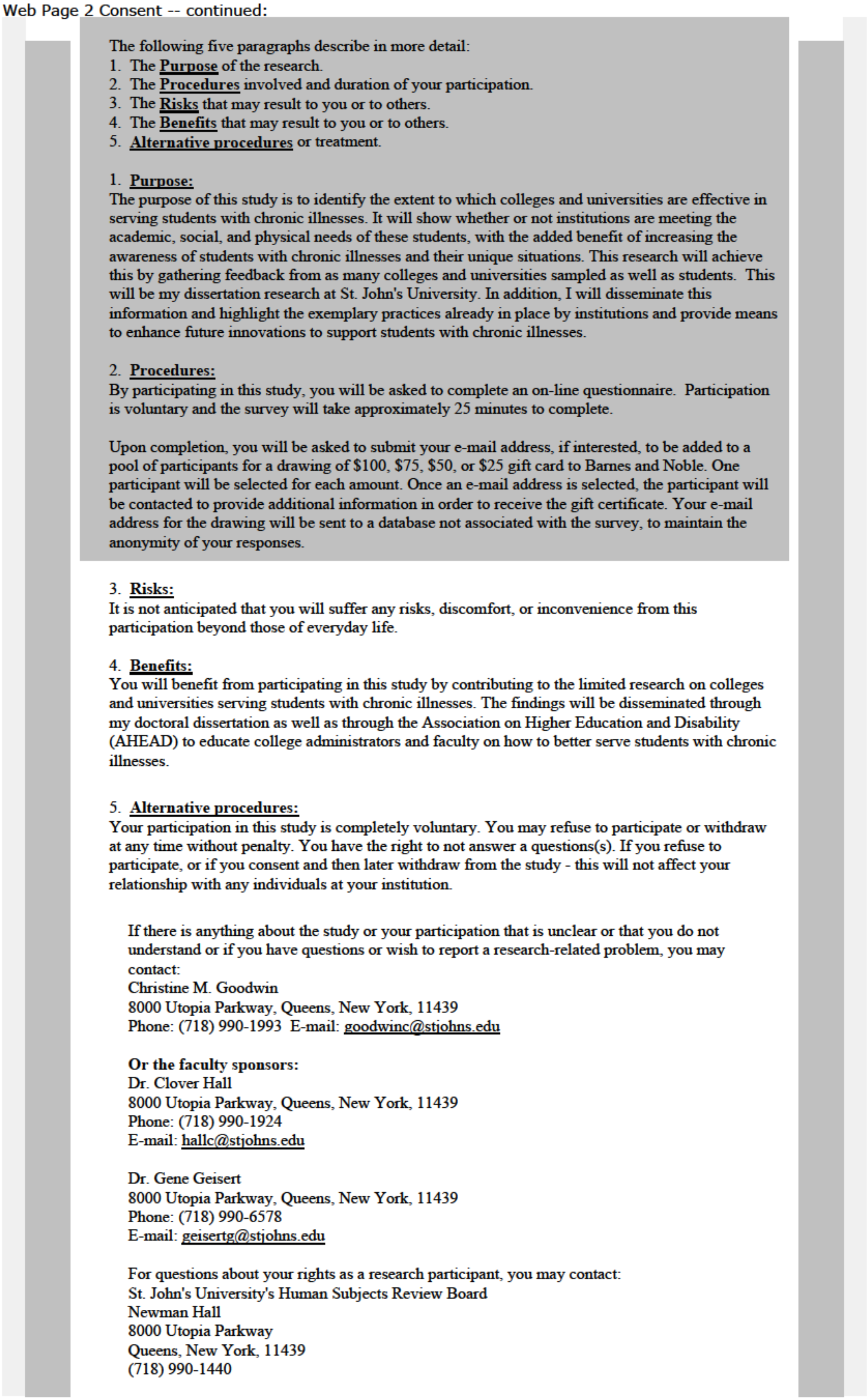
You have been invited to take part in a research study which will study how colleges and universities serve students with chronic illnesses. This study will be conducted by Christine M. Goodwin, an Instructional Leadership student at St. John's University, Queens, New York as part of my doctoral dissertation. My faculty sponsors are Dr. Clover Hall and Dr. Gene Geisert.

If you agree to be in this study, you will be asked to complete an on-line questionnaire about your chronic illnesses; the practices, policies, and services regarding students with chronic illnesses at your institution; your satisfaction with these services; questions based on hypothetical scenarios; demographic information; and information regarding your institution.

Participation in this study will be approximately 25 minutes and will take place completely on-line. **You must be 18 years of age or older to participate.**

Records of this study will be kept confidential by the researcher, and **you (and your institution) will not be identified** in any written or verbal reports. Your responses to the questionnaire may only be inspected by the researcher and by the human subjects review board at St. John's University and St. John's University Graduate Program in Instructional Leadership. All responses will be anonymous.

Web Page 2 Consent -- continued:



The following five paragraphs describe in more detail:
1. The **Purpose** of the research.
2. The **Procedures** involved and duration of your participation.
3. The **Risks** that may result to you or to others.
4. The **Benefits** that may result to you or to others.
5. **Alternative procedures** or treatment.

1. **Purpose:**

The purpose of this study is to identify the extent to which colleges and universities are effective in serving students with chronic illnesses. It will show whether or not institutions are meeting the academic, social, and physical needs of these students, with the added benefit of increasing the awareness of students with chronic illnesses and their unique situations. This research will achieve this by gathering feedback from as many colleges and universities sampled as well as students. This will be my dissertation research at St. John's University. In addition, I will disseminate this information and highlight the exemplary practices already in place by institutions and provide means to enhance future innovations to support students with chronic illnesses.

2. **Procedures:**

By participating in this study, you will be asked to complete an on-line questionnaire. Participation is voluntary and the survey will take approximately 25 minutes to complete.

Upon completion, you will be asked to submit your e-mail address, if interested, to be added to a pool of participants for a drawing of $100, $75, $50, or $25 gift card to Barnes and Noble. One participant will be selected for each amount. Once an e-mail address is selected, the participant will be contacted to provide additional information in order to receive the gift certificate. Your e-mail address for the drawing will be sent to a database not associated with the survey, to maintain the anonymity of your responses.

3. **Risks:**

It is not anticipated that you will suffer any risks, discomfort, or inconvenience from this participation beyond those of everyday life.

4. **Benefits:**

You will benefit from participating in this study by contributing to the limited research on colleges and universities serving students with chronic illnesses. The findings will be disseminated through my doctoral dissertation as well as through the Association on Higher Education and Disability (AHEAD) to educate college administrators and faculty on how to better serve students with chronic illnesses.

5. **Alternative procedures:**

Your participation in this study is completely voluntary. You may refuse to participate or withdraw at any time without penalty. You have the right to not answer a questions(s). If you refuse to participate, or if you consent and then later withdraw from the study - this will not affect your relationship with any individuals at your institution.

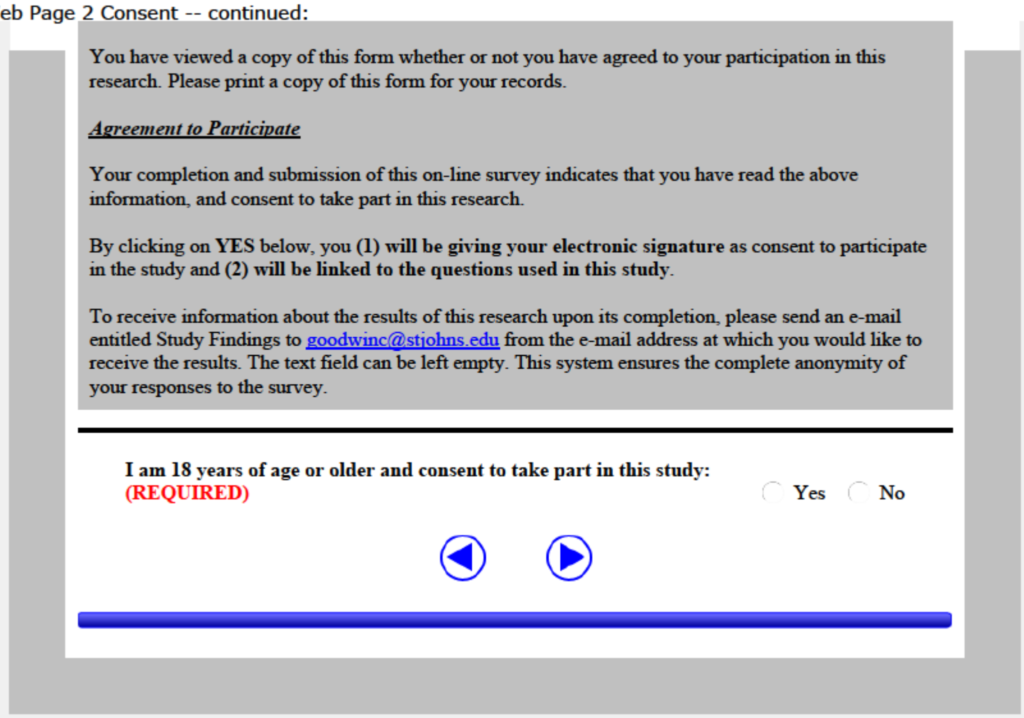
If there is anything about the study or your participation that is unclear or that you do not understand or if you have questions or wish to report a research-related problem, you may contact:
Christine M. Goodwin
8000 Utopia Parkway, Queens, New York, 11439
Phone: (718) 990-1993 E-mail: goodwinc@stjohns.edu

Or the faculty sponsors:
Dr. Clover Hall
8000 Utopia Parkway, Queens, New York, 11439
Phone: (718) 990-1924
E-mail: hallc@stjohns.edu

Dr. Gene Geisert
8000 Utopia Parkway, Queens, New York, 11439
Phone: (718) 990-6578
E-mail: geisertg@stjohns.edu

For questions about your rights as a research participant, you may contact:
St. John's University's Human Subjects Review Board
Newman Hall
8000 Utopia Parkway
Queens, New York, 11439
(718) 990-1440

Web Page 2 Consent -- continued:



You have viewed a copy of this form whether or not you have agreed to your participation in this research. Please print a copy of this form for your records.

Agreement to Participate

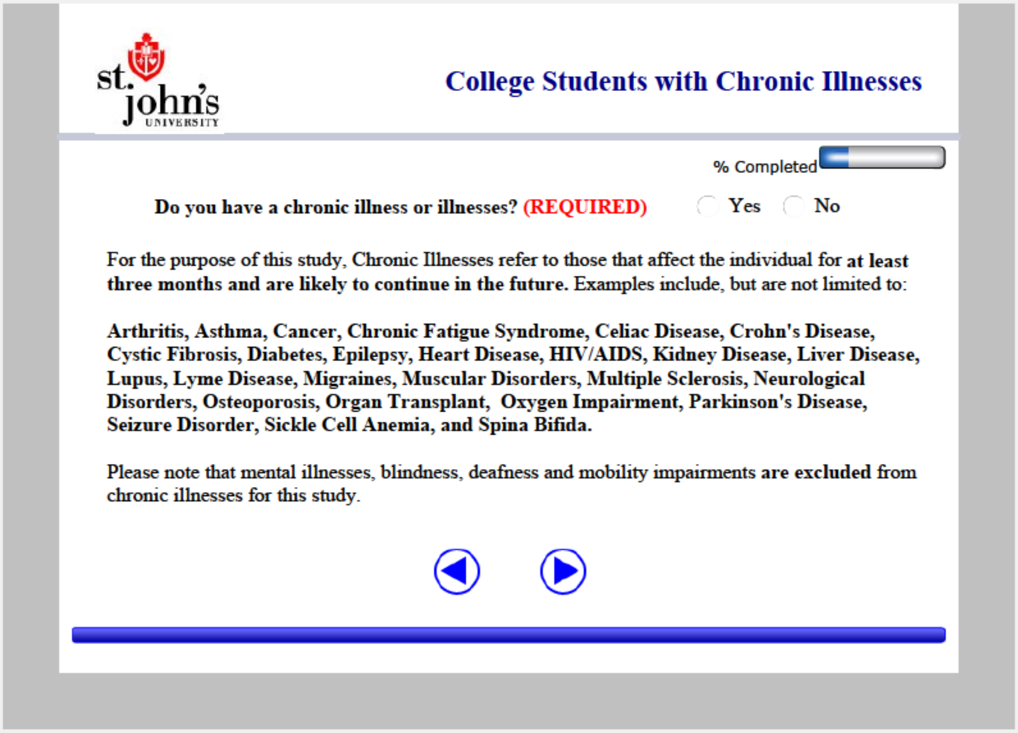
Your completion and submission of this on-line survey indicates that you have read the above information, and consent to take part in this research.

By clicking on YES below, you (1) **will be giving your electronic signature** as consent to participate in the study and (2) **will be linked to the questions used in this study**.

To receive information about the results of this research upon its completion, please send an e-mail entitled Study Findings to goodwinc@stjohns.edu from the e-mail address at which you would like to receive the results. The text field can be left empty. This system ensures the complete anonymity of your responses to the survey.

I am 18 years of age or older and consent to take part in this study: (REQUIRED) ○ **Yes** ○ **No**

Web Page 3 Chronic:



College Students with Chronic Illnesses

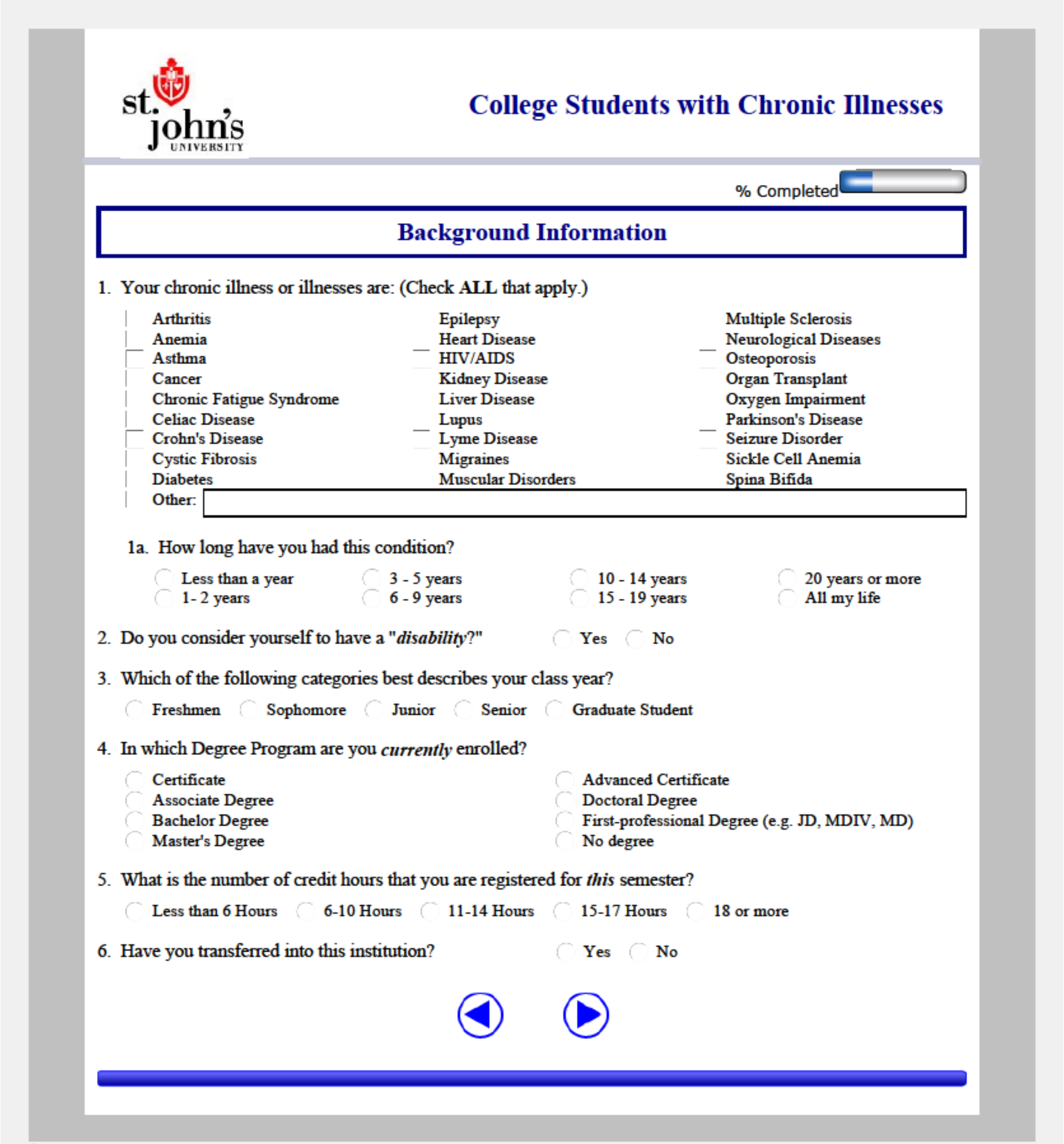
Do you have a chronic illness or illnesses? (REQUIRED) ○ **Yes** ○ **No**

For the purpose of this study, Chronic Illnesses refer to those that affect the individual for **at least three months and are likely to continue in the future.** Examples include, but are not limited to:

Arthritis, Asthma, Cancer, Chronic Fatigue Syndrome, Celiac Disease, Crohn's Disease, Cystic Fibrosis, Diabetes, Epilepsy, Heart Disease, HIV/AIDS, Kidney Disease, Liver Disease, Lupus, Lyme Disease, Migraines, Muscular Disorders, Multiple Sclerosis, Neurological Disorders, Osteoporosis, Organ Transplant, Oxygen Impairment, Parkinson's Disease, Seizure Disorder, Sickle Cell Anemia, and Spina Bifida.

Please note that mental illnesses, blindness, deafness and mobility impairments **are excluded** from chronic illnesses for this study.

Web Page 4 Background:



College Students with Chronic Illnesses

Background Information

1. Your chronic illness or illnesses are: (Check **ALL** that apply.)

☐ Arthritis
☐ Anemia
☐ Asthma
☐ Cancer
☐ Chronic Fatigue Syndrome
☐ Celiac Disease
☐ Crohn's Disease
☐ Cystic Fibrosis
☐ Diabetes
☐ Epilepsy
☐ Heart Disease
☐ HIV/AIDS
☐ Kidney Disease
☐ Liver Disease
☐ Lupus
☐ Lyme Disease
☐ Migraines
☐ Muscular Disorders
☐ Multiple Sclerosis
☐ Neurological Diseases
☐ Osteoporosis
☐ Organ Transplant
☐ Oxygen Impairment
☐ Parkinson's Disease
☐ Seizure Disorder
☐ Sickle Cell Anemia
☐ Spina Bifida
☐ Other: ____________________

1a. How long have you had this condition?

