

Postsecondary Physical Support Programs, Independent Living and Economic Self-Sufficiency for Individuals with Significant Physical Disabilities

By

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Abstract

This study explores the extent to which completion of an undergraduate degree that includes disability management course work contributes to independent living and economic self-sufficiency of graduates with severe physical disabilities. Observations of these graduates' independent living and economic self-sufficiency status at a single point in time after graduation are reported. Finally, recommendations for how disability service professionals can respond to these findings are offered. Conclusions suggest that current and future students will benefit from a paradigm shift that includes a critical examination to ensure that the student's postsecondary decision considers potential earning capacity after graduation is sufficient to cover the individual's cost of care while ensuring that the individual is in the best position to maintain a livable wage that is inclusive of disability-related costs. This requires an analysis beyond the typical evaluation of interests, strengths and abilities when disability service professionals are collaborating with an individual on developing an employment goal.

Acknowledgments

The idea for this study began as an outgrowth of my desire to share the unique aspects of a disability service model that utilizes a comprehensive approach to service delivery in higher education. Prior to coming to Auburn University to pursue my PhD in August 2008, I spent the previous eight years completing undergraduate and master's degrees at Wright State University (WSU) in Dayton, Ohio. WSU has a long tradition of providing a disability service program that not only fulfills obligations as required by federal law, but also has a disability management component that helps students with significant physical disabilities to gain the skills necessary to succeed at the university and beyond. It is from this perspective that I attempted to examine the benefits of the disability services approach so that other institutions may see the return on investment for a discretionary program that has the potential to open the arena of higher education and the primary labor market to individuals with significant disabilities.

Throughout the past eight years, several individuals have also believed in this research. First, I would like to thank the members of my doctoral committee, Rebecca S. Curtis, PhD (Chair), Marie F. Kraska, PhD, Caroline Dunn, PhD and LeeAnn Alderman, PhD. These dynamic individuals shared my belief in the need for research that explored these services that were beneficial for academically qualified students with high support needs. I am especially thankful to Drs. Kraska and Curtis for encouraging me to explore my passion and then help me shape it into a study that will hopefully be meaningful to the scholarly community. The critical eyes of Drs. Alderman and Dunn also helped to sharpen the focus of this study.

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LIST OF ABBREVIATIONS

ADA	Americans with Disabilities Act	IEP	Individualized Education Program
ADL	Activities of Daily Living	IPE	Individualized Plan for Employment
AT	Assistive Technology	PA	Personal Assistant
CSP	Comprehensive Service Program	PAS	Personal Assistance Services
HCBS	Home and Community-Based Services	PSE	Postsecondary Education
IADL	Instrumental Activities of Daily Living	STEM	Science, Technology, Engineering and Mathematics
ICF/DD	Intermediate Care Facility for the Developmentally Disabled	TDMP	Transitional Disability Management Program
IDEA	Individuals with Disabilities Education Act	VR	Vocational Rehabilitation
		WSU	Wright State University

CHAPTER I. INTRODUCTION

The ramifications of having a severe physical disability in America are clear: less education, less employment, less income, and greater poverty (Hedrick et al., 2010; Stumbo, Martin, & Hedrick, 2009). These educational and economic disadvantages are lifelong and often more limiting than the actual disability itself. One of the major challenges of having a severe physical disability is the need for continuous, consistent, and well-trained personal assistance. This, in turn, becomes problematic because of dysfunctional, fragmented, or insufficient systems of personal assistance services (PAS). Examples of problems include inadequacy of service models (Ahlström & Wadensten, 2010; Kelly, 2010; Kyung, Fox, & White, 2006; Misra, Orslene, & Walls, 2010; Wadensten & Ahlström, 2009a; Wadensten & Ahlström, 2009b), support structures and policy priorities (Gibson, Brooks, DeMatteo, & King, 2009; Nosek & Howland, 1993; Rowell & Connelly, 2008; Stumbo et al., 2009), personal assistance training and personal assistance management training (Schopp et al., 2007) and financing (Stout, Hagglund, & Clark, 2008).

The extent to which these difficulties may or may not translate into significant problems within postsecondary settings is not known, simply because there is extremely limited data about personal assistance services available to persons with severe physical disabilities provided by disability support offices in higher education (Stumbo et al., 2009). Substantial research is needed on the factors that contribute to the recruitment and retention of students with significant physical disabilities in higher education.

Statement of the Research Problem

The extent to which the difficulties listed above may or may not translate into significant problems within postsecondary settings is not known, simply because there is extremely limited data about personal assistance services available to persons with severe physical disabilities provided by disability support offices in higher education (Stumbo et al., 2009). Substantial research is needed on the factors that contribute to the recruitment and retention of students with significant physical disabilities in higher education. The focus of this study was the lack of information related to the level of self-sufficiency of individuals after completing a disability management program.

Need for the Study

The Comprehensive Service Program (CSP) model, long established, has proven useful for teaching functional living skills. However, in recent years, the CSP model has become more focused on routinely providing services for the greatest number of students rather than experimenting with how it can improve on the delivery. This is evidenced by the fact that, to date, the criteria for evaluation set forth by Klopping (1978) have been tested on a very limited basis. An institution that was recognized by Klopping for successfully implementing the comprehensive approach was the University of Illinois. According to Klopping, it was “one of the earliest and most successful programs in serving disabled students in the postsecondary setting” (Klopping, 1978, p. 59).