○ Less than a year ○ 3 - 5 years ○ 10 - 14 years ○ 20 years or more
○ 1- 2 years ○ 6 - 9 years ○ 15 - 19 years ○ All my life

2. Do you consider yourself to have a "*disability*?" ○ Yes ○ No

3. Which of the following categories best describes your class year?

○ Freshmen ○ Sophomore ○ Junior ○ Senior ○ Graduate Student

4. In which Degree Program are you *currently* enrolled?

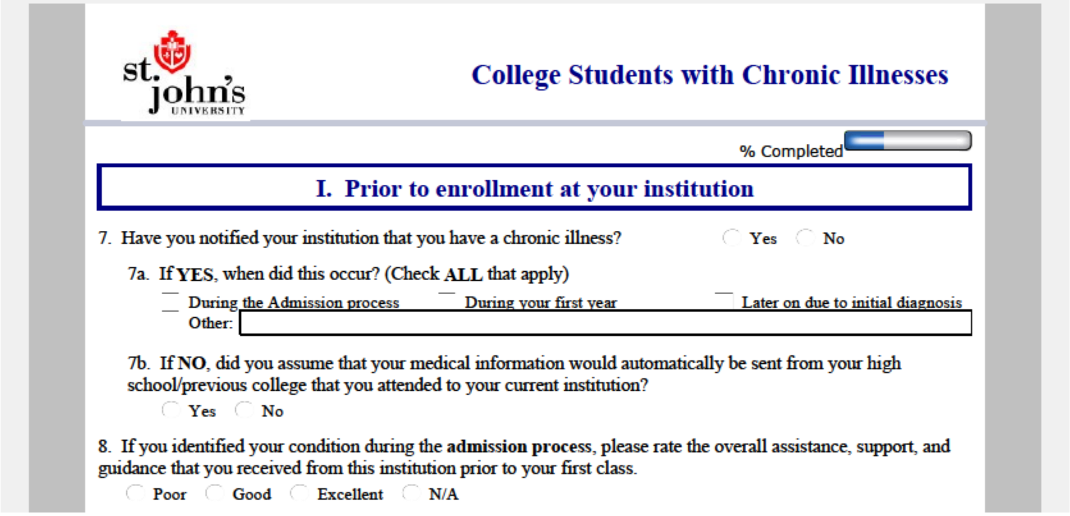
○ Certificate
○ Associate Degree
○ Bachelor Degree
○ Master's Degree
○ Advanced Certificate
○ Doctoral Degree
○ First-professional Degree (e.g. JD, MDIV, MD)
○ No degree

5. What is the number of credit hours that you are registered for *this* semester?

○ Less than 6 Hours ○ 6-10 Hours ○ 11-14 Hours ○ 15-17 Hours ○ 18 or more

6. Have you transferred into this institution? ○ Yes ○ No

Web Page 5:



College Students with Chronic Illnesses

I. Prior to enrollment at your institution

7. Have you notified your institution that you have a chronic illness? ○ Yes ○ No

7a. If **YES**, when did this occur? (Check **ALL** that apply)

☐ During the Admission process ☐ During your first year ☐ Later on due to initial diagnosis
☐ Other: ____________________

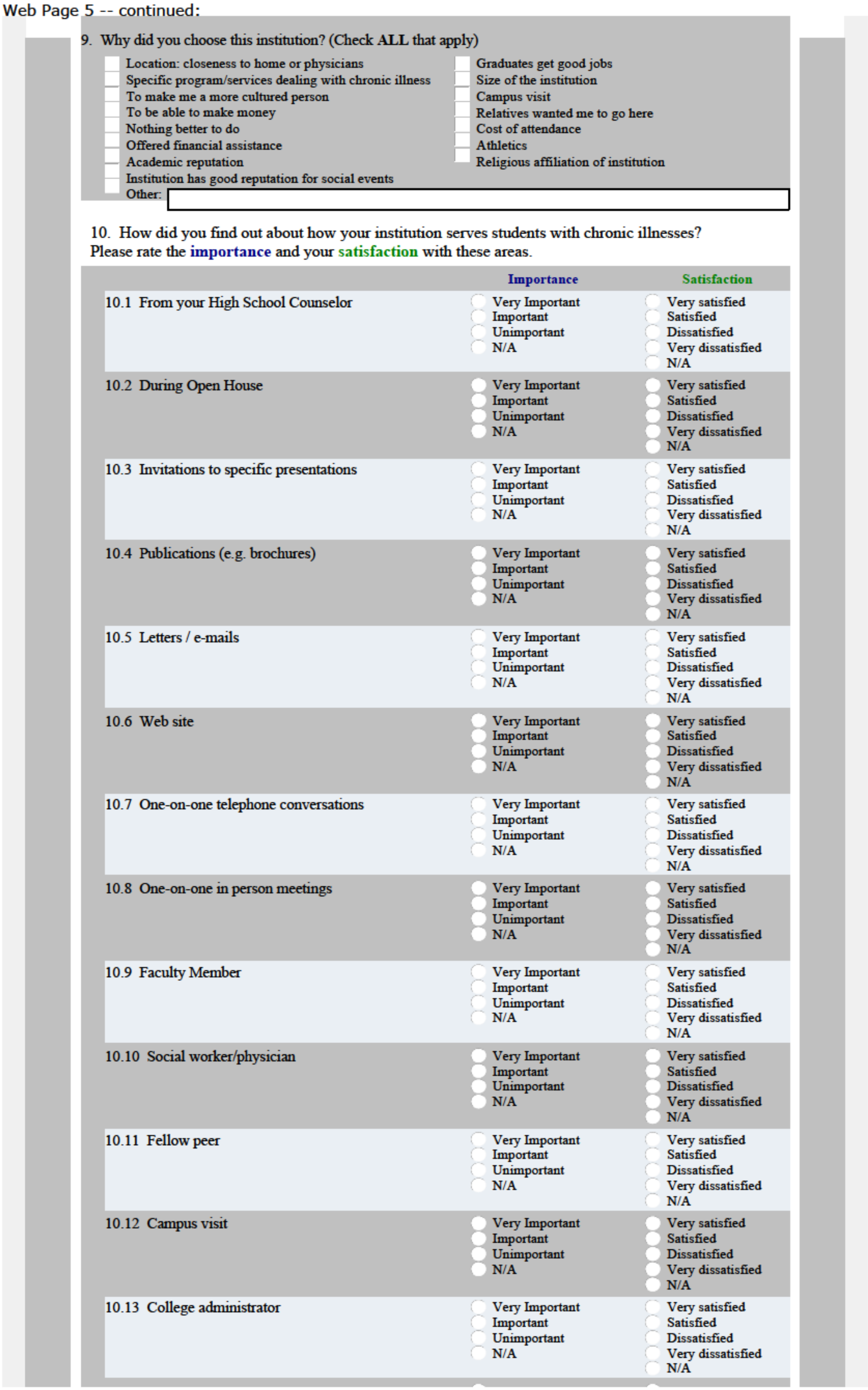
7b. If **NO**, did you assume that your medical information would automatically be sent from your high school/previous college that you attended to your current institution?

○ Yes ○ No

8. If you identified your condition during the **admission process**, please rate the overall assistance, support, and guidance that you received from this institution prior to your first class.

○ Poor ○ Good ○ Excellent ○ N/A

Web Page 5 -- continued:



9. Why did you choose this institution? (Check **ALL** that apply)

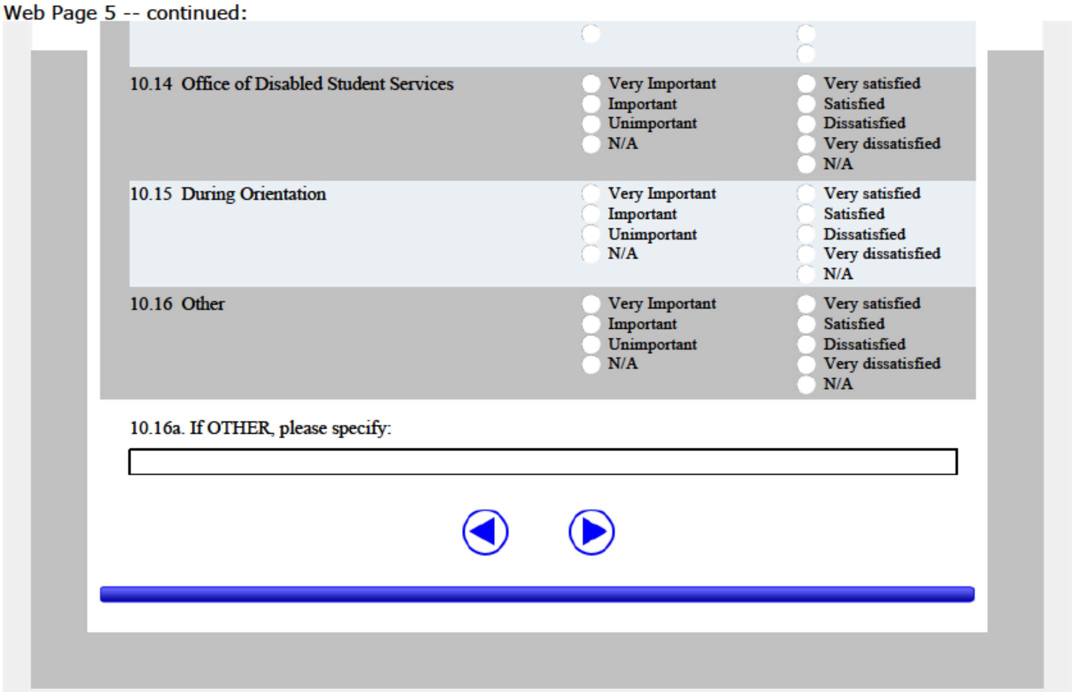
☐ Location: closeness to home or physicians
☐ Specific program/services dealing with chronic illness
☐ To make me a more cultured person
☐ To be able to make money
☐ Nothing better to do
☐ Offered financial assistance
☐ Academic reputation
☐ Institution has good reputation for social events
☐ Other:

☐ Graduates get good jobs
☐ Size of the institution
☐ Campus visit
☐ Relatives wanted me to go here
☐ Cost of attendance
☐ Athletics
☐ Religious affiliation of institution

10. How did you find out about how your institution serves students with chronic illnesses?
Please rate the **importance** and your **satisfaction** with these areas.

	Importance	**Satisfaction**
10.1 From your High School Counselor	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.2 During Open House	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.3 Invitations to specific presentations	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.4 Publications (e.g. brochures)	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.5 Letters / e-mails	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.6 Web site	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.7 One-on-one telephone conversations	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.8 One-on-one in person meetings	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.9 Faculty Member	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.10 Social worker/physician	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.11 Fellow peer	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.12 Campus visit	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.13 College administrator	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A

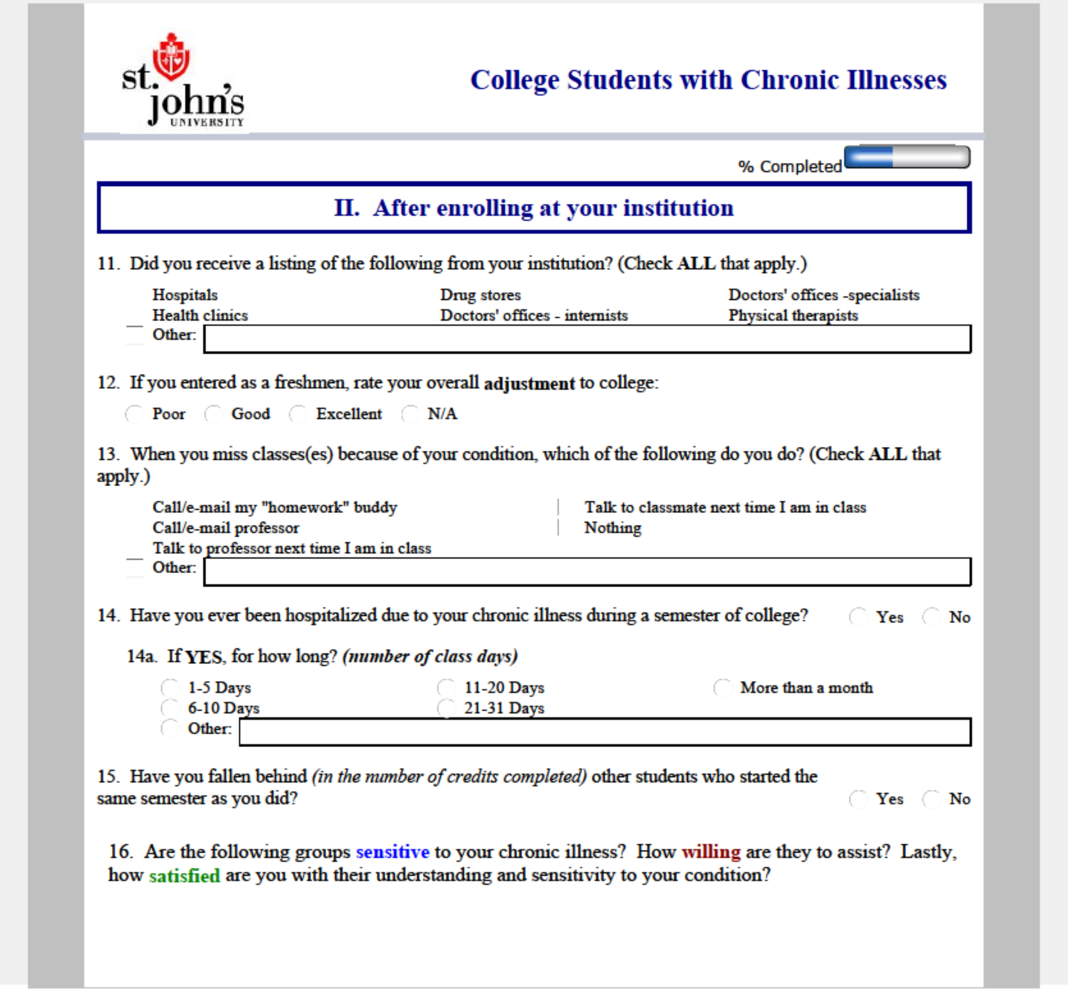
Web Page 5 -- continued:



10.14 Office of Disabled Student Services	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.15 During Orientation	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
10.16 Other	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A

10.16a. If OTHER, please specify:

Web Page 6:



College Students with Chronic Illnesses

% Completed

II. After enrolling at your institution

11. Did you receive a listing of the following from your institution? (Check **ALL** that apply.)

Hospitals	Drug stores	Doctors' offices -specialists
Health clinics	Doctors' offices - internists	Physical therapists

Other:

12. If you entered as a freshmen, rate your overall **adjustment** to college:

○ Poor ○ Good ○ Excellent ○ N/A

13. When you miss classes(es) because of your condition, which of the following do you do? (Check **ALL** that apply.)

Call/e-mail my "homework" buddy	Talk to classmate next time I am in class
Call/e-mail professor	Nothing
Talk to professor next time I am in class	

Other:

14. Have you ever been hospitalized due to your chronic illness during a semester of college? ○ Yes ○ No

14a. If **YES**, for how long? ***(number of class days)***

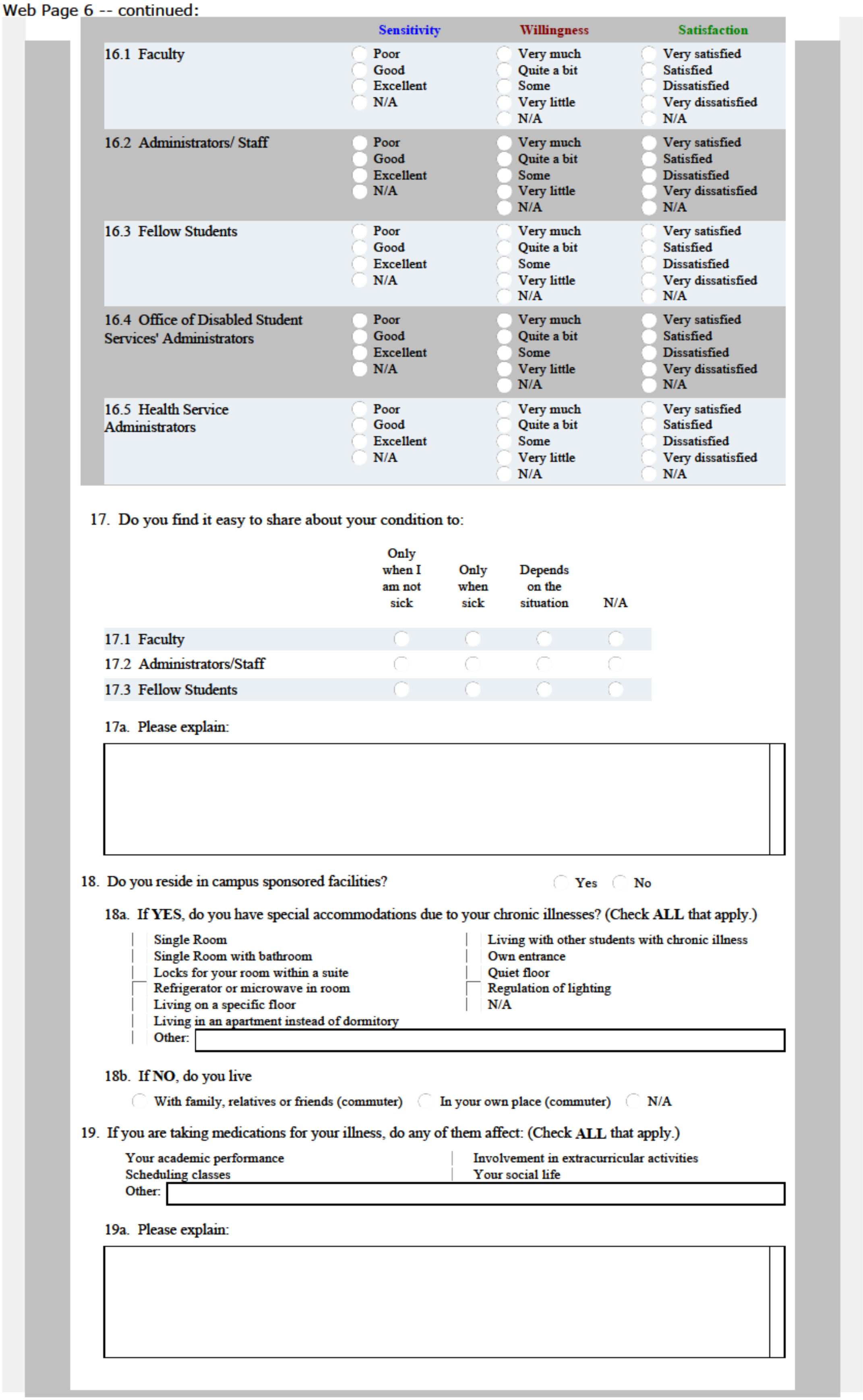
○ 1-5 Days	○ 11-20 Days	○ More than a month
○ 6-10 Days	○ 21-31 Days	

○ Other:

15. Have you fallen behind *(in the number of credits completed)* other students who started the same semester as you did? ○ Yes ○ No

16. Are the following groups **sensitive** to your chronic illness? How **willing** are they to assist? Lastly, how **satisfied** are you with their understanding and sensitivity to your condition?

Web Page 6 -- continued:



	Sensitivity	Willingness	Satisfaction
16.1 Faculty	○ Poor ○ Good ○ Excellent ○ N/A	○ Very much ○ Quite a bit ○ Some ○ Very little ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
16.2 Administrators/ Staff	○ Poor ○ Good ○ Excellent ○ N/A	○ Very much ○ Quite a bit ○ Some ○ Very little ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
16.3 Fellow Students	○ Poor ○ Good ○ Excellent ○ N/A	○ Very much ○ Quite a bit ○ Some ○ Very little ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
16.4 Office of Disabled Student Services' Administrators	○ Poor ○ Good ○ Excellent ○ N/A	○ Very much ○ Quite a bit ○ Some ○ Very little ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
16.5 Health Service Administrators	○ Poor ○ Good ○ Excellent ○ N/A	○ Very much ○ Quite a bit ○ Some ○ Very little ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A

17. Do you find it easy to share about your condition to:

	Only when I am not sick	Only when sick	Depends on the situation	N/A
17.1 Faculty	○	○	○	○
17.2 Administrators/Staff	○	○	○	○
17.3 Fellow Students	○	○	○	○

17a. Please explain:

18. Do you reside in campus sponsored facilities? ○ Yes ○ No

18a. If **YES**, do you have special accommodations due to your chronic illnesses? (Check **ALL** that apply.)

- ☐ Single Room
- ☐ Single Room with bathroom
- ☐ Locks for your room within a suite
- ☐ Refrigerator or microwave in room
- ☐ Living on a specific floor
- ☐ Living in an apartment instead of dormitory
- ☐ Other:
- ☐ Living with other students with chronic illness
- ☐ Own entrance
- ☐ Quiet floor
- ☐ Regulation of lighting
- ☐ N/A

18b. If **NO**, do you live

○ With family, relatives or friends (commuter) ○ In your own place (commuter) ○ N/A

19. If you are taking medications for your illness, do any of them affect: (Check **ALL** that apply.)

- ☐ Your academic performance
- ☐ Scheduling classes
- ☐ Other:
- ☐ Involvement in extracurricular activities
- ☐ Your social life

19a. Please explain:

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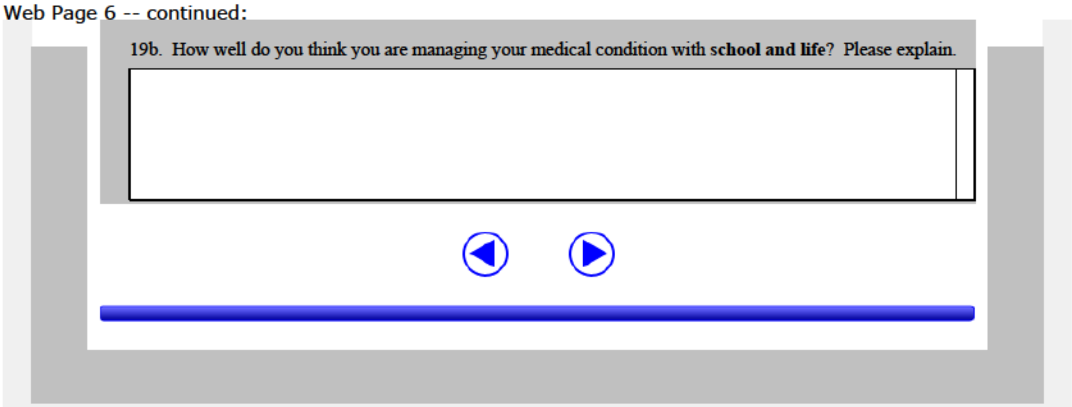

19b. How well do you think you are managing your medical condition with **school and life**? Please explain.

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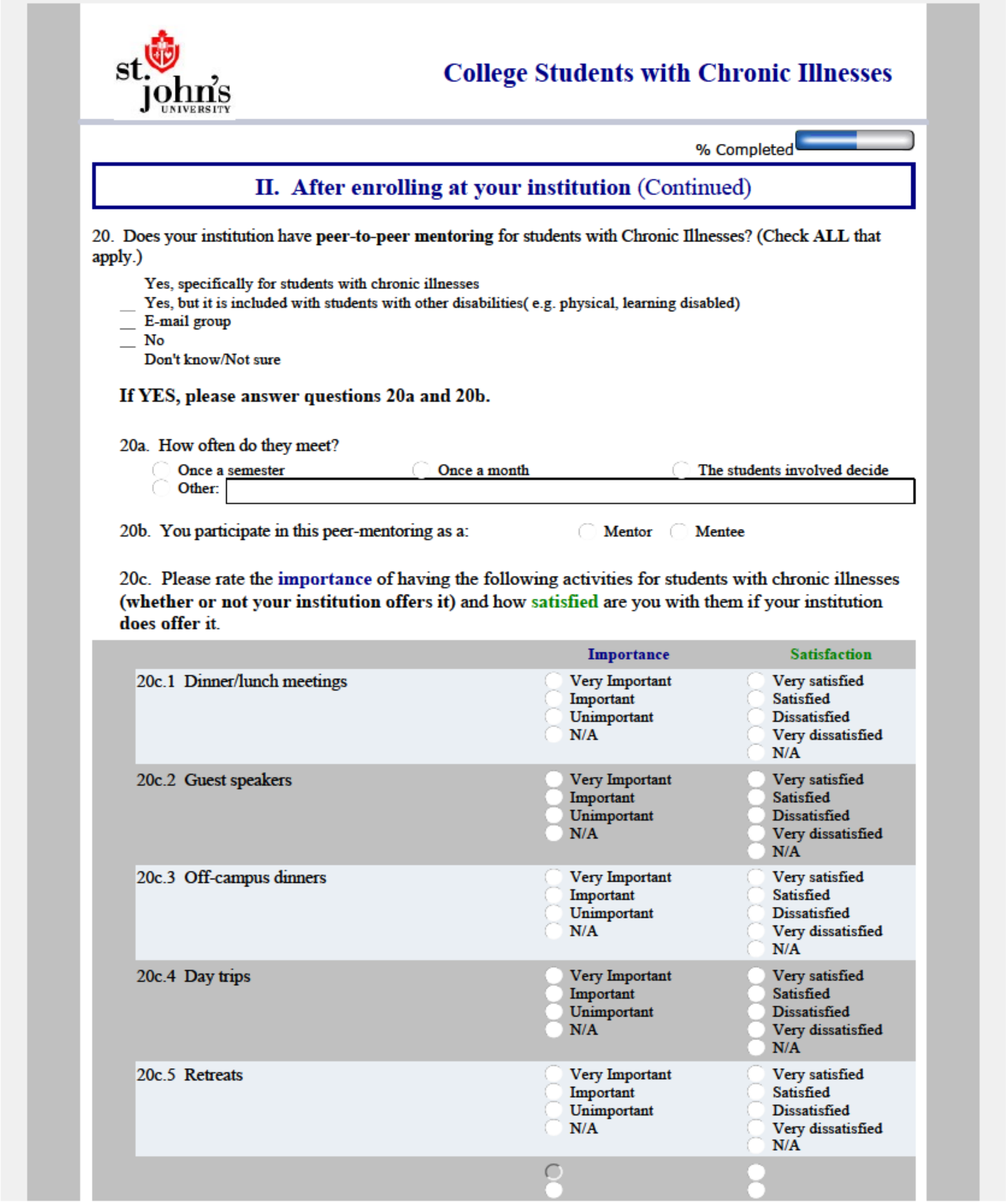

College Students with Chronic Illnesses

% Completed

II. After enrolling at your institution (Continued)

20. Does your institution have **peer-to-peer mentoring** for students with Chronic Illnesses? (Check **ALL** that apply.)

Yes, specifically for students with chronic illnesses
__ Yes, but it is included with students with other disabilities(e.g. physical, learning disabled)
__ E-mail group
__ No
Don't know/Not sure

If YES, please answer questions 20a and 20b.

20a. How often do they meet?

○ Once a semester ○ Once a month ○ The students involved decide
○ Other:

20b. You participate in this peer-mentoring as a: ○ Mentor ○ Mentee

20c. Please rate the importance of having the following activities for students with chronic illnesses **(whether or not your institution offers it)** and how satisfied are you with them if your institution **does offer it**.

	Importance	**Satisfaction**
20c.1 Dinner/lunch meetings	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
20c.2 Guest speakers	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
20c.3 Off-campus dinners	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
20c.4 Day trips	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
20c.5 Retreats	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A

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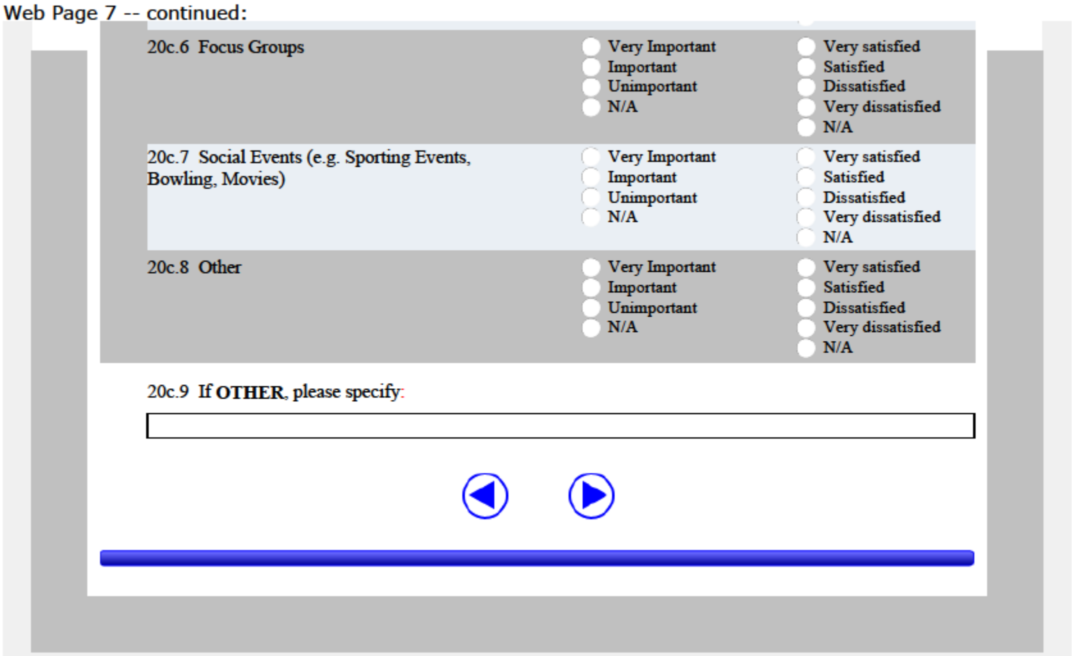

20c.6 Focus Groups	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
20c.7 Social Events (e.g. Sporting Events, Bowling, Movies)	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
20c.8 Other	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A

20c.9 If **OTHER**, please specify:

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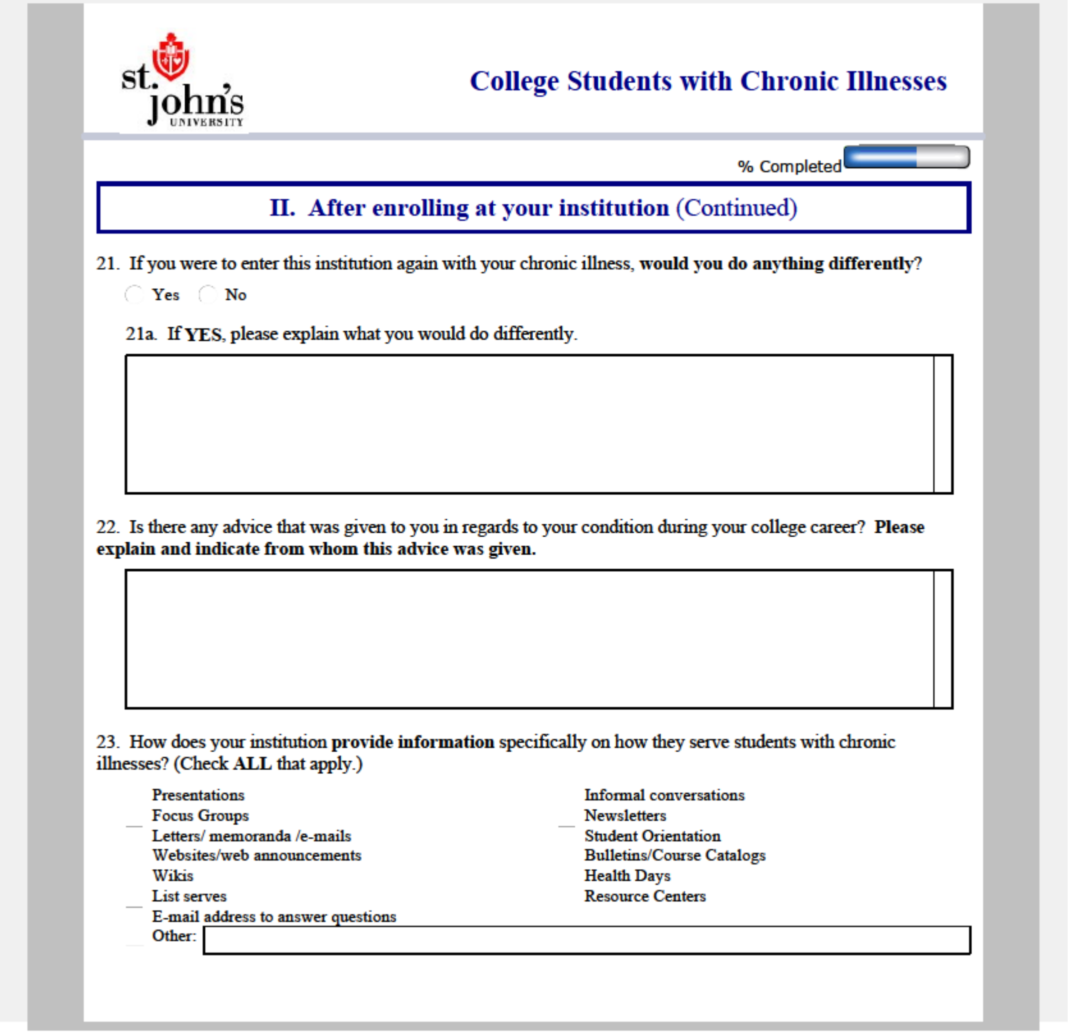

College Students with Chronic Illnesses

II. After enrolling at your institution (Continued)

21. If you were to enter this institution again with your chronic illness, **would you do anything differently**?

○ Yes ○ No

21a. If **YES**, please explain what you would do differently.

22. Is there any advice that was given to you in regards to your condition during your college career? **Please explain and indicate from whom this advice was given.**

23. How does your institution **provide information** specifically on how they serve students with chronic illnesses? (Check **ALL** that apply.)