Along with the programmatic components of the CSP model, Klopping calls for the collection of data on graduates who have obtained successful employment. Klopping recognized the need to determine the rate at which graduates are progressing from dependent to

independent living status. He defined these particular evaluation criteria as “dependence upon SSI [Supplemental Security Income], welfare, and other transfer payments” (Kloepping, 1978).

Purpose of the Study

The purpose of this research was to explore whether the services that support young adults’ self-determination and self-management skills (along with assistive technology) at the university level lead to individuals’ functional independence, or self-sufficiency after graduation.

Research Questions

RQ₁: To what extent do individuals who completed a disability management curriculum indicate the following aspects of functional independence as defined in the Comprehensive Service Program (CSP) model?

1. Living arrangement, including planning and budgeting
2. Activities of Daily Living (ADL)
3. ADL assistance including level of assistance and source
4. Gainful activity status such as employment or returning to school
5. Income source
6. Healthcare insurance source

RQ₂: Which disability management courses do individuals complete as a set?

Definition of Terms

The following section provides definitions to increase understanding of certain terms used throughout the study.

Activities of Daily Living (ADL): Activities necessary to carry out basic human functions, such as bathing, dressing, eating, getting around inside the home, toileting and transferring from bed to chair (Hoening et al., 2003). However, Weiner & Hanley (1989) noted that ADLs do not

measure the full range of activities necessary for independent living in the community. To partly fill this gap in disability classification, the "Instrumental Activities of Daily Living" or IADLs were developed (Wiener & Hanley, 1989). The IADLs capture a range of activities that are more complex than those needed for personal self-care, including handling personal finances, meal preparation, shopping, travelling, doing housework, using the telephone, and taking medications (Wiener, Hanley, Clark, & Van Nostrand, 1990). These tasks are regarded as necessary for independent community living (Tilly, Goldenson, & Kasten, 2001).

Benefit Status: Refers to whether an individual is relying on transfer payments as a sole means of support (Kloeping, 1978, p. 59). Individuals who receive at least one dollar in monthly transfer payments are simultaneously entitled to benefits under one of the nation's public health insurance programs. The Medicaid benefit is designed for individuals who receive at least one dollar of monthly Supplemental Security Income or are at 300% of the federal poverty level or below. Medicare benefits are designed for individuals over the age of 65 or who have an earnings record under which they have paid into the Social Security trust fund for at least 18 months. Alternatively, the individual is able to rely on earned income and where necessary, a series of federal incentives that allow workers with disabilities to maintain access to Medicaid as a secondary insurance in order to cover the cost of long-term services that are typically beyond the limits of private insurance. The latter condition is typically present in primary labor market positions as defined by Hagner (2000). He states, "In the upper or primary sector, workers enjoy relatively high wages, fringe benefits, satisfactory working conditions, and employment 'security.'" Further one of the central aims of vocational rehabilitation is for individuals to achieve self-sufficiency and be able to support themselves through earned income.

Disability Management Training Program: Each institution has their own method for implementing program principles, all participating institutions seem to follow the following core principles: (A) Improve students' knowledge of disability laws and resources; (B) Improve students' skills in advocating for access and reasonable accommodations; (C) Maximize students' independence in the performance of ADLs; (D) Improve students' physical and/or functional capacity; (E) Improve students' social integration into the campus and community; (F) Promote student acquisition of the knowledge and skills necessary to benefit maximally from the use of assistive technology (AT); (G) Promote student acquisition of the knowledge and skills necessary for independent personal assistance management; (H) Promote successful transition to internships and/or permanent employment following an graduation; and (I) Improve skills at advocating for and finding accessible housing post-graduation (Hedrick, 2008).

Functional independence: A set of factors that lead to economic and personal self-sufficiency. Self-sufficiency from an economic perspective is characterized in the literature as the ability of individuals to support themselves through earned income. From this perspective, terminal placement of a consumer in a secondary sector job is problematic in several respects: Wages in the secondary sector are not high enough to allow an individual to dispense with the need for additional unearned income, and secondary jobs provide fewer benefits, are less safe, and offer less employer support and less job security. According to dual labor market theorists, secondary sector workers can expect little job-related training, few transferrable skills, and more difficulty advancing beyond the beginning stages of career development (Hagner, 2000). The personal domain of self-sufficiency refers to the degree to which individuals are able to perform various adult roles (Halpern, 1993). These outcomes are of particular interest because they encompass the many ways in which a person can interact with his or her environment (Halpern,

1993). These interactions are often called community adjustment, community integration, independent living, and interdependent living.

Gainful Activity: Activity that furthers the individual's ability to achieve self-support. This may include paid work or further education/training required to secure employment in the primary labor market. Kloepping (1978) argues that the postsecondary experience is "a condensed version of society in general" (p. 61). Accordingly, the experience needs to include training in functional skills that allow the individual to achieve and maintain employment in the primary sector.

Assumptions of the Study

1. An instrument has been devised that will permit the subjects to report their evaluations accurately.
2. Present and former participants in psychoeducational settings can and do make appraisals of the type of education they are receiving or have received.
3. Participants will respond to survey items with their true feelings (Kraska-Miller & Miller, 2010). Participation in this study is voluntary and participants are free to withdraw their participation at any will time without ramification (Simon & Goes, 2011).
4. The study sample is sufficiently representative of the population under study. Previous pilot investigations have helped to ensure item efficacy in addressing research questions with the desired sample (Simon & Goes, 2011).

Limitations of the Study

Limitations of the study include:

1. Study results can only be generalized to a population that has completed a disability management program or other type of training in self-sufficiency.

2. Outcomes for students cannot be compared between institutions that have implemented the CSP model. While a handful of universities have implemented the core tenets of the model, each institution has tailored their program differently in order to suit campus climate and the specific needs of their students.
3. The sample is limited to individuals who have completed an undergraduate degree that included coursework in disability management.
4. The sample provided by Wright State University is adequate and comprehensive.

Significance of the Study

Service and funding gaps continue to point to a number of areas in which further investigation is warranted. While the 2012 study conducted by Hedrick and colleagues provides exploratory information on the specific services offered on various campuses across the country for individuals with high support needs, these authors recommend that, "students who require PAS should be queried about their satisfaction with the current array of services at their schools, with a focus on availability, adequacy, and relationship to success in school, and potentially, in their careers" (Hedrick et al., 2012). Investigations are also needed into any additional barriers and facilitators experienced by individuals with severe physical disabilities as they attempt to progress through postsecondary degree programs. Pilot programs based on this research should be developed and evaluated by both the service consumers and providers. Results of successful programs need to be disseminated so that pilot-program, evidence-based practices can be implemented and their wider adoption ensured (Stumbo et al., 2009).

According to Test and Cease-Cook, evidence-based practice has been defined in vocational rehabilitation research as "a total process beginning with knowing what clinical

questions to ask, how to find the best practice, and how to critically appraise the evidence for validity and applicability to the particular care situation” (Test & Cease-Cook, 2012).

The call for more widespread dissemination of evidence-based best practice research is also supported by Getzel when she states, "ongoing research and evaluation activities are needed to determine the effectiveness of programs and supports for college students with disabilities whether developed by for-profit organizations or by university and college personnel” (Getzel, 2008). Such research and evaluation activities are the hallmark of universities. Additional research may encourage other universities to replicate and improve upon the CSP model to open higher education and, by extension, the primary labor markets for individuals with the most significant physical disabilities who have perfectly intact processing functions (Hagner, 2000). This objective is supported by existing research by Stumbo and others, which concludes that without adequate access to personal assistance, individuals with severe physical disabilities simply cannot attend and graduate from postsecondary degree programs. It is clear that if individuals with high support needs cannot live within the educational environment, they will not be able to succeed in the educational environment (Stumbo et al., 2009).

Summary

This study examined the extent to which completion of an undergraduate program that included coursework in disability management led to graduates being able to practice functional independence at a single time point after graduation. This is encompassed within the larger ideal of aspiring toward both personal and economic self-sufficiency.

CHAPTER 2. REVIEW OF LITERATURE

Chapter one introduced the research problem for this study and provided background information. Also, two research questions were formulated. This chapter discusses the history of Universal Instructional Design and Technology, examines the skills that are essential for students with significant physical disabilities in higher education, and reports on how these students—after completing secondary school—are not prepared to self-manage their disabilities during college, when the burden shifts to the student to ensure that accurate disability accommodations are implemented. If identified in college, students will need to make an effort to articulate their specific needs to their professors despite not having a set of successful strategies from high school to draw upon (Eckes & Ochoa, 2005).

After a discussion of the importance of external funding in order to implement such a program (Alabama Medicaid Agency, 2010; Kloeping, 1978; Stumbo et al., 2009), the Comprehensive Service Program (CSP) is offered as a model for providing support services to students with significant physical disabilities at the university level.

Current Constructs for Accommodation of Students with Disabilities in Higher Education

Generally, the existing literature indicates that students must be self-determined coming out of secondary school. Test and Cease-Cook (2012) point to the ability of students to provide or direct their care in a self-determined manner as an evidence-based indicator of post-school success. Independent living instruction can include, but is not limited to: (a) leisure skills, (b) social skills, (c) self-care skills, and (d) other adaptive behavior skills. Test and Cease-Cook

specifically cite research that indicates students who had higher daily living skills were more likely to have a higher quality of life (i.e., independent living) and to be engaged in post-school employment or training. Self-determination can include choice-making, problem-solving, decision-making, goal-setting and attainment, self-regulation, self-awareness, self-efficacy, and self-advocacy. Further, Test and Cease-Cook note that students who had higher self-determination skills were more likely to be engaged in activities leading to positive post-school outcomes. Finally, students who indicated high levels of satisfaction with instruction and support received during high school were more likely to be engaged in post-school education than those who indicated otherwise. In particular, students who received transition planning services during the year prior to leaving high school were more likely to be engaged in post-school education (Test & Cease-Cook, 2012).

However, additional research also indicates that students are more likely to succeed at a university where Universal Instructional Design and Technology concepts are employed (Campbell, 2004; Getzel, 2008). Universal Instructional Design is "the design of instructional materials and activities that make the learning goals achievable by individuals with wide differences in their abilities to see, hear, speak, move, read, write, understand English, attend, organize, engage, and remember" (Campbell, 2004).

The idea of Universal Design was first introduced in the field of architecture. While working at North Carolina State University, Ron Mace (1997) coined Universal Design as a way to define the movement toward general accessibility of newly-erected structures. This idea that new structures offered universal access to address the varying abilities of their patrons was new at the time, although later this concept was adopted by educators and applied to the field of teaching and disability studies. The movement toward Universal Design challenged the locus of

responsibility for accessibility and assistive technology, and acknowledged the need for "alternatives to suit many different people's needs" (Campbell, 2004).