- Presentations
- Focus Groups
- Letters/ memoranda /e-mails
- Websites/web announcements
- Wikis
- List serves
- E-mail address to answer questions
- Other:
- Informal conversations
- Newsletters
- Student Orientation
- Bulletins/Course Catalogs
- Health Days
- Resource Centers

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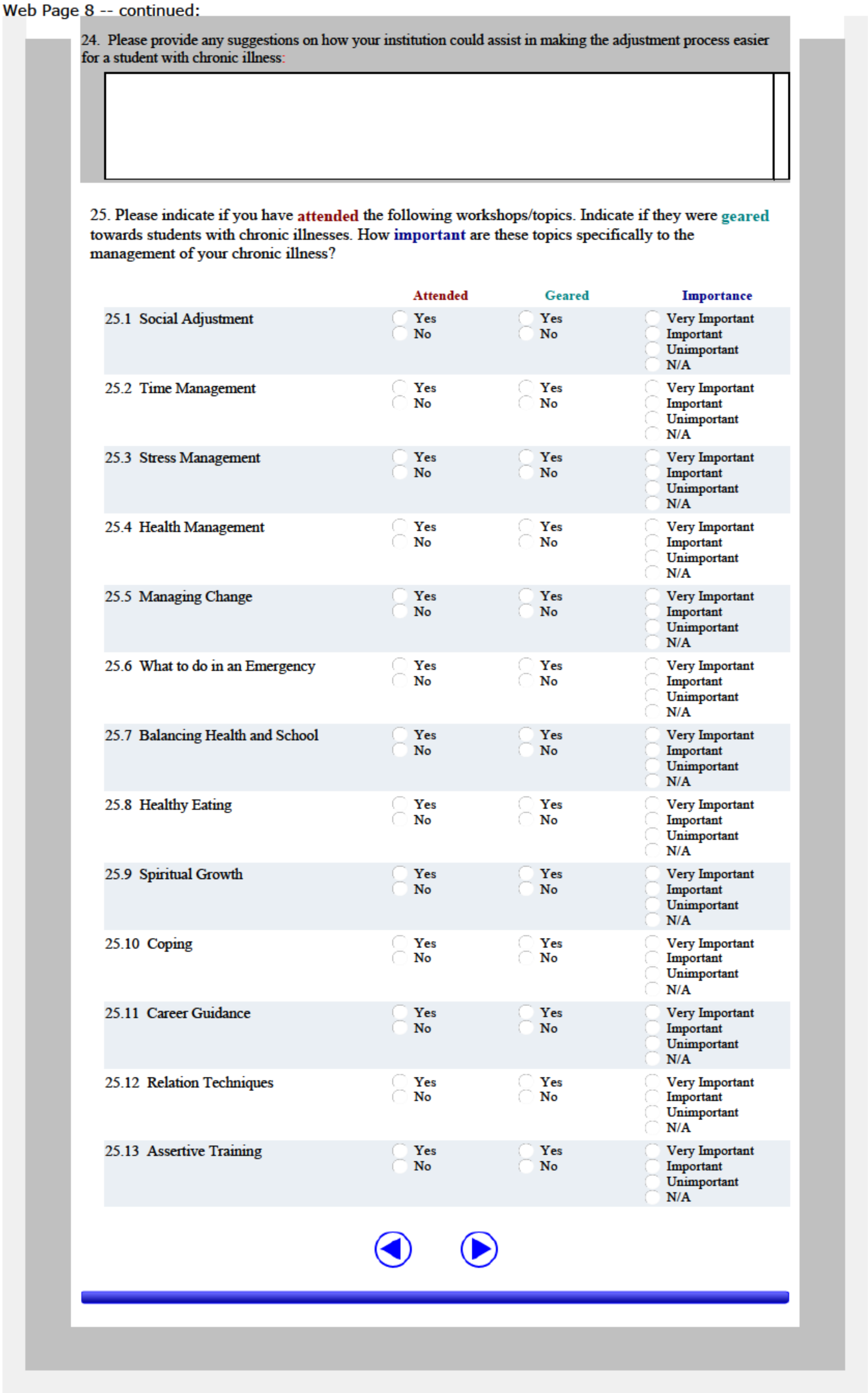

24. Please provide any suggestions on how your institution could assist in making the adjustment process easier for a student with chronic illness:

25. Please indicate if you have **attended** the following workshops/topics. Indicate if they were **geared** towards students with chronic illnesses. How **important** are these topics specifically to the management of your chronic illness?

	Attended	**Geared**	**Importance**
25.1 Social Adjustment	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.2 Time Management	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.3 Stress Management	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.4 Health Management	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.5 Managing Change	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.6 What to do in an Emergency	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.7 Balancing Health and School	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.8 Healthy Eating	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.9 Spiritual Growth	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.10 Coping	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.11 Career Guidance	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.12 Relation Techniques	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A
25.13 Assertive Training	○ Yes ○ No	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A

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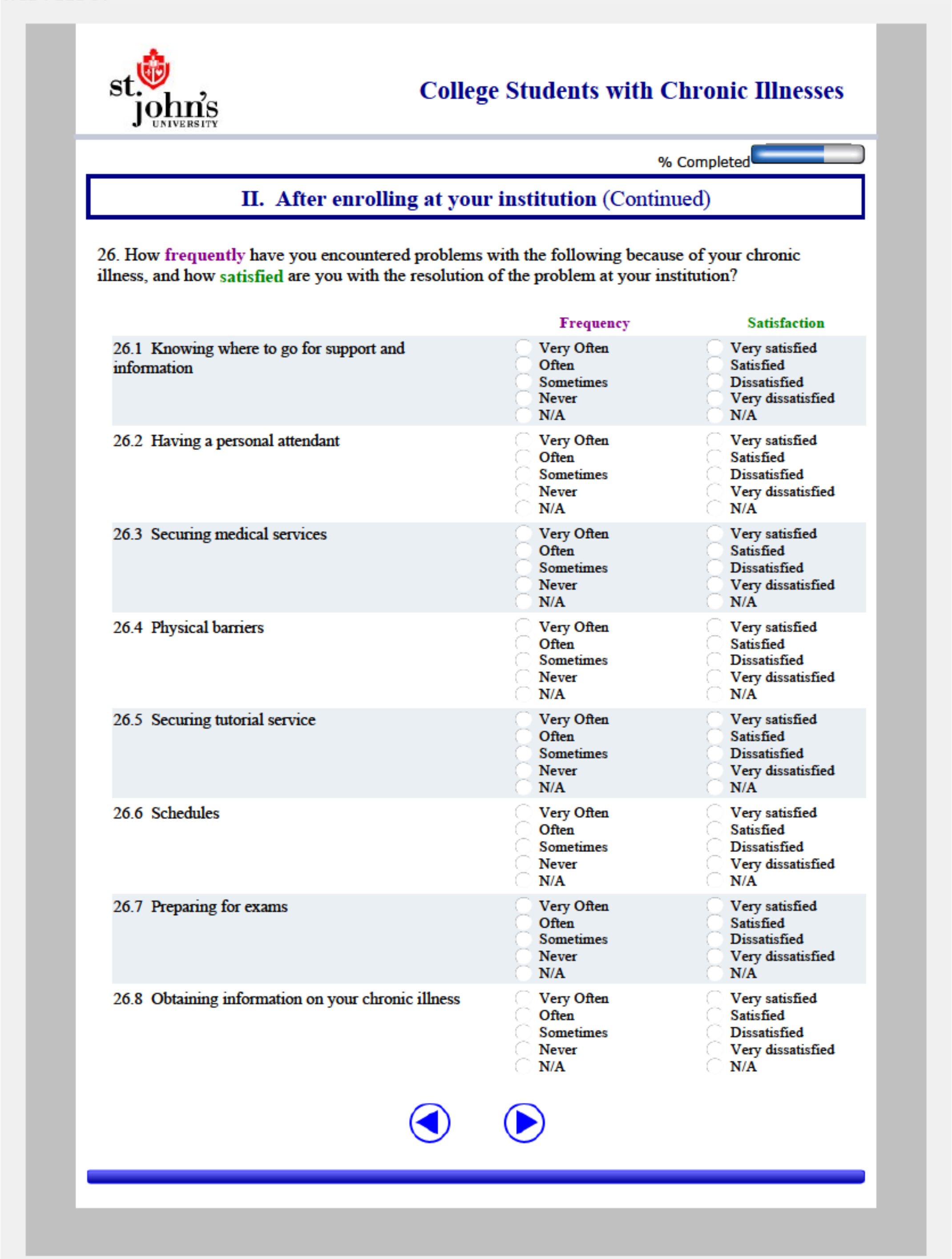

College Students with Chronic Illnesses

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II. After enrolling at your institution (Continued)

26. How **frequently** have you encountered problems with the following because of your chronic illness, and how **satisfied** are you with the resolution of the problem at your institution?

	Frequency	Satisfaction
26.1 Knowing where to go for support and information	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
26.2 Having a personal attendant	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
26.3 Securing medical services	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
26.4 Physical barriers	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
26.5 Securing tutorial service	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
26.6 Schedules	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
26.7 Preparing for exams	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
26.8 Obtaining information on your chronic illness	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A

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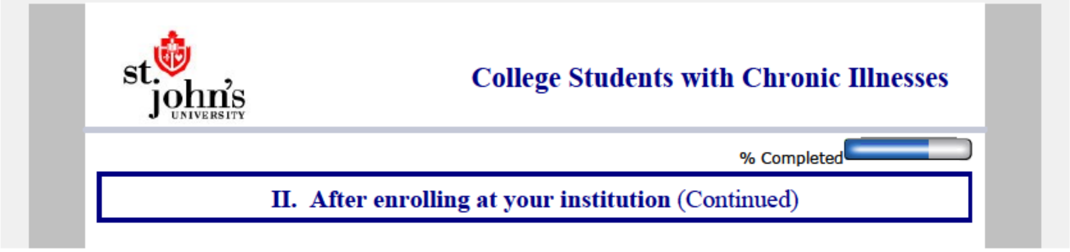

College Students with Chronic Illnesses

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II. After enrolling at your institution (Continued)

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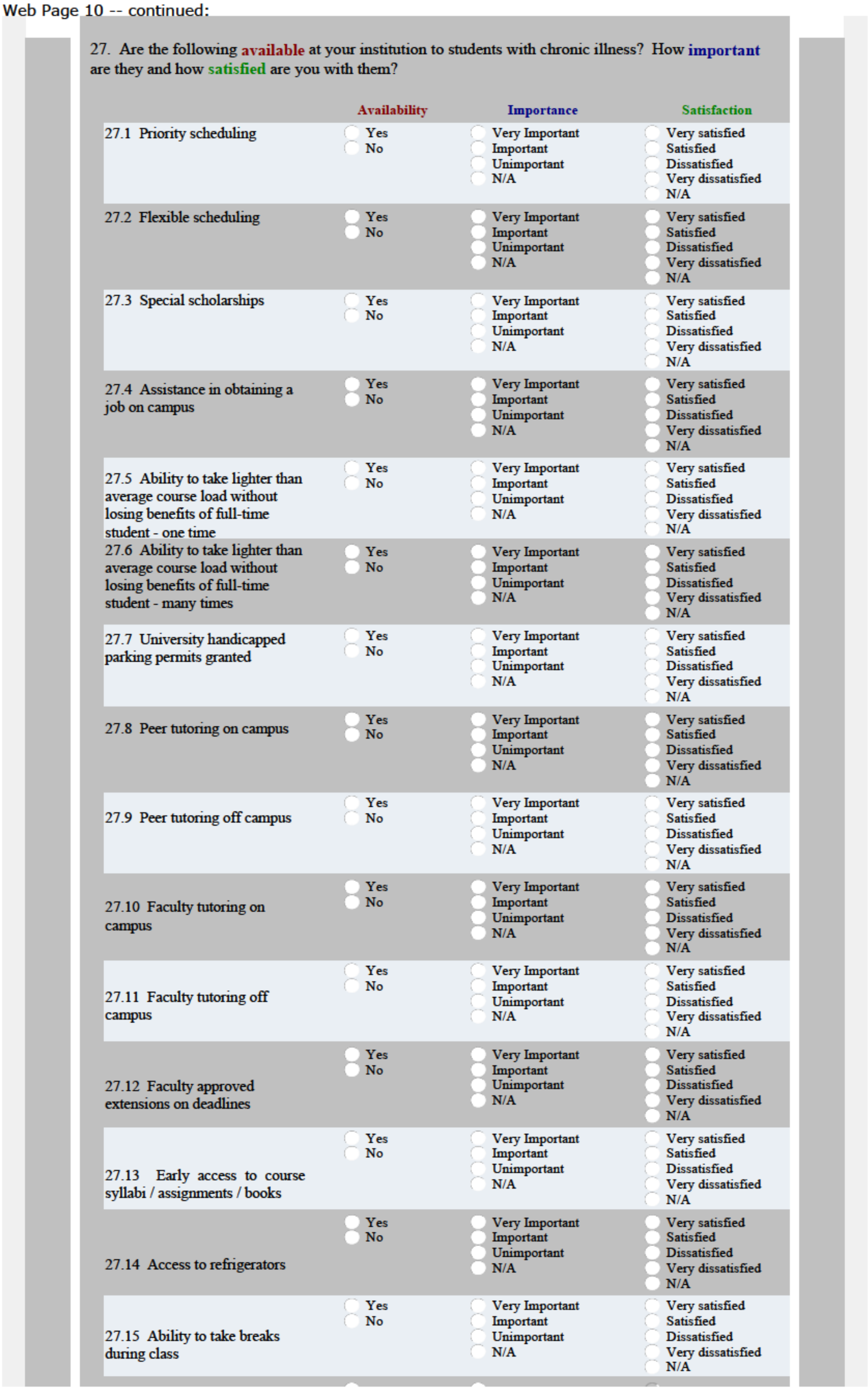

27. Are the following **available** at your institution to students with chronic illness? How **important** are they and how **satisfied** are you with them?

	Availability	Importance	Satisfaction
27.1 Priority scheduling	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.2 Flexible scheduling	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.3 Special scholarships	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.4 Assistance in obtaining a job on campus	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.5 Ability to take lighter than average course load without losing benefits of full-time student - one time	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.6 Ability to take lighter than average course load without losing benefits of full-time student - many times	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.7 University handicapped parking permits granted	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.8 Peer tutoring on campus	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.9 Peer tutoring off campus	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.10 Faculty tutoring on campus	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.11 Faculty tutoring off campus	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.12 Faculty approved extensions on deadlines	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.13 Early access to course syllabi / assignments / books	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.14 Access to refrigerators	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.15 Ability to take breaks during class	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A

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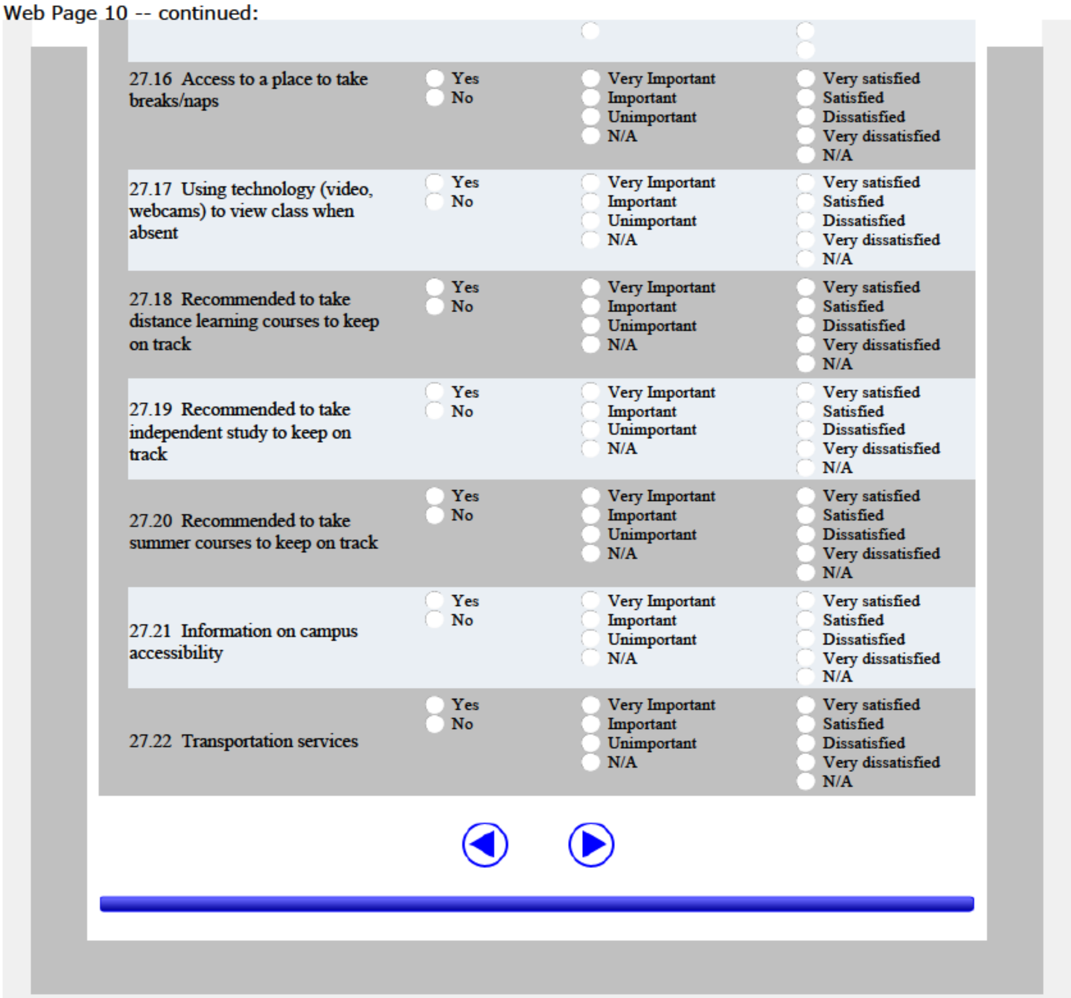

		○	○ ○
27.16 Access to a place to take breaks/naps	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.17 Using technology (video, webcams) to view class when absent	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.18 Recommended to take distance learning courses to keep on track	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.19 Recommended to take independent study to keep on track	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.20 Recommended to take summer courses to keep on track	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.21 Information on campus accessibility	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
27.22 Transportation services	○ Yes ○ No	○ Very Important ○ Important ○ Unimportant ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A

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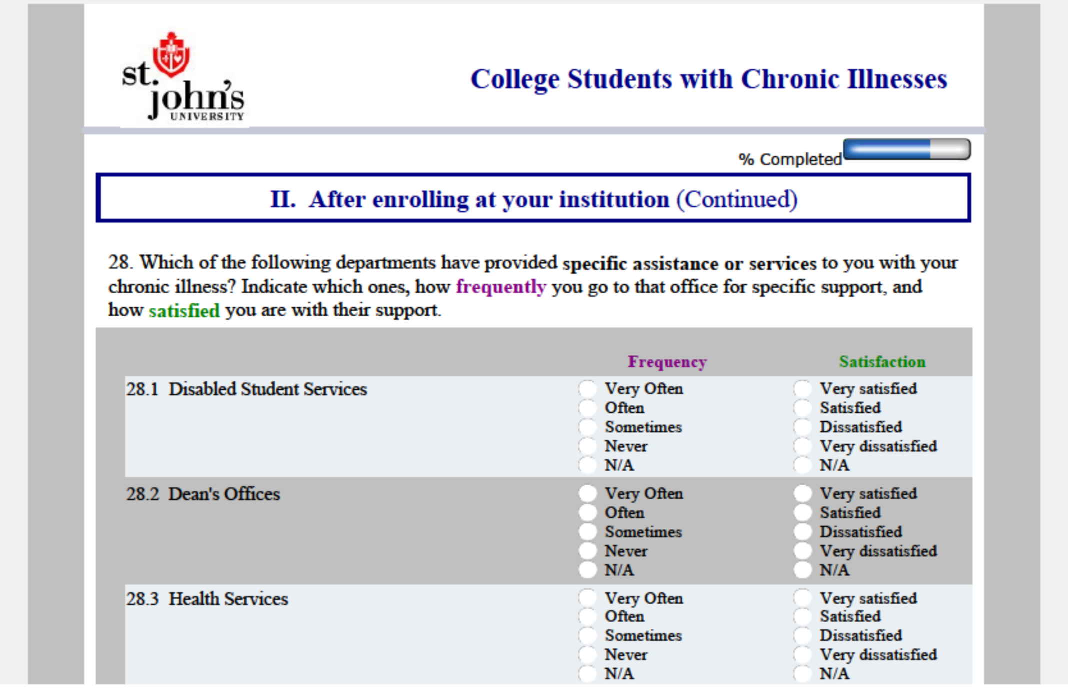

College Students with Chronic Illnesses

% Completed

II. After enrolling at your institution (Continued)

28. Which of the following departments have provided **specific assistance or services** to you with your chronic illness? Indicate which ones, how **frequently** you go to that office for specific support, and how **satisfied** you are with their support.

	Frequency	Satisfaction
28.1 Disabled Student Services	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.2 Dean's Offices	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.3 Health Services	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A

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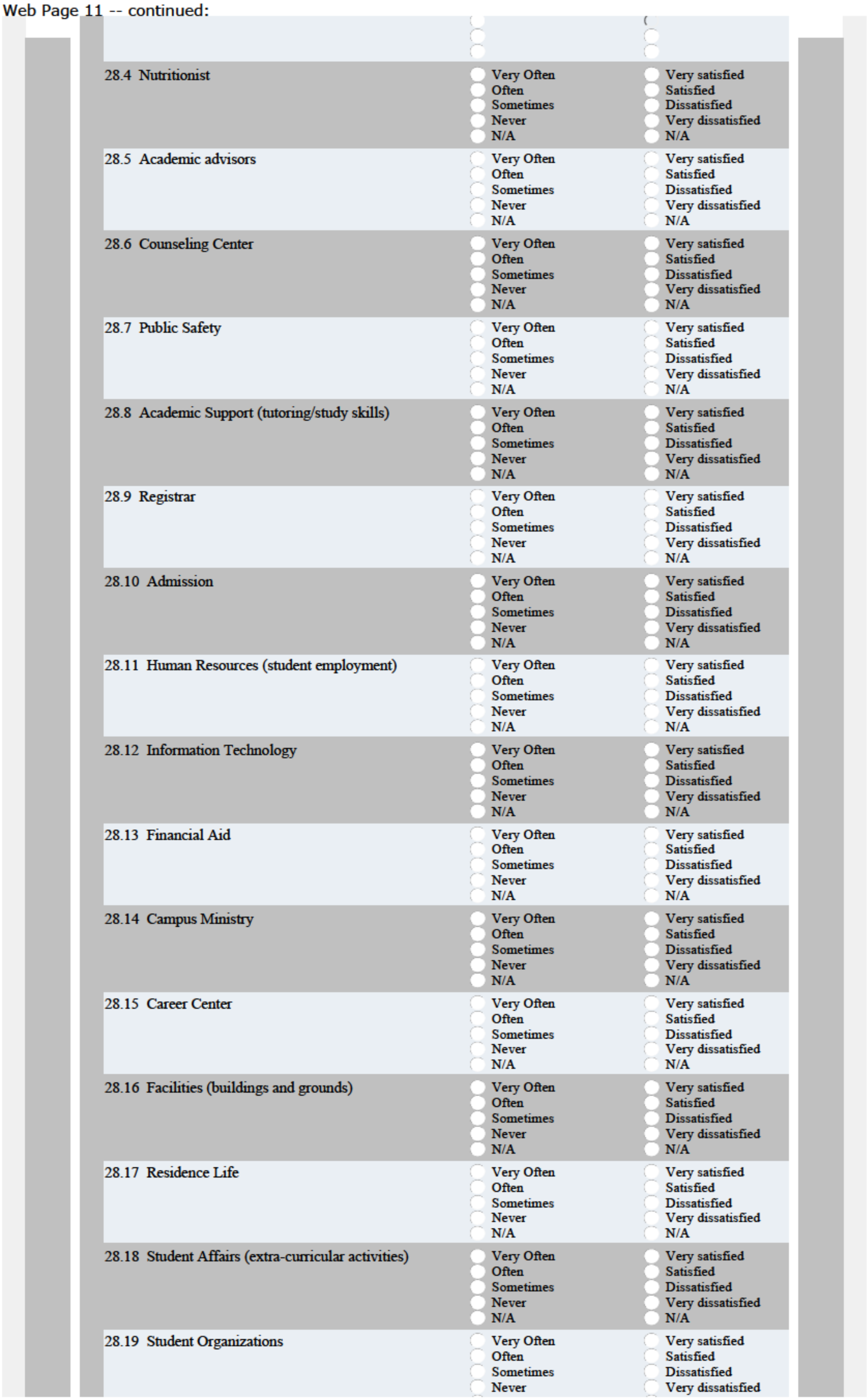

	○ ○ ○	○ ○ ○
28.4 Nutritionist	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.5 Academic advisors	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.6 Counseling Center	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.7 Public Safety	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.8 Academic Support (tutoring/study skills)	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.9 Registrar	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.10 Admission	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.11 Human Resources (student employment)	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.12 Information Technology	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.13 Financial Aid	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.14 Campus Ministry	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.15 Career Center	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.16 Facilities (buildings and grounds)	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.17 Residence Life	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.18 Student Affairs (extra-curricular activities)	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.19 Student Organizations	○ Very Often ○ Often ○ Sometimes ○ Never	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied

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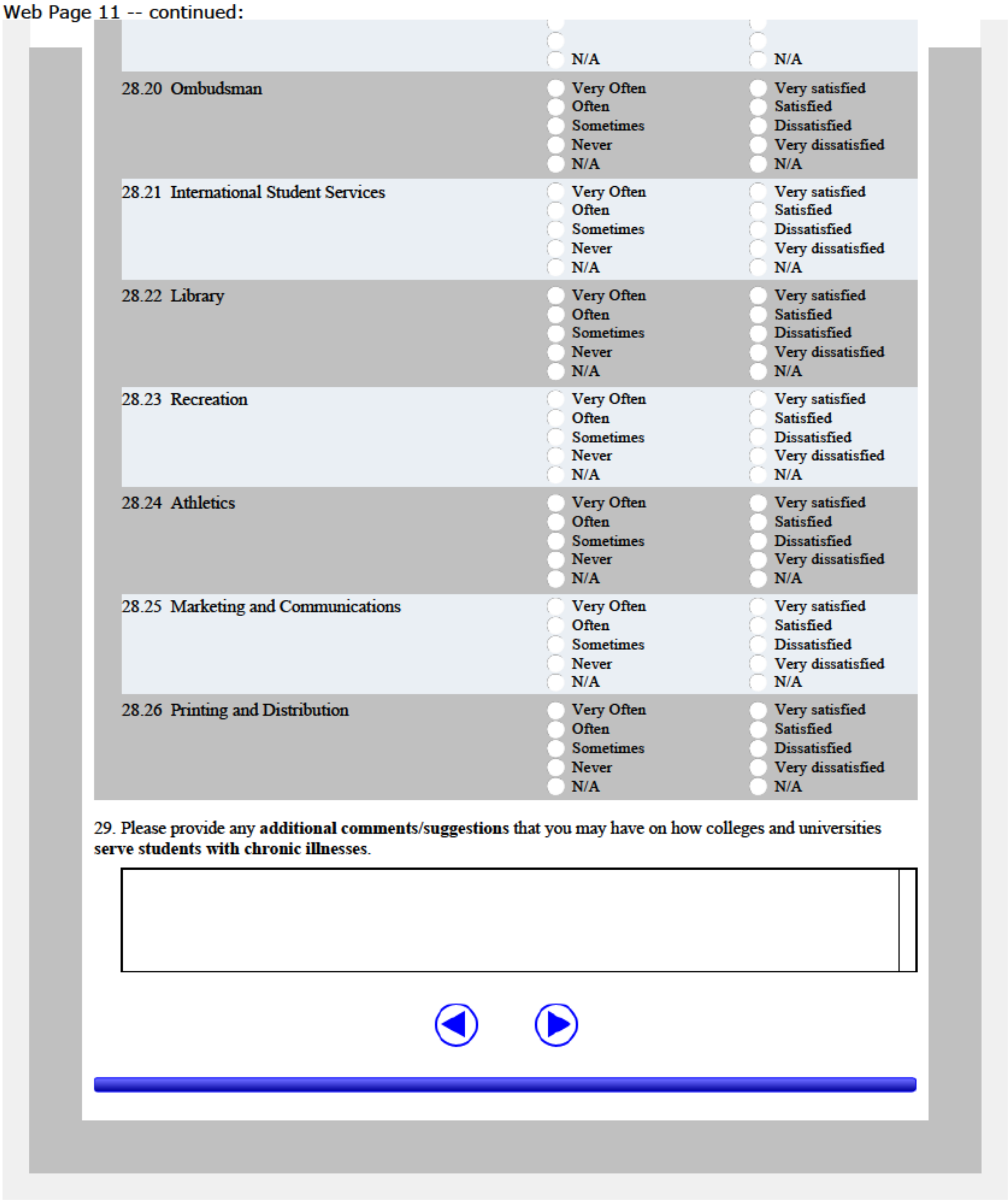
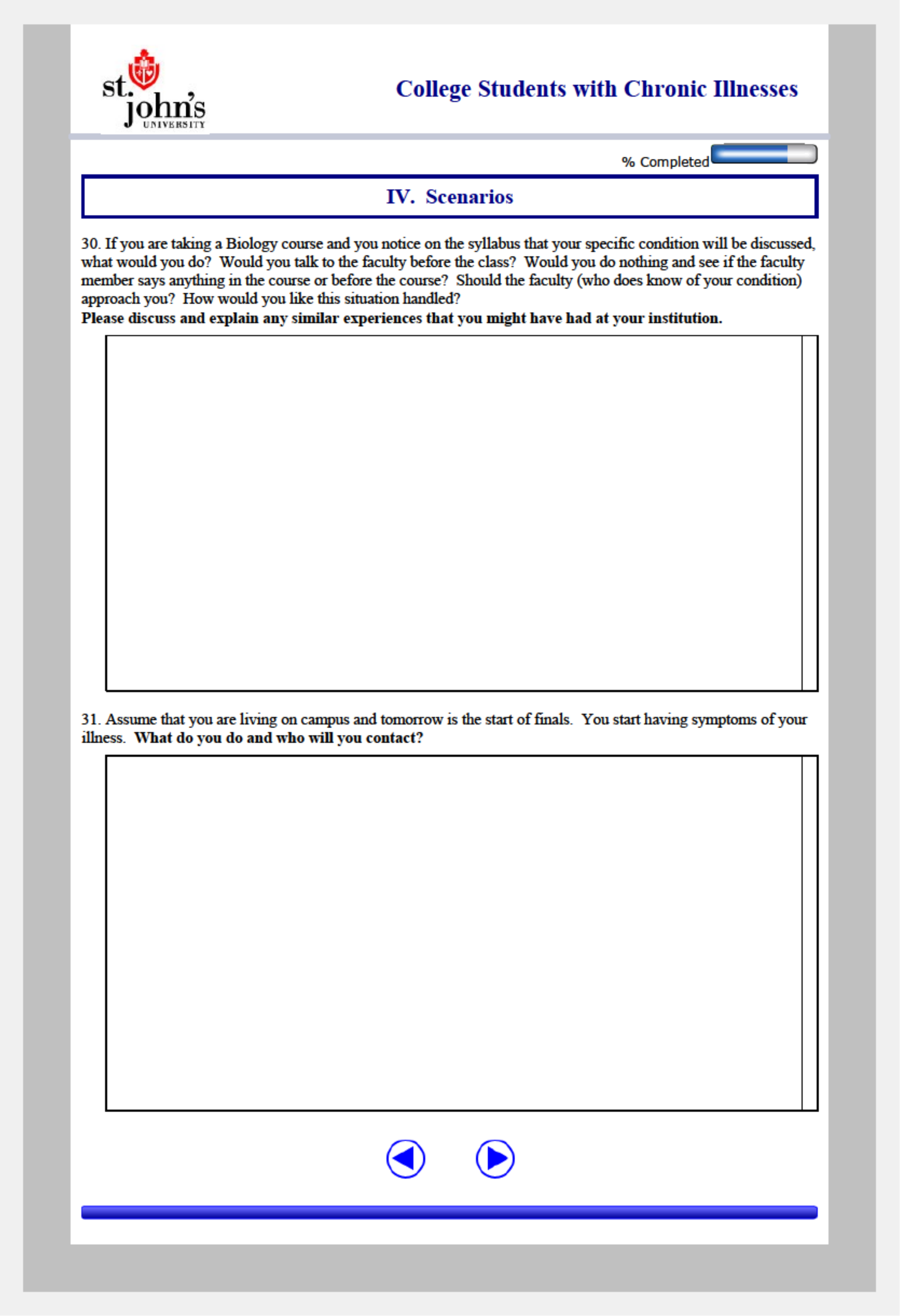


	○ N/A	○ N/A
28.20 Ombudsman	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.21 International Student Services	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.22 Library	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.23 Recreation	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.24 Athletics	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.25 Marketing and Communications	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A
28.26 Printing and Distribution	○ Very Often ○ Often ○ Sometimes ○ Never ○ N/A	○ Very satisfied ○ Satisfied ○ Dissatisfied ○ Very dissatisfied ○ N/A

29. Please provide any **additional comments/suggestions** that you may have on how colleges and universities **serve students with chronic illnesses**.

Web Page 12:



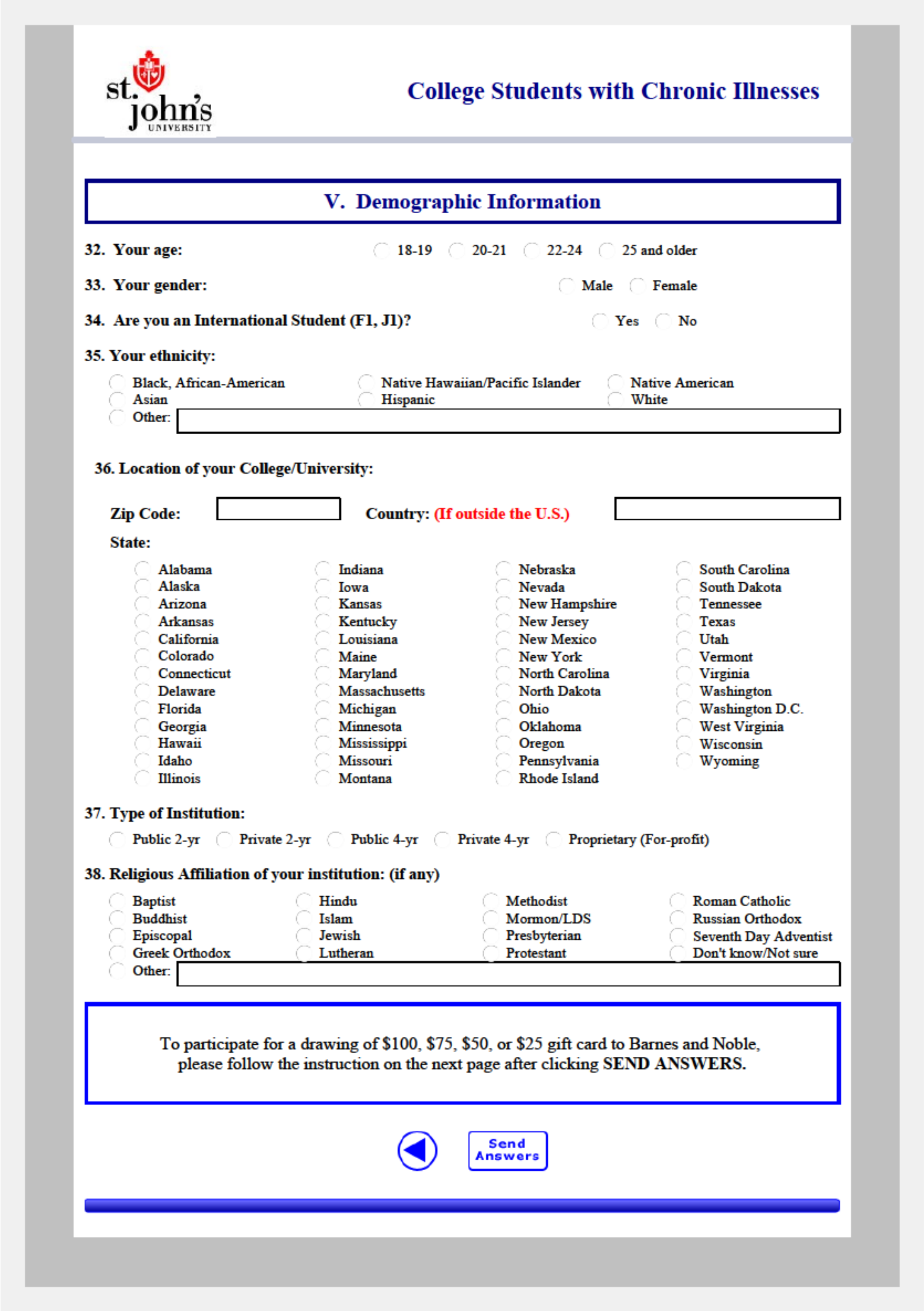
College Students with Chronic Illnesses

IV. Scenarios

30. If you are taking a Biology course and you notice on the syllabus that your specific condition will be discussed, what would you do? Would you talk to the faculty before the class? Would you do nothing and see if the faculty member says anything in the course or before the course? Should the faculty (who does know of your condition) approach you? How would you like this situation handled?
Please discuss and explain any similar experiences that you might have had at your institution.