In describing the scope of this evolving responsibility Bowe (2000) noted that the historical trend in education has been to accommodate individual needs, without changing courses. For example, students who are deaf must arrange for sign language interpreters to translate the spoken lectures in the classroom. Similarly, blind students need to secure course materials in accessible formats. Bowe refers to this traditional method of accommodation as "accessibility." He notes that since 1977, schools, colleges, universities and other educational institutions have provided accessibility measures such as interpreters, note-takers, etc., free of charge to students as part of the institutions' obligations under federal law. As part of the accommodations process, many students have used assistive technology to facilitate their reading, writing, and other academic activities (Bowe, 2000).

Bowe calls upon the educator to embrace a framework of Universal Design, wherein materials are designed to be accessible to everyone regardless of whether or not disability is present. According to Bowe, Universal Design challenges the educator to re-evaluate who should be responsible for accessibility, and more specifically, assistive technology. Universal Design framework calls for instructors to re-examine the fundamental aspects of content delivery (Bowe, 2000).

Bowe challenges the notion that there is no one best modality through which to convey information. Rather he encourages instructors to present information in a variety of formats so that the student can choose a method that is most conducive to their learning style. This choice should be driven by learner preference rather than presence of any particular disability (Bowe, 2000).

Since 1977, students have benefited from the initiatives of educational institutions to provide accommodations such as sign language interpreters and class note-takers. Campbell cites research from the HEATH Resource Center (1999), which indicates that “the percentage of freshman who self-reported a disability increased from 3% in 1978 to over 9% in 1998” (p. 167). The increase in the availability of assistive technologies has provided many learners with, previously unavailable, access to higher education. The assistive technologies that have opened the door for individuals with disabilities are the same technologies adopted and utilized by those without disabilities (Campbell, 2004).

Current research has highlighted a series of characteristics that are essential to the recruitment, retention and persistence of students with disabilities at institutions of higher learning. According to Elizabeth Evans-Getzel, Professor of Rehabilitation Research and Training at Virginia Commonwealth University, these student-support factors include, “services that will develop stronger self-determination skills and support the development of young adults' self-management skills through exposure to assistive technologies that will facilitate self-sufficiency” (p. 209). Self-determination according to Getzel, is a “set of personal or interpersonal skills that include acceptance of a disability and how it affects learning; understanding which support services are needed; knowing how to describe one's disability and the need for certain supports to service providers; and having the determination to overcome obstacles that may be presented” (p. 210).

The concepts of self-determination and self-management skills in higher education have been synthesized by some authors into a singular term “academic autonomy” Getzel (citing Costello & English, 2001), defines academic autonomy as, “the capacity of students to deal with ambiguity and to monitor and control their own behaviors in ways that allow them to attain their

educational goals” (p. 211). These authors recommend that university-based disability service providers consider providing experiences for students to assist them in achieving more academic autonomy, in addition to the accommodations students were deemed eligible to receive. Consequently, “there must also be a culture that supports professional development among the faculty, whereby they can be knowledgeable about the characteristics and needs of students with disabilities” (Getzel, 2008).

In a companion study, Getzel and colleagues examined the utility of self-determination skills with college students in Virginia, who possessed a cross-section of disability diagnoses. They examined a study conducted with postsecondary education students in 2- and 4-year college settings to ascertain what skills these students believed were essential. The specific purposes of the study were to identify (a) skills that effective self-advocates used to ensure they stay in college and to obtain needed supports and (b) the essential self-determination skills to remain and persist in college (Getzel & Thoma, 2008).

The findings from the latter investigation indicated that the strategies that were most influential on the success of these participants were in areas relating to (a) problem solving, (b) understanding one's disability, (c) goal setting, and (d) self-management as critical skills that students need to be effective advocates for themselves in order to secure needed supports and services. This same set of skills has also been identified in the literature as essential for college students with disabilities (Getzel & Thoma, 2008).

However, the authors advise that such conclusions must be taken within the context of the sample limitations. The authors see the need for replication with a larger sample that is not generated by purposeful selection of a potentially biased third-party such as the individuals employed by the disabilities offices at the various site institutions. The authors also recognize

the validity issues that exist with exclusively using self-reported data and their various effects (Getzel & Thoma, 2008).

Pingry (2007) conducted a study to determine the disability types and services that predicted student graduation rates from three universities in the Midwestern United States. The records of 1,289 anonymous students were examined ex post facto to ascertain information about students, disability related services they received, and student graduation status. A hierarchical logistic regression framework was used to construct a model of factors that best predict graduation among students with disabilities in college. That model includes: being female, being 23 years of age and older, having a physical disability, using alternative format tests, taking distraction reduced testing, having flexibility in assignment/test dates, learning strategies assistance, and physical therapy/ functional training (Pingry, 2007).

While results of the logistic regression on the sample of students with physical disabilities indicated that the factors that were strongest predictors of graduation were (1) being female, and (2) age 23 to 30, some factors were excluded from the regression analysis because they did not have a cell frequency greater than five. Chief among these was the presence of a university sponsored functional training program. These services were divided into two factors. Functional training involved physical wellness or capacity building. Broader disability management included the ability to complete or direct the completion of daily living activities. Only one of the three universities included in the study offered a robust array of services in these areas, thereby creating a relatively small sample from which to draw conclusions about the effect of the services on graduation rates. However, a chi-square test of the students with physical disabilities who did receive such services was noteworthy. Of the 430 students in this study who were identified as having physical disabilities, 76 students received physical therapy and

functional training, and 74 graduated. Similarly, of 25 students who received disability management training, all graduated (Pingry, 2007).