31. Assume that you are living on campus and tomorrow is the start of finals. You start having symptoms of your illness. **What do you do and who will you contact?**

Web Page 13 Send Answers:



College Students with Chronic Illnesses

V. Demographic Information

32. Your age: ○ 18-19 ○ 20-21 ○ 22-24 ○ 25 and older

33. Your gender: ○ Male ○ Female

34. Are you an International Student (F1, J1)? ○ Yes ○ No

35. Your ethnicity:

- ○ Black, African-American
- ○ Asian
- ○ Other: ________
- ○ Native Hawaiian/Pacific Islander
- ○ Hispanic
- ○ Native American
- ○ White

36. Location of your College/University:

Zip Code: ________ **Country:** **(If outside the U.S.)** ________

State:

- ○ Alabama
- ○ Alaska
- ○ Arizona
- ○ Arkansas
- ○ California
- ○ Colorado
- ○ Connecticut
- ○ Delaware
- ○ Florida
- ○ Georgia
- ○ Hawaii
- ○ Idaho
- ○ Illinois
- ○ Indiana
- ○ Iowa
- ○ Kansas
- ○ Kentucky
- ○ Louisiana
- ○ Maine
- ○ Maryland
- ○ Massachusetts
- ○ Michigan
- ○ Minnesota
- ○ Mississippi
- ○ Missouri
- ○ Montana
- ○ Nebraska
- ○ Nevada
- ○ New Hampshire
- ○ New Jersey
- ○ New Mexico
- ○ New York
- ○ North Carolina
- ○ North Dakota
- ○ Ohio
- ○ Oklahoma
- ○ Oregon
- ○ Pennsylvania
- ○ Rhode Island
- ○ South Carolina
- ○ South Dakota
- ○ Tennessee
- ○ Texas
- ○ Utah
- ○ Vermont
- ○ Virginia
- ○ Washington
- ○ Washington D.C.
- ○ West Virginia
- ○ Wisconsin
- ○ Wyoming

37. Type of Institution:

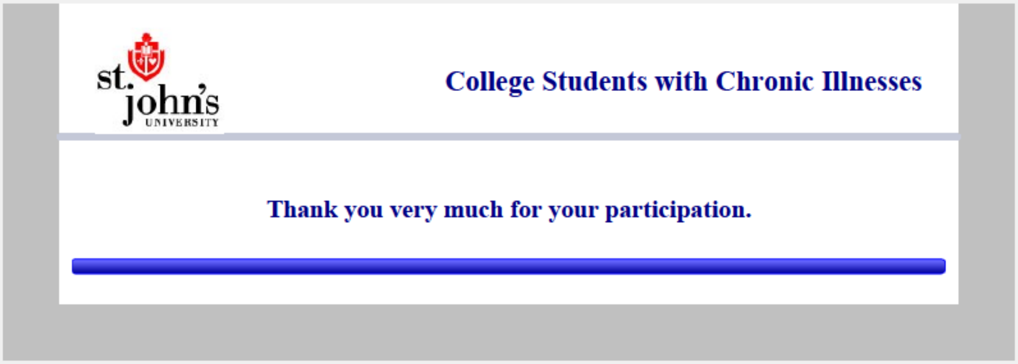
○ Public 2-yr ○ Private 2-yr ○ Public 4-yr ○ Private 4-yr ○ Proprietary (For-profit)

38. Religious Affiliation of your institution: (if any)

- ○ Baptist
- ○ Buddhist
- ○ Episcopal
- ○ Greek Orthodox
- ○ Other: ________
- ○ Hindu
- ○ Islam
- ○ Jewish
- ○ Lutheran
- ○ Methodist
- ○ Mormon/LDS
- ○ Presbyterian
- ○ Protestant
- ○ Roman Catholic
- ○ Russian Orthodox
- ○ Seventh Day Adventist
- ○ Don't know/Not sure

To participate for a drawing of $100, $75, $50, or $25 gift card to Barnes and Noble, please follow the instruction on the next page after clicking **SEND ANSWERS.**

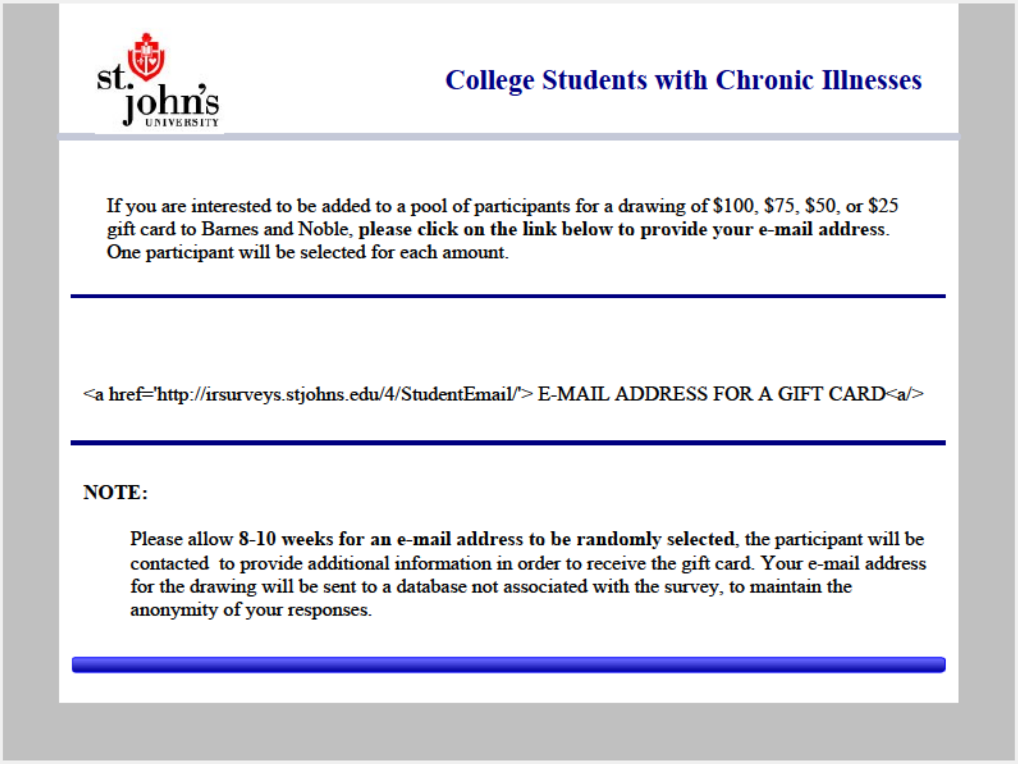
Web Page 14 Thanks:



College Students with Chronic Illnesses

Thank you very much for your participation.

Web Page 15 E-Mail:



College Students with Chronic Illnesses

If you are interested to be added to a pool of participants for a drawing of $100, $75, $50, or $25 gift card to Barnes and Noble, **please click on the link below to provide your e-mail address**. One participant will be selected for each amount.

<a href='http://irsurveys.stjohns.edu/4/StudentEmail/'> E-MAIL ADDRESS FOR A GIFT CARD<a/>

NOTE:

Please allow **8-10 weeks for an e-mail address to be randomly selected**, the participant will be contacted to provide additional information in order to receive the gift card. Your e-mail address for the drawing will be sent to a database not associated with the survey, to maintain the anonymity of your responses.

APPENDIX E:

Sample of Promotional Postcard and Flyer

Student Version

Do you have a Chronic Illness?

If so, your assistance is needed in a very important research study of how college students with chronic illnesses are served by colleges and universities. Your opinions are vital in discovering how you are being served. All responses will be totally anonymous. The survey should not take more than 25 minutes to complete. Please go to **http://irsurveys.stjohns.edu/4/GoodwinStudent/** to complete this survey.

Once you have completed the survey, you will have the opportunity to submit your name for a drawing for a $100, $75, $50, or $25 gift card to Barnes and Noble.

Thank you very much for your willingness to participate in this research!

For the purpose of this study, ***Chronic Illnesses*** refer to one that affect the individual for at least three months and are likely to continue in the future. Examples include, but are not limited to Arthritis, Asthma, Cancer, Chronic Fatigue Syndrome, Celiac Disease, Crohn's Disease, Cystic Fibrosis, Diabetes, Epilepsy, Heart Disease, HIV/AIDS, Kidney Disease, Liver Disease, Lupus, Lyme Disease, Migraines, Muscular Disorders, Multiple Sclerosis, Neurological Disorders, Osteoporosis, Organ Transplant, Oxygen Impairment, Parkinson's Disease, Seizure Disorder, Sickle Cell Anemia, and Spina Bifida.

Thank you!!

My name is Christine Goodwin. I understand how hard it is to balance living with a chronic illness with college, life, and family. I was diagnosed with Kidney Disease when I was 15 and received a Kidney Transplant eight months later. I am pursuing my doctoral degree at St. John's University and am researching how colleges and universities are serving students with chronic illness. The data collected from these surveys will be used for the completion of my doctoral dissertation at St. John's University-NY, and then will be shared with the Association on Higher Education and Disability (AHEAD) to inform college administrators on how best to serve students with chronic illnesses. Again, thank you very much for your time and support. I wish you good health and the best in completing your studies.

If you have any questions, please contact me at:
Phone: (718) 990-1993
E-mail: goodwinc@stjohns.edu

Administrator Version

I Need Your Help!

I am a doctoral candidate and would like your assistance with my research. I am conducting a study on how colleges and universities serve students with chronic illnesses. I am inviting you to participate in a survey regarding the policies, procedures and services your institution has for students with chronic illnesses. Although participation in this study is voluntary, your *input is vital* to make this study successful. Your responses will be totally anonymous. The survey should take approximately 25 minutes to complete.

Please go to

http://irsurveys.stjohns.edu/4/GoodwinInstitution/

to complete the survey.

Thank you.

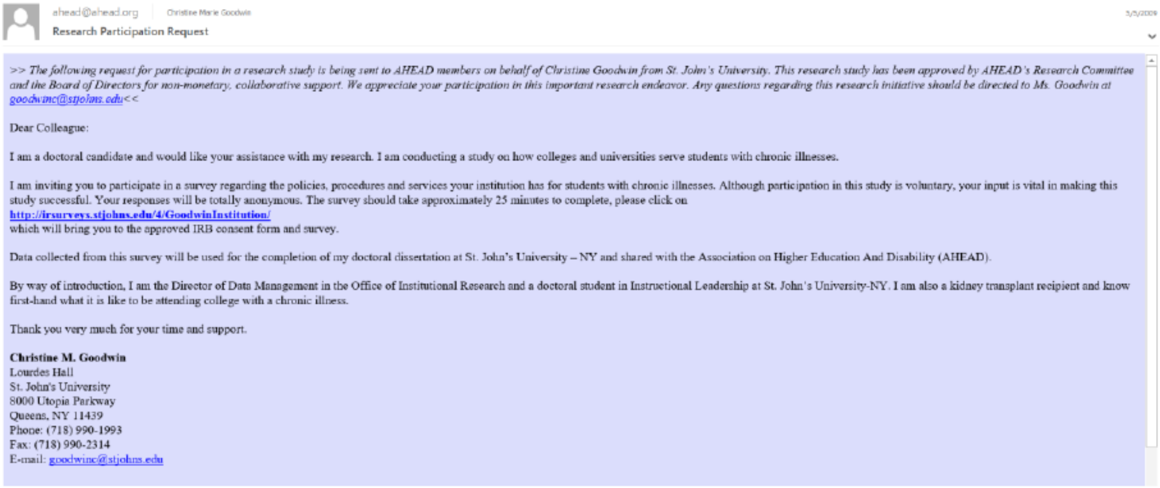
Thank you!!

My name is Christine Goodwin. I understand how hard it is to balance living with a chronic illness with college, life, and family. I was diagnosed with Kidney Disease when I was 15 and received a Kidney Transplant eight months later. I am pursuing my doctoral degree at St. John's University and am researching how colleges and universities are serving students with chronic illness. The data collected from these surveys will be used for the completion of my doctoral dissertation at St. John's University-NY, and then will be shared with the Association on Higher Education and Disability (AHEAD) to inform college administrators on how best to serve students with chronic illnesses.

Thank you very much for your time and support.

APPENDIX F:

Sample E-mail to Administrators through AHEAD



ahead@ahead.org | Christine Marie Goodwin

5/5/2009

Research Participation Request

>> The following request for participation in a research study is being sent to AHEAD members on behalf of Christine Goodwin from St. John's University. This research study has been approved by AHEAD's Research Committee and the Board of Directors for non-monetary, collaborative support. We appreciate your participation in this important research endeavor. Any questions regarding this research initiative should be directed to Ms. Goodwin at goodwinc@stjohns.edu<<

Dear Colleague:

I am a doctoral candidate and would like your assistance with my research. I am conducting a study on how colleges and universities serve students with chronic illnesses.

I am inviting you to participate in a survey regarding the policies, procedures and services your institution has for students with chronic illnesses. Although participation in this study is voluntary, your input is vital in making this study successful. Your responses will be totally anonymous. The survey should take approximately 25 minutes to complete, please click on
http://irsurveys.stjohns.edu/4/GoodwinInstitution/
which will bring you to the approved IRB consent form and survey.

Data collected from this survey will be used for the completion of my doctoral dissertation at St. John's University – NY and shared with the Association on Higher Education And Disability (AHEAD).

By way of introduction, I am the Director of Data Management in the Office of Institutional Research and a doctoral student in Instructional Leadership at St. John's University-NY. I am also a kidney transplant recipient and know first-hand what it is like to be attending college with a chronic illness.

Thank you very much for your time and support.

Christine M. Goodwin
Lourdes Hall
St. John's University
8000 Utopia Parkway
Queens, NY 11439
Phone: (718) 990-1993
Fax: (718) 990-2314
E-mail: goodwinc@stjohns.edu

APPENDIX G:

Sample E-mail to Students

I am a kidney transplant recipient and am going for my Doctorate in Education at St. John's University in NY. My topic is how colleges/universities serve students with chronic illnesses. I understand how hard it is to balance living with a chronic illness with college, life, and family. I was diagnosed with kidney disease when I was 15 and subsequently received a transplant.

I need your assistance. I am looking for college-aged students (18 years of age in undergraduate or graduate/law school) with a chronic illness(es) to complete a survey where they can share their experiences of going to college or graduate/law school with a chronic illness. As you can understand, it is very important to obtain this information. Please note that my survey is completely anonymous and has been approved by the Institutional Review Board at St. John's University-NY. The data from this survey will be used for the completion of my doctoral dissertation as well as then shared with the Association on Higher Education and Disability (AHEAD) to inform college administrators on how best to serve students with chronic illnesses.

If you meet these criteria, I would greatly appreciate it if you would click on the link below and complete the survey by July 1, 2009. Every response counts!
http://irsurveys.stjohns.edu/4/GoodwinStudent/

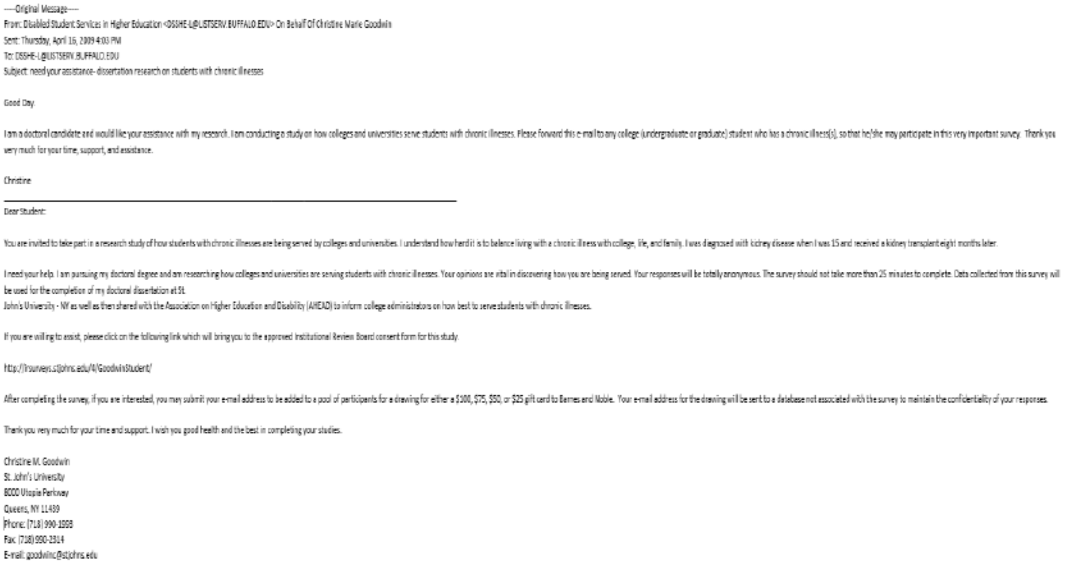
Even if you do not fit the above criteria, but know of someone who fits the above criteria, I would ask that you forward this to them.

After completing the survey, if interested, the participant may submit their e-mail address to be added to a pool of participants for a drawing for a Barnes and Noble gift card. The e-mail address for the drawing will be sent to a database not associated with the survey to maintain the confidentiality of the responses.

Thank you very much.
Christine

APPENDIX H:

E-mail to Administrators to invite students to participate in the Student Survey



-----Original Message-----
From: Disabled Student Services in Higher Education <DSSHE-L@LISTSERV.BUFFALO.EDU> On Behalf Of Christine Marie Goodwin
Sent: Thursday, April 16, 2009 4:03 PM
To: DSSHE-L@LISTSERV.BUFFALO.EDU
Subject: need your assistance- dissertation research on students with chronic illnesses

Good Day:

I am a doctoral candidate and would like your assistance with my research. I am conducting a study on how colleges and universities serve students with chronic illnesses. Please forward this e-mail to any college (undergraduate or graduate) student who has a chronic illness(s), so that he/she may participate in this very important survey. Thank you very much for your time, support, and assistance.

Christine

Dear Student:

You are invited to take part in a research study of how students with chronic illnesses are being served by colleges and universities. I understand how hard it is to balance living with a chronic illness with college, life, and family. I was diagnosed with kidney disease when I was 15 and received a kidney transplant eight months later.

I need your help. I am pursuing my doctoral degree and am researching how colleges and universities are serving students with chronic illnesses. Your opinions are vital in discovering how you are being served. Your responses will be totally anonymous. The survey should not take more than 25 minutes to complete. Data collected from this survey will be used for the completion of my doctoral dissertation at St.
John's University - NY as well as then shared with the Association on Higher Education and Disability (AHEAD) to inform college administrators on how best to serve students with chronic illnesses.