Pingry defines functional training as services that provide the opportunity for strength development, physical conditioning and capacity building for students whose disabilities significantly limit the effective utilization of the fitness and recreational resources and programs that are otherwise available to students. Through participation in the services, students with severe physical disabilities are afforded the opportunity to maximize their functional potential, relieve stress and increase their tolerances relative to the rigorous demands of campus life through the milieu of adaptive exercises. The physical therapists and graduate assistants aid students in developing and implementing personal exercise programs, particularly for developing and maintaining range of motion, strength and conditioning. The staff can also assist students with the development of transfer skills, e.g., getting back into a wheelchair from the floor, manual wheelchair skills, and gait training with or without assistive devices. Supplemental to the active therapy program, a limited number of physical agents are available for the treatment of acute and chronic musculoskeletal injuries and dysfunction (Pingry, 2007, p. 46-47).

Similarly, Pingry defines disability management training in the context of a university residence hall operated by the office of disabilities that specializes in accommodating the residential needs of students with severe physical disabilities who require assistance in the performance of basic activities of daily living. Students needing assistance in the performance of activities of daily living are afforded the opportunity to participate in training to improve their knowledge and skills in independent living, and are empowered by the responsibility to share with the residential hall administrative team for hiring, training, scheduling, managing, and evaluating personal attendant staff. A Transitional Disability Management Plan (TDMP) is

developed between the Residential Hall Disability Specialist, student, and others identified by the student for involvement in the TDMP process. The purpose of the TDMP is to improve each student's management of his/her disability-related needs (Pingry, 2007, p. 47).

In another study relative to successful disability services, Stumbo and colleagues found that, for individuals with the most significant physical disabilities the presence of assistive technology and other curricular supports are irrelevant without provision for personal assistance services. According to Stumbo and others, "assistive technology (AT) can often augment but not replace human help for these individuals. What is often not noted in the literature is that for individuals with severe physical disabilities, access to personal assistance is necessary 24 hours a day, 7 days a week, 365 days a year. While the person will not require assistance every minute of every day, proximal standby help must be continuously available" (Stumbo et al., 2009).

Contrary to present research, all too often AT is seen as a substitute for longitudinally more expensive human personal assistance. According to Hoenig et al. (2003), in their cross-sectional study of 2,368 community dwellers older than 65 years with one or more limitations in basic Activities of Daily Living (ADLs) as defined in the 1994 National Long Term Care Survey, the relation between technological assistance and personal assistance was examined. Activities of daily living are defined as activities necessary to carry out basic human functions, such as bathing, dressing, eating, getting around inside the home, toileting and transferring from bed to chair.

The findings of Hoenig et al. (2003) indicated that among people with ADL limitations, several models showed a strong and consistent relation between technological assistance and personal assistance, whereby use of equipment was associated with fewer hours of help.

Therefore, these authors inferred that among people with disabilities, use of assistive technology was associated with fewer hours of personal assistance (Hoenig, Taylor Jr., & Sloan, 2003).

However, Weiner & Hanley (1989) noted that ADLs do not measure the full range of activities necessary for independent living in the community. To partly fill this gap in disability classification, the "instrumental activities of daily living" or IADLs were developed (Wiener & Hanley, 1989). The IADLs capture a range of activities that are more complex than those needed for personal self-care, including handling personal finances, meal preparation, shopping, travelling, doing housework, using the telephone, and taking medications (Wiener, Hanley, Clark, & Van Nostrand, 1990). These tasks are regarded as necessary for independent community living (Tilly, Goldenson, & Kasten, 2001).

Agree and Freeman (2003), examined differences in reports of residual disability and unmet need by type of long-term care arrangement (AT or personal care). This study compared three specific dimensions of residual difficulty (pain, fatigue, and time intensity) and reports of unmet need across care arrangements. Samples from the U. S. 1994-1995 National Health Interview Survey Phase 2 Disability Supplements include adults with limitations in bathing, transferring, walking, and getting outside. Even when differences in underlying disability are accounted for, AT confers no additional benefit in the three dimensions of residual difficulty analyzed here. AT users equally or more often report that tasks are tiring, time consuming, or painful, even when they use technology with human assistance. Though this would appear to indicate unmet needs for care, fewer AT users report a desire for hands-on personal care. This implies that disability alleviation by technology is no better on specific dimensions of difficulty (Agree & Freedman, 2003).

A subsequent study also indicates that AT is not a strict substitute for human assistance. Agree and Freeman (2005) indicated that the use of AT was associated with reductions in informal care hours, especially for those who were unmarried, better educated, or had better cognitive abilities, but appeared to supplement formal care services for these groups. Individuals with cognitive impairment were less likely than others to substitute AT with either type of personal care. These authors conclude that such models raise the possibility that reductions of informal care hours may be accomplished with a combination of formal care and assistive devices, rather than from either alternative alone (Agree, Freedman, Cornman, Wolf, & Marcotte, 2005).

In order to lessen the potential for adverse outcomes across all segments of the population, contemporary research suggests a hybrid model, which allows for AT to augment formal or informal human assistance but not replace it completely. Agree and Freeman (2005) suggest that reduced hours of informal care, e.g., care provided by a family member or neighbor, cannot be attributed solely to the incorporation of AT, but rather may be due to the combination of formal care and assistive devices. The association between these types of care suggest that potential improvements in care management could be made through increased use of care managers or provision of information about AT to health care providers. Ultimately these devices may improve the quality of life of older persons and promote independence; however, their ability to substitute AT for more expensive formal care is not yet established (Agree et al., 2005).