If you are willing to assist, please click on the following link which will bring you to the approved Institutional Review Board consent form for this study.

http://lrsurveys.stjohns.edu/4/GoodwinStudent/

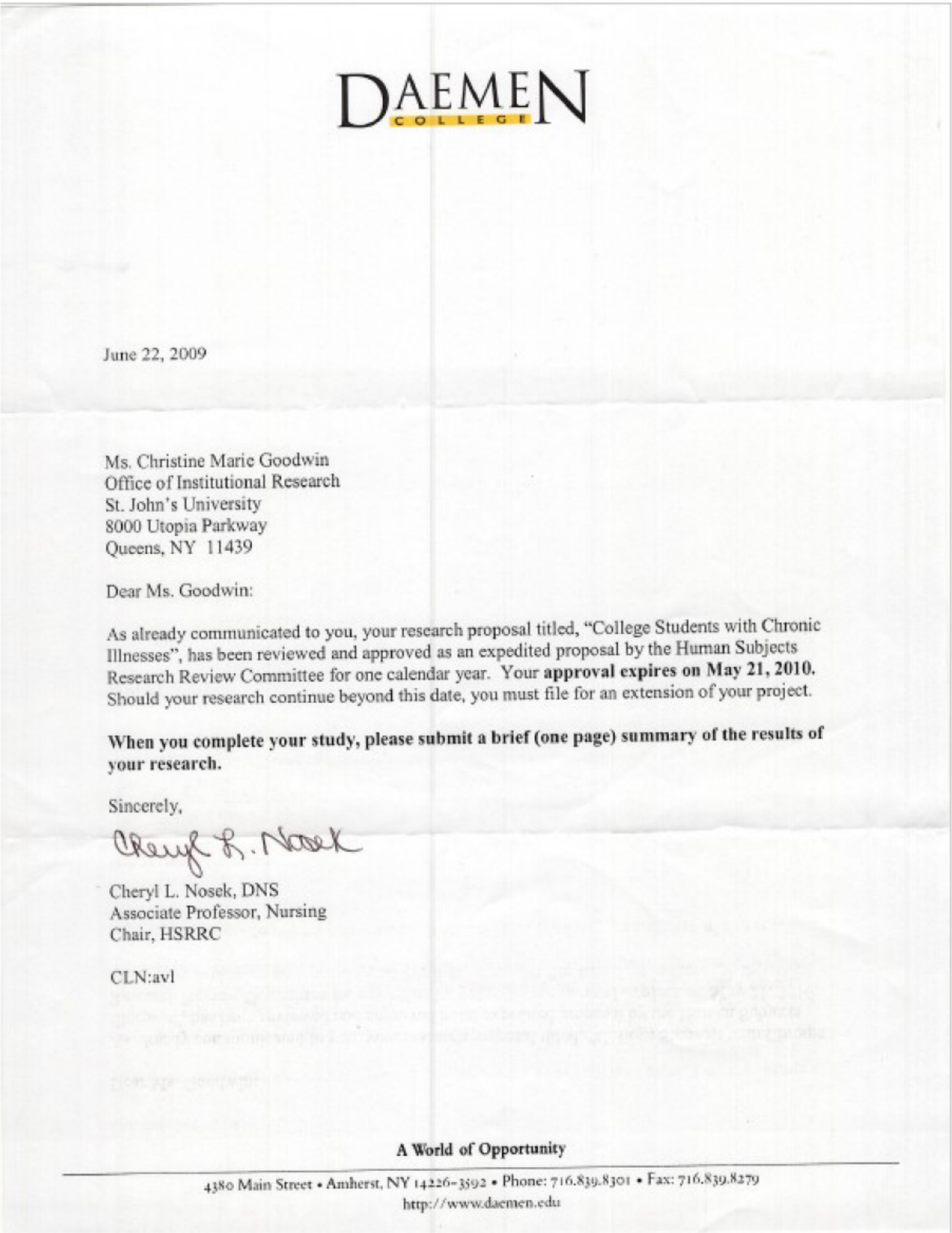
After completing the survey, if you are interested, you may submit your e-mail address to be added to a pool of participants for a drawing for either a $100, $75, $50, or $25 gift card to Barnes and Noble. Your e-mail address for the drawing will be sent to a database not associated with the survey to maintain the confidentiality of your responses.

Thank you very much for your time and support. I wish you good health and the best in completing your studies.

Christine M. Goodwin
St. John's University
8000 Utopia Parkway
Queens, NY 11439
Phone: (718) 990-1998
Fax: (718) 990-2314
E-mail: goodwinc@stjohns.edu

APPENDIX I:

Approval of Institutional Review Board at Daemen College



DAEMEN
COLLEGE

June 22, 2009

Ms. Christine Marie Goodwin
Office of Institutional Research
St. John's University
8000 Utopia Parkway
Queens, NY 11439

Dear Ms. Goodwin:

As already communicated to you, your research proposal titled, "College Students with Chronic Illnesses", has been reviewed and approved as an expedited proposal by the Human Subjects Research Review Committee for one calendar year. Your **approval expires on May 21, 2010.** Should your research continue beyond this date, you must file for an extension of your project.

When you complete your study, please submit a brief (one page) summary of the results of your research.

Sincerely,

Cheryl L. Nosek

Cheryl L. Nosek, DNS
Associate Professor, Nursing
Chair, HSRRC

CLN:avl

A World of Opportunity

4380 Main Street • Amherst, NY 14226-3592 • Phone: 716.839.8301 • Fax: 716.839.8279
http://www.daemen.edu

APPENDIX J:

Distribution of Institutional and Student Responses used within this Research

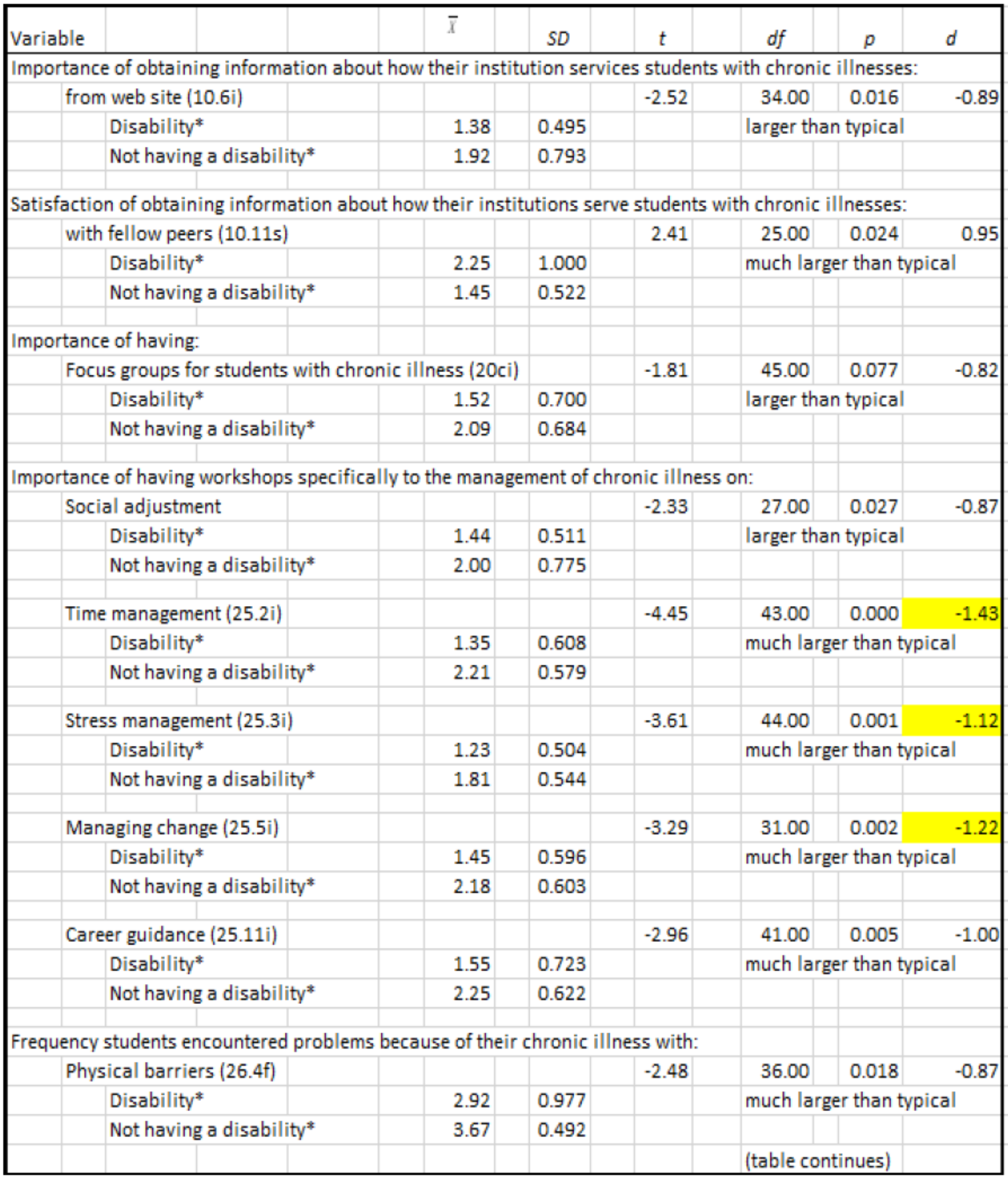
Response									
#	I	S	v	I	S	#	I	#	I
1			38	1		74	1	109	
2	1		39			75	1	110	2
3			40	1		76	1	111	
4			41	4		77	1	112	1
5			42	1	1	78	2	113	
6		1	43	1		79	5	114	2
7	3	1	44		3	80	1	115	2
8		1	45	2		81		116	1
9			46	3		82	3	117	1
10	1		47	6		83	2	118	
11	1		48	2		84	1	119	
12			49	3	1	85	1	120	1
13	1		50	2		86	3	121	1
14	3	1	51	2		87		122	
15	2		52			88	1	123	1
16		1	53			89		124	
17			54	7	1	90	1	125	3
18		1	55	1	1	91		126	
19			56	1		92	3	127	1
20	1		57			93	np	128	1
21	1	1	58		1	94		129	2
22	3	1	59	1	1	95		130	
23	2		60			96	1	131	2
24	3		61	2		97		132	1
25	2		62	1		98		133	7
26	1		63			99	1	134	1
27	2		64	1		100	np	135	
28	3	1	65			101		136	1
29	1	2	66	1		102	2	137	1
30			67	1		103		138	1
31		1	68		1	104			
32	3		69			105	4		
33	1		70		1	106	1		
34		1	71	3	1	107	4		
35			72	1	1	108	1		
36	1		73	1	1				
37	3								

Note. np represents respondents that did not fully participate in the survey.

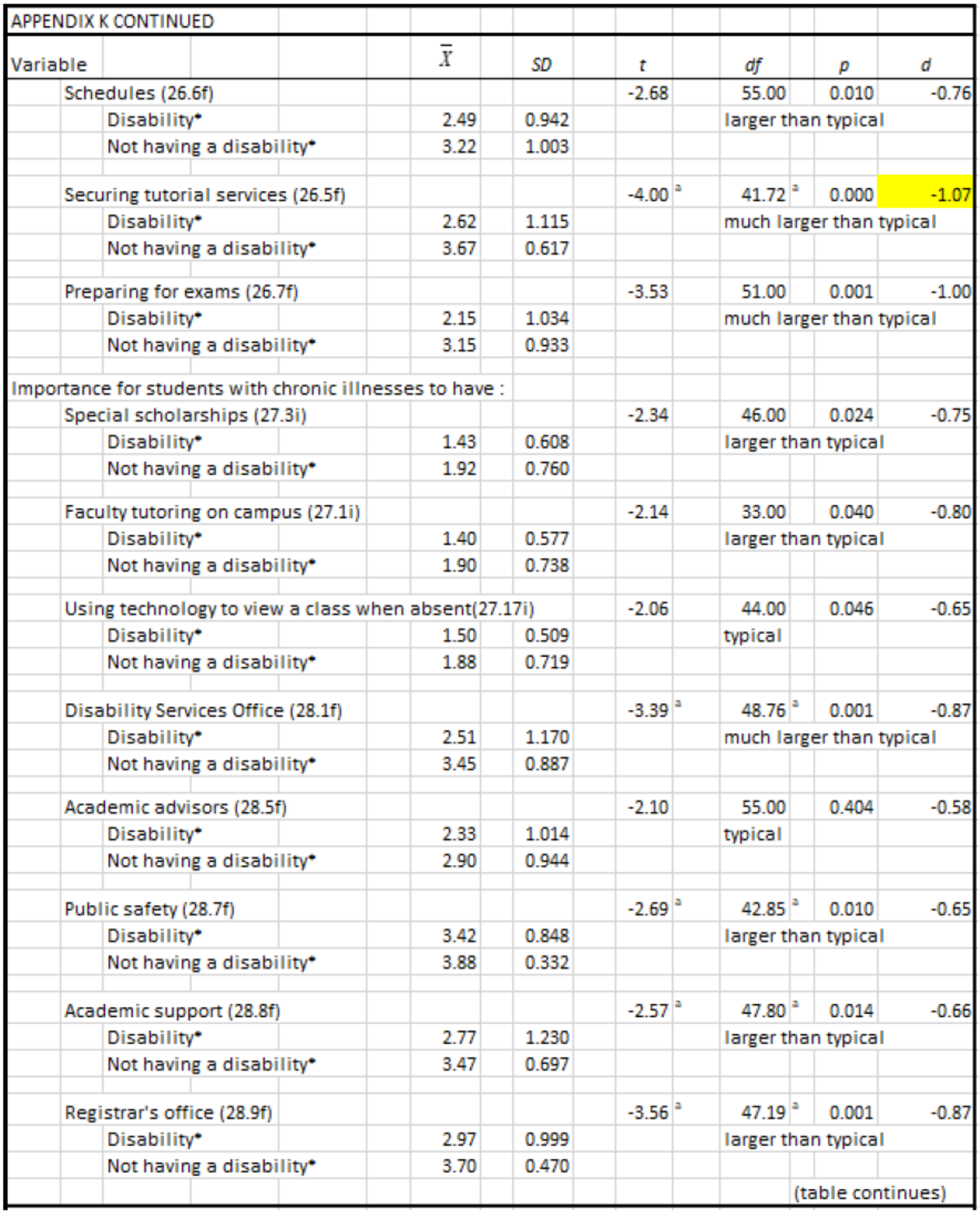
Student Surveys(S) are numbered from 1 to 73, and Institutional Surveys (I) are numbered from 1 to 138.

APPENDIX K:

Significant differences in t-test between responses of those who consider themselves as having a disability with those who do not



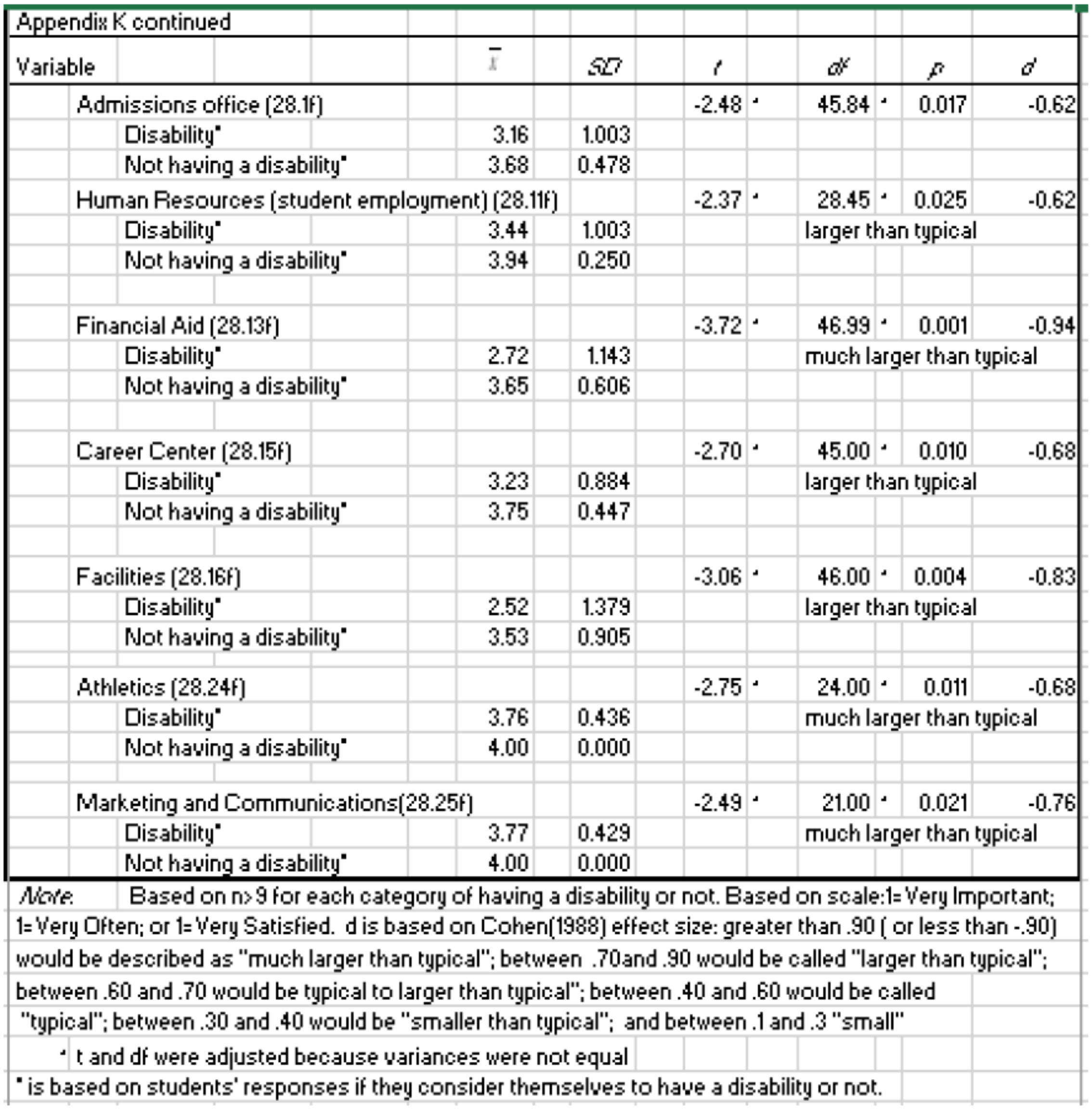
Variable	$\bar{X}$	*SD*	*t*	*df*	*p*	*d*
Importance of obtaining information about how their institution services students with chronic illnesses:						
from web site (10.6i)			-2.52	34.00	0.016	-0.89
Disability*	1.38	0.495		larger than typical		
Not having a disability*	1.92	0.793				
Satisfaction of obtaining information about how their institutions serve students with chronic illnesses:						
with fellow peers (10.11s)			2.41	25.00	0.024	0.95
Disability*	2.25	1.000		much larger than typical		
Not having a disability*	1.45	0.522				
Importance of having:						
Focus groups for students with chronic illness (20ci)			-1.81	45.00	0.077	-0.82
Disability*	1.52	0.700		larger than typical		
Not having a disability*	2.09	0.684				
Importance of having workshops specifically to the management of chronic illness on:						
Social adjustment			-2.33	27.00	0.027	-0.87
Disability*	1.44	0.511		larger than typical		
Not having a disability*	2.00	0.775				
Time management (25.2i)			-4.45	43.00	0.000	-1.43
Disability*	1.35	0.608		much larger than typical		
Not having a disability*	2.21	0.579				
Stress management (25.3i)			-3.61	44.00	0.001	-1.12
Disability*	1.23	0.504		much larger than typical		
Not having a disability*	1.81	0.544				
Managing change (25.5i)			-3.29	31.00	0.002	-1.22
Disability*	1.45	0.596		much larger than typical		
Not having a disability*	2.18	0.603				
Career guidance (25.11i)			-2.96	41.00	0.005	-1.00
Disability*	1.55	0.723		much larger than typical		
Not having a disability*	2.25	0.622				
Frequency students encountered problems because of their chronic illness with:						
Physical barriers (26.4f)			-2.48	36.00	0.018	-0.87
Disability*	2.92	0.977		much larger than typical		
Not having a disability*	3.67	0.492				
				(table continues)		