In a culminating report by Freeman and colleagues (2006), the authors note that among older Americans living in the community and experiencing difficulty in self-care activities, the independent use of technology increased substantially, offsetting the use of personal care. Shifts

in forms of assistance toward the independent use of AT accounted for about half of the observed decline between 1992 and 2001 in the number of older people dependent on personal care in daily activities. Assistive technology appears to be especially important to lessen dependence on personal care for walking, particularly for the population of individuals who are 80 years of age or older (Freedman, Agree, Martin, & Cornman, 2006).

The limitations of this study, however, include the fact that many technologies that influence quality of life, such as aids for transportation, communication, and other medical information, and household technologies, were not included. Furthermore, it was not possible to explore whether increases in accessible environments have furthered declines in reports of underlying difficulty. Consequently, this assessment of the role of technology in alleviating dependence on personal care is likely to be conservative. Moreover, this study was unable to identify specific devices linked to declines in dependence. Finally, because this study was descriptive in nature, it cannot be concluded with certainty that expansion of AT use caused declines in personal care. To the contrary, older individuals may increasingly turn to technological solutions if personal care is not readily available (Freedman et al., 2006).

As noted, the Pingry research also suggests that there must be a curriculum that provides students with skills required for independent living and economic self-sufficiency. Students coming from the K-12 system have the intellect to complete college level work, but few have experience with self-care management skills that are required to excel academically. This is a direct illustration of Maslow's hierarchy of needs. A student cannot be expected to succeed in higher order academics unless self-care skills are at least concurrently addressed through a program, which includes functional training for students with the most significant physical

disabilities (National Council on Disability Federal Advisory Committee on Youth, 2001; Pingry, 2007).

Benz and colleagues (2000), examined student and program factors that predicted positive graduation and employment outcomes for secondary students who participated in a statewide transition program in Oregon, and by exploring students' perceptions of the relevance of these services for encouraging them to stay in and complete school. The Youth Transition Program (YTP) is a transition program for youth with disabilities operated collaboratively by the Oregon Department of Education, State Rehabilitation Division, the University of Oregon and local education agencies. The YTP serves youth with disabilities, who require support beyond the services typically available through a district's traditional general education, special education, and school-to-work programs to achieve their secondary and postsecondary employment and continuing education goals.

Although youth participating in the YTP are representative of all secondary youth with disabilities with respect to primary disabling condition, students typically are referred to the program by school staff because of additional barriers to secondary completion and transition success (e.g., at risk of dropping out of school, limited or negative job experiences, teenage parenting responsibilities, unstable living situation). The goal of the YTP is to improve participants' postschool outcomes and prepare them for meaningful competitive employment or career-related postsecondary training (Benz, Lindstrom, & Yovanoff, 2000).

The YTP provides services to students beginning during the last two years they are in high school and continuing, if needed, during the early transition years after leaving school. Through the YTP, students receive (a) transition planning focused on post-school goals and self-determination, and help to coordinate school plans with relevant adult agencies; (b) instruction in

academic, vocational, independent living, and personal-social content areas, and help to stay in school and obtain a completion document; (c) paid job training while in the program, and help to secure employment or enter postsecondary training upon leaving the program; and (d) follow-up support services for up to two years after leaving the program, provided on an as-needed basis. At the time of publication, this model had been implemented in 80% of the high schools across Oregon (Benz et al., 2000).

Data from an external evaluation of program effectiveness (1995), indicated that (a) 90% of YTP participants obtained a high school completion document; (b) 82% of participants were placed successfully in a competitive job, postsecondary training, or a combination of both at the point of program exit; and (c) rates of engagement in employment or education remained consistently above 80% for program completers during the first two years after leaving the program. Outcomes for YTP participants were educationally and statistically significant compared to two groups—a statewide sample of students who received special education services in Oregon but who were not in the YTP, and a statewide sample of transition-aged youth who received Vocational Rehabilitation services but who were not in the YTP (Benz et al., 2000).

A follow-up study was undertaken to examine relationships between education and transition outcomes for students with disabilities and factors that have been suggested by research and implemented over time as part of the YTP. Benz and colleagues utilized logistic regression procedures to examine student and program factors that predicted (a) receipt of a standard high school diploma at program exit, and (b) placement in employment or continuing education at program exit. The researchers reported having selected a standard high school diploma as their educational outcome of interest because “it is recognized as a highly desirable

completion document for all students and because there are increasing concerns about its accessibility to many high school students, especially those with disabilities” (p. 512). Likewise, the investigators selected engagement in work or schooling activities as their post-school outcome because “it has long been recognized as a desirable achievement indicator for students with and without disabilities” (Benz & Lindstrom, 2000, p.512).

This study encompassed a final sample of 709 students, which was similar to the population of YTP participants in the database (N= 1,611) with respect to gender, ethnicity, and primary disability. This sample was also similar with respect to gender and primary disability to the population of students with disabilities aged 15 to 21 (N= 13,160) who were served in Oregon's high schools during the 1997-98 school year (Benz et al., 2000).

Results indicated that 439 of the 709 students sampled (62%) graduated with a standard diploma. Factors that predicted receipt of a standard diploma included enrollment in the YTP for 12 or more months and retention of two or more jobs while in high school. Students who were in the YTP for 12 or more months were almost two times more likely to graduate with a standard diploma than were students who were in the program less than a year. Similarly, students who held two or more paid jobs while in the program and students who completed four or more transition goals while in the program were two times more likely to graduate with a standard high school diploma (Benz et al., 2000).

These findings were similar to student outcomes for engagement in productive school/work activities post-graduation. Students who held two or more jobs while in the program were almost two times more likely to be engaged in work or continuing education at exit than students who held fewer than two jobs. Students who completed four or more transition goals while in the program were almost four times more likely to be productively engaged at program

exit than were students who completed fewer than four transition goals (Benz et al., 2000). Further review of the data indicates that, 387 (55%) of the program participants reported enrollment in continuing education as one of the transition goals achieved. Other items queried included information related to goals such as independent living, transportation, and economic sufficiency (Benz et al., 2000).

These authors note that while caution should be exercised in generalizing these results to other contexts because their findings emerged out of a study in one particular state. At the same time, their findings are consistent with those from earlier research, and in some cases these results embellish and extend current knowledge about effective and promising practices that improve secondary and postsecondary outcomes for students with disabilities (Benz et al., 2000). Benz and colleagues point to previous research (Halpern, 1993) that suggests there is a moderate relationship between graduation with a diploma and postsecondary outcomes, and smaller relationships exist among postsecondary outcome domains such as employment, continuing education, and independent living.

Halpern suggests three domains for studying quality of life: (1) physical and mental well-being, (2) performance of various adult roles, and (3) a sense of personal fulfillment (Halpern, 1993). Within these three domains Halpern identifies 15 outcomes that address quality of life measures for emerging adults with disabilities. According to Halpern, “The outcomes represented in the physical and mental well-being domain include basic entitlements that should be available to all people. Unless these outcomes are achieved, at least to some reasonable extent, achieving the outcomes in the other domains would probably be difficult. Four such ‘basic’ outcomes have been identified: 1. Physical and mental health. 2. Food, clothing, and lodging. 3. Financial security. 4. Safety from harm” (p. 490). Halpern contends that, “If these

outcomes are to be viewed as basic entitlements, the primary conceptual and measurement issue is probably the identification and specification of ‘minimal conditions’ that should be available to everyone as a foundation for experiencing an acceptable quality of life. Such conditions will include preventing or coping with health problems, freedom from severe hunger or homelessness, a regular income of sufficient size to avoid total impoverishment, and a living environment that does not place a person in constant jeopardy of physical or emotional harm” (Halpern, 1993, p. 490).

The next level of Halpern’s taxonomy is the performance of adult roles. These outcomes are of particular interest because they encompass the many ways in which a person can interact with his or her environment. These interactions are often called community adjustment, community integration, independent living, and interdependent living.

The first of these outcomes is mobility and community access. An example of the access measure would be the degree to which an individual is able to utilize some form of transportation effectively. Second among the adult role outcomes is vocation, career and employment. This indicator reflects the extent to which an individual has obtained employment that is aligned with their career interests.

The third role outcome relates to leisure and recreation, which is the extent to which an individual utilizes free time to pursue activities of their choice. The fourth outcome measure in the adult roles domain is the cultivation of personal relationships and social networks. This indicator reflects the degree to which an individual has maintained positive involvement with friends.

The fifth community adjustment outcome is educational attainment. This educational measure is determined by whether an individual has obtained a high school diploma or other

equivalent document. The sixth adult role outcome relates to spiritual fulfillment. This is defined by the extent to which an individual is able to participate in spiritual activities of their choice.

The seventh outcome area within the adult roles domain involves citizenship. Citizenship in this context is the extent to which an individual is able to exercise their right to vote without the influence of others. The final (and eighth) outcome within the adult role performance domain relates to social responsibility. This indicator extends the concept of citizenship to include a reflection of the degree to which an individual understands their obligation to obey civil authority and not break laws (Halpern, 1993).

Halpern notes that, “Each of these adult roles presents opportunities for enhancing quality of life, and yet it is not essential that each person participate at similar levels of involvement within each role. People must choose the roles that they want to perform, based on their own needs, interests, and preferences. Social expectations and norms must also be considered, especially if an individual chooses to behave in a manner that is highly divergent from such expectations and norms in his or her community” (Halpern, 1993, p. 491). This recognition of the need for individual autonomy leads to the final domain in Halpern’s taxonomy, personal fulfillment. This third dimension of quality of life is entirely person centered, even though it is influenced by interactions with one’s environment. Three outcomes, all presupposing the presence of personal choice, are included in this domain including (1) happiness, (2) satisfaction, and (3) a sense of general well-being (Halpern, 1993).

According to Halpern, “Happiness is a transient state of affect, usually governed by events that are happening at the moment. Satisfaction refers to behavior patterns and events over a longer period of time, but is often specific to a given adult role. For example, one can be very unsatisfied at work but highly satisfied with personal and social relationships. General well-

being, the most durable of the outcomes, implies an enduring sense of satisfaction with the quality of one's life, almost irrespective of the events and conditions that lead to happiness or situation-specific satisfaction” (Halpern, 1993, p. 492).

From the perspective of secondary and transition practice, these findings suggest that educators must address specifically and directly the instructional requirements associated with school performance, secondary completion, and post-school preparation. Some of the specific services suggested include instruction in functional academics within the context of student identified transition goals. In this study, transition goals identified by students fell into areas necessary for self-sufficiency.