APPENDIX K CONTINUED

Variable	$\bar{X}$	*SD*	*t*	*df*	*p*	*d*
Schedules (26.6f)			-2.68	55.00	0.010	-0.76
Disability*	2.49	0.942		larger than typical		
Not having a disability*	3.22	1.003				
Securing tutorial services (26.5f)			-4.00[a]	41.72[a]	0.000	-1.07
Disability*	2.62	1.115		much larger than typical		
Not having a disability*	3.67	0.617				
Preparing for exams (26.7f)			-3.53	51.00	0.001	-1.00
Disability*	2.15	1.034		much larger than typical		
Not having a disability*	3.15	0.933				
Importance for students with chronic illnesses to have :						
Special scholarships (27.3i)			-2.34	46.00	0.024	-0.75
Disability*	1.43	0.608		larger than typical		
Not having a disability*	1.92	0.760				
Faculty tutoring on campus (27.1i)			-2.14	33.00	0.040	-0.80
Disability*	1.40	0.577		larger than typical		
Not having a disability*	1.90	0.738				
Using technology to view a class when absent(27.17i)			-2.06	44.00	0.046	-0.65
Disability*	1.50	0.509		typical		
Not having a disability*	1.88	0.719				
Disability Services Office (28.1f)			-3.39[a]	48.76[a]	0.001	-0.87
Disability*	2.51	1.170		much larger than typical		
Not having a disability*	3.45	0.887				
Academic advisors (28.5f)			-2.10	55.00	0.404	-0.58
Disability*	2.33	1.014		typical		
Not having a disability*	2.90	0.944				
Public safety (28.7f)			-2.69[a]	42.85[a]	0.010	-0.65
Disability*	3.42	0.848		larger than typical		
Not having a disability*	3.88	0.332				
Academic support (28.8f)			-2.57[a]	47.80[a]	0.014	-0.66
Disability*	2.77	1.230		larger than typical		
Not having a disability*	3.47	0.697				
Registrar's office (28.9f)			-3.56[a]	47.19[a]	0.001	-0.87
Disability*	2.97	0.999		larger than typical		
Not having a disability*	3.70	0.470				

(table continues)



Appendix K continued

Variable	$\bar{x}$	*SD*	*t*	*df*	*p*	*d*
Admissions office (28.1f)			-2.48 [a]	45.84 [a]	0.017	-0.62
Disability[b]	3.16	1.003				
Not having a disability[b]	3.68	0.478				
Human Resources (student employment) (28.11f)			-2.37 [a]	28.45 [a]	0.025	-0.62
Disability[b]	3.44	1.003		larger than typical		
Not having a disability[b]	3.94	0.250				
Financial Aid (28.13f)			-3.72 [a]	46.99 [a]	0.001	-0.94
Disability[b]	2.72	1.143		much larger than typical		
Not having a disability[b]	3.65	0.606				
Career Center (28.15f)			-2.70 [a]	45.00 [a]	0.010	-0.68
Disability[b]	3.23	0.884		larger than typical		
Not having a disability[b]	3.75	0.447				
Facilities (28.16f)			-3.06 [a]	46.00 [a]	0.004	-0.83
Disability[b]	2.52	1.379		larger than typical		
Not having a disability[b]	3.53	0.905				
Athletics (28.24f)			-2.75 [a]	24.00 [a]	0.011	-0.68
Disability[b]	3.76	0.436		much larger than typical		
Not having a disability[b]	4.00	0.000				
Marketing and Communications(28.25f)			-2.49 [a]	21.00 [a]	0.021	-0.76
Disability[b]	3.77	0.429		much larger than typical		
Not having a disability[b]	4.00	0.000				

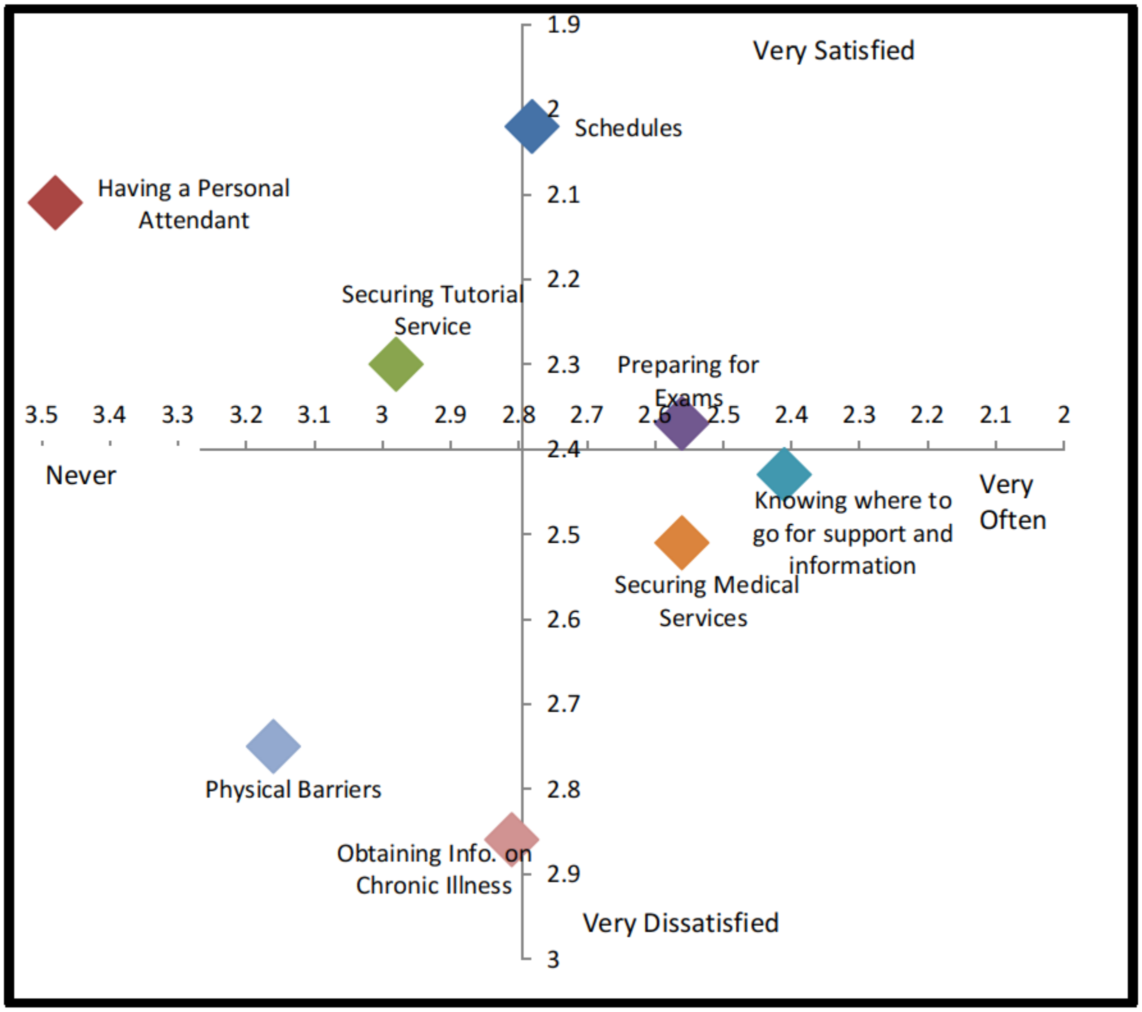
Note. Based on n>9 for each category of having a disability or not. Based on scale:1= Very Important; 1= Very Often; or 1= Very Satisfied. d is based on Cohen(1988) effect size: greater than .90 (or less than -.90) would be described as "much larger than typical"; between .70and .90 would be called "larger than typical"; between .60 and .70 would be typical to larger than typical"; between .40 and .60 would be called "typical"; between .30 and .40 would be "smaller than typical"; and between .1 and .3 "small"

[a] t and df were adjusted because variances were not equal

[b] is based on students' responses if they consider themselves to have a disability or not.

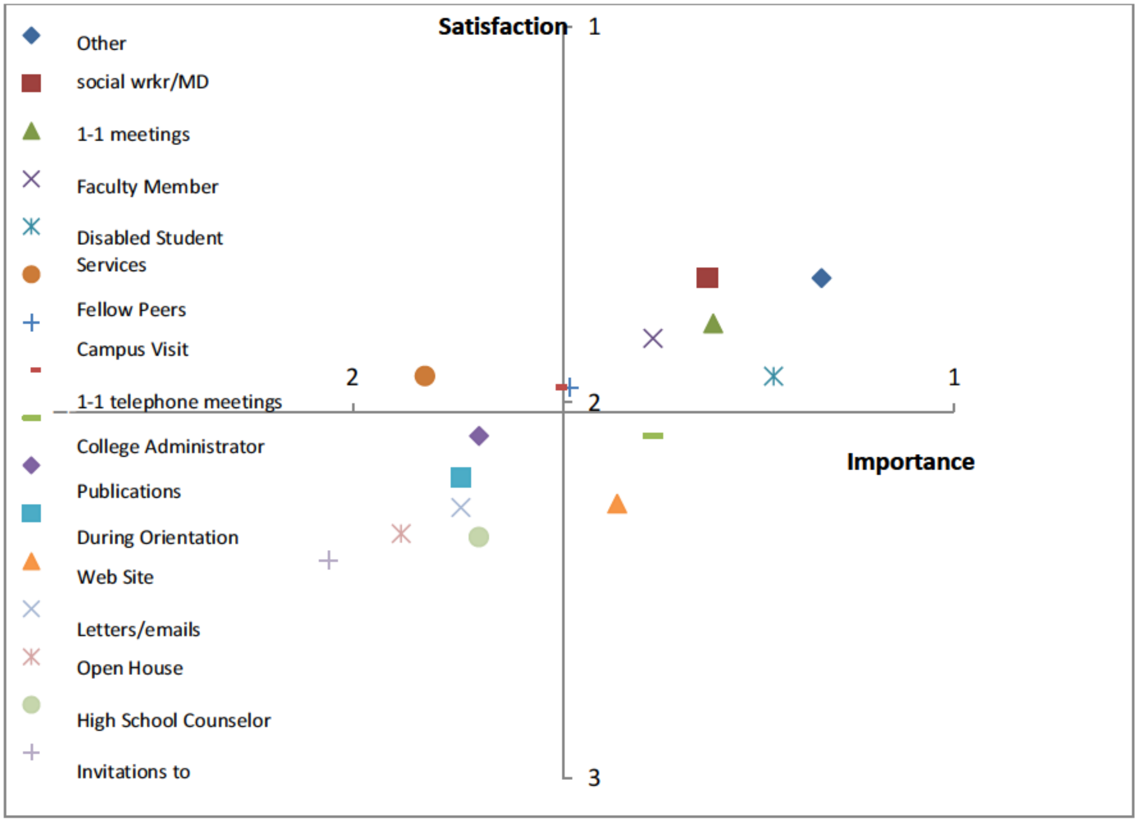
APPENDIX L:

Students' Satisfaction with the Frequency that They Encountered Issues



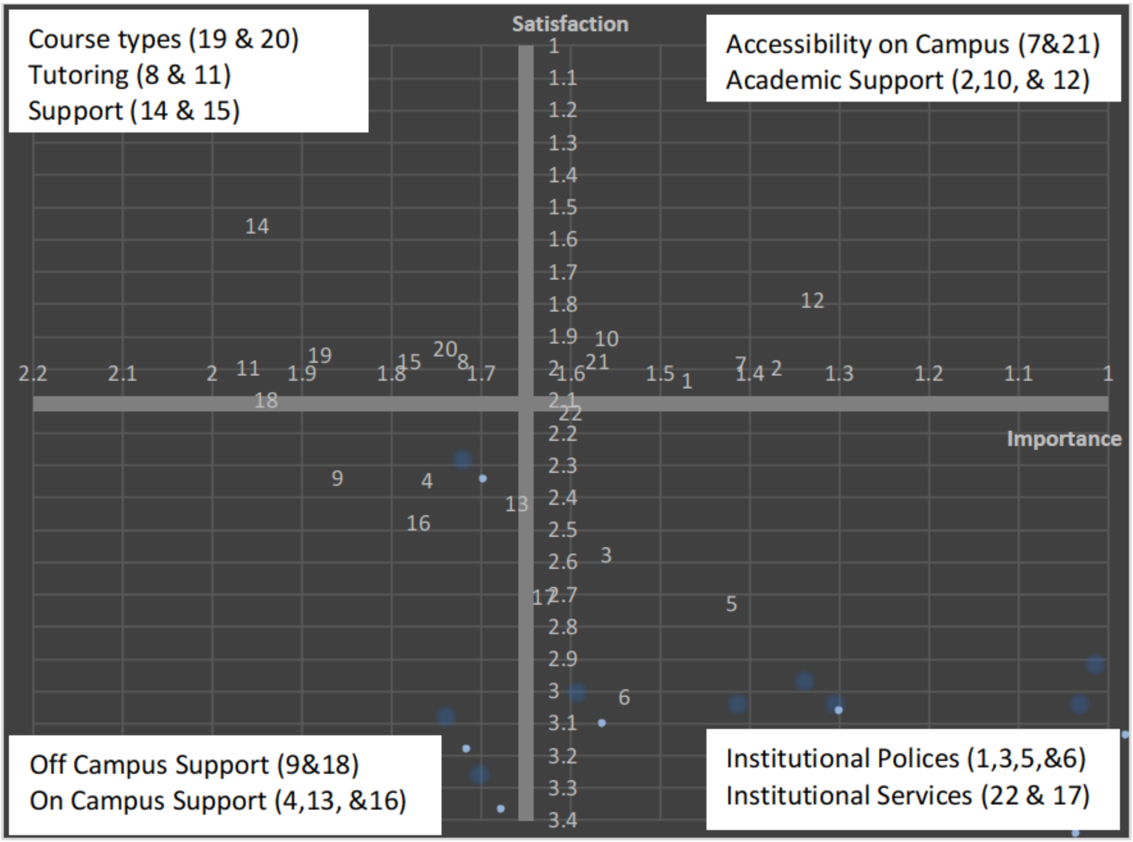
APPENDIX M:

The Importance and Satisfaction with Various Means of Students Obtaining Information on How Their Institution Serves SWCI



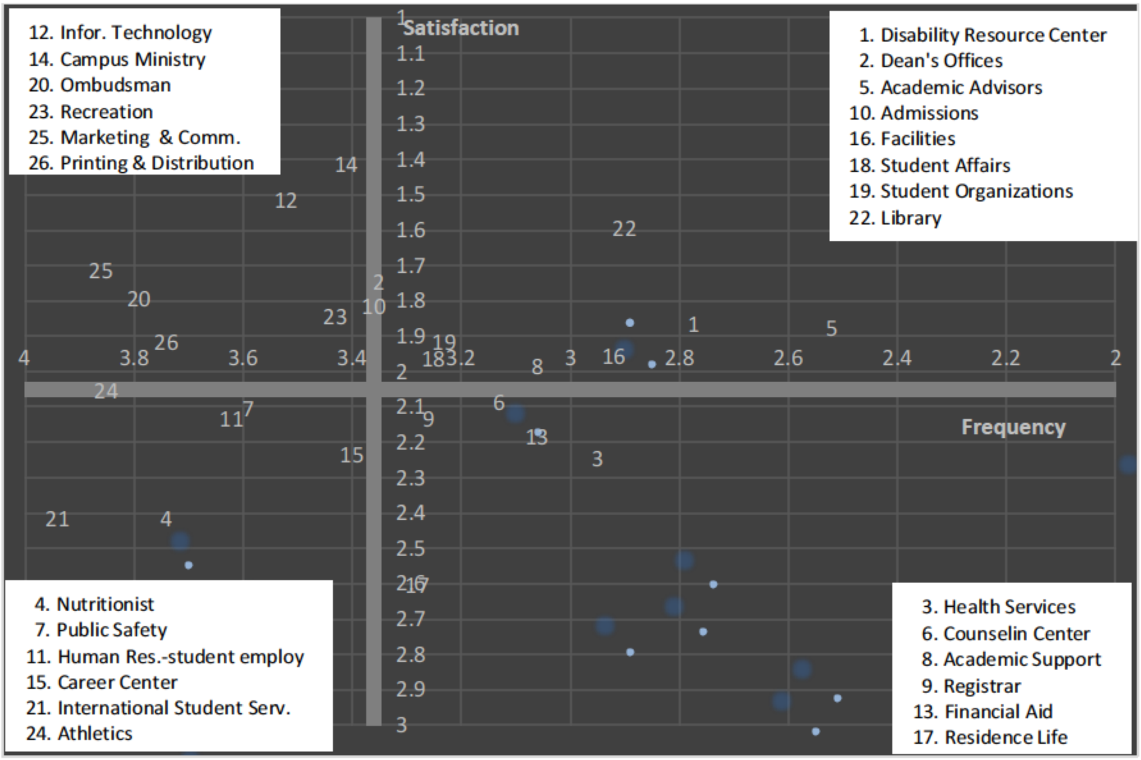
APPENDIX N:

The Importance and Satisfaction of SWCI of Various Institutional Services



APPENDIX O:

The Importance and Satisfaction of SWCI with Various Institutional Departments



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