Benz and colleagues conclude that, if graduation with a high school diploma and preparation for adult roles in continuing education, employment, and independent living are equally important outcomes for students with disabilities and equally necessary targets for the delivery of secondary and transition services, then future research should examine the impact of special and general education policies regarding graduation with a standard high school diploma.

Students with disabilities have long found it difficult to incorporate a functional transition education with community-based instruction into a curriculum that also satisfies the academic requirements for a standard high school diploma. These authors also acknowledge that alternative completion documents whose curricular requirements may allow for an increased focus on the teaching of functional skills are “viewed as less than desirable by many students, parents, and teachers because of the limited value of these alternative completion documents to postsecondary providers such as college personnel, military recruiters, and employers” (Benz et al., 2000).

The outcomes of students with significant physical disabilities participating in a secondary curriculum that does not balance functional skills and academic requirements are demonstrated by Stumbo and others when they state, "Secondary schools are required to provide personal services and aides [that will enable students to receive a free and appropriate public education in the least restrictive environment], while postsecondary institutions are under no obligation to provide aids, devices, or services of a personal nature that are not otherwise provided to their students without disabilities" (p.17).

As a result, the personal assistance support model with which the student and family are most familiar from secondary school, wherein personal services are provided at no cost by the local education agency as part of students' entitlement to a free and appropriate public education, is rendered irrelevant in the milieu of higher education, where no such entitlement exists. Frequently, students have not acquired the knowledge, skills and self-confidence necessary to effectively manage such services independent of familial and/or school assistance (Stumbo et al., 2009).

Models of Severe Physical Disability

The four main models of disability identified in disability studies are the medical model, the social model, the analytical model and the relational model. The experience of disability and the variety of attitudes towards it are complex, and each of the disability models covers only part of this complexity: the medical model focuses on the body and its functions; the social model focuses on the interactions between people with disabilities as a minority group and the environment inhabited by the non-disabled majority; the analytical model is concerned with the internal experience of disability, and the relational model, which builds on the analytical model,

adds the missing element: the struggle through the developmental process towards interaction with the external world.

With regard to the social model of disability, Jager and Bowman (2005) suggest that persons with disabilities can be identified by the presence of two unifying and interrelated factors: (1) having an ongoing physical or mental condition that society deems unusual, and (2) facing discrimination and exclusion as a result of having that condition. This viewpoint places much of the nexus on the social attitudes toward persons with disabilities. Such emphasis is central for thinking about disability in terms of society, since disabilities are labeled as such by other members of a society. Disability exists in society because certain conditions are thought by the majority of members of the society to be far enough from the norm that they significantly affect daily activities in some way (Jaeger & Bowman, 2005). This viewpoint is reinforced by the use of norm-referenced criterion in the medical model from which many decisions on service eligibility are based (Smart, 2009). According to Smart, “The entire focus is on changing the individual (rehabilitation) rather than changing the environment (accommodation). In the medical model, disability is thought to be dysfunction, abnormality, pathology, disease, or defect” (Smart, 2006), as compared to the general population.

Medical Model

Smart (2006) contends that the medical model has provided the basis for much of the legislation that mandates services for people with disabilities and also guides the reimbursement and payment systems of government agencies and insurance companies. Therefore, both the services and funding the individual with a disability receives are based on the medical model. The profession of medicine has been based on the two outcome paradigms of cure or death and vestiges of this paradigm are reflected in current payment systems. Therefore, after medical

stabilization, much of the funding is withdrawn, not taking into consideration the individual's greatest needs. Nonetheless, disabilities are chronic conditions, which require care and not cure (p. 42).

Smart also notes that health maintenance, patient education, maintaining the highest quality of life, avoiding secondary conditions, and responding to interaction of the disability with the aging process are all medical services that are necessary for someone with a disability, but typically are not funded.

Smart concludes that the medical model does not take the environment into consideration. Smart contends that, “payers will not see the individual benefits (or overall social benefit) of paying for services such as marital counseling or other types of counseling. Environmental and social interventions frequently are not funded. Inter-professional collaboration is often thwarted when government agencies and insurance companies do not facilitate the funding, assuming that medical practitioners are the sole authority on disability” (Smart, 2006, p. 43).

The medical model of disability also suggests that with the correct intervention, all human abnormalities could be corrected. Institutions dedicated to perfecting the imperfect were established with the hope that these inadequacies could be cured by professional intervention. When cure was not possible, persons with disabilities could at least be trained to become functional enough to behave acceptably in social situations (Mackelprang & Salsgiver, 2009).

Mackelprang and Salsgiver (2009) argue that the medical model assumes that the individual with a disability exists in a vacuum. The medical model is not concerned with factors external to the individual. Even when the medical model acknowledges environmental influences, they are not considered to be agents of change. Further, the medical model assumes

biomedical dysfunction, more specifically, that there is something drastically wrong with the person with a disability: The biological organism is out of sync with the natural order of the universe. The medical model also centers on action: It relies on the intervention of professionals, and solutions to problems are made possible by the knowledge and skills of physicians, physical therapists, occupational therapists, clinical therapists, professional counselors, certified special education teachers, and other professionals to determine course of treatment and intervention. Accordingly, the locus of control in this framework resides exclusively with professionals to determine how the individual with a disability is to be treated (and educated). These decisions are made with the underlying goal to seek perfection, cure, or the eradication of the physical or mental dysfunction, making the abnormal normal through treatment (Mackelprang & Salsgiver, 2009).

Wilson (2003) provides additional explanation of the medical model when she describes the nature of the medical profession. “The medical profession is perceived both by its own members and by the public as a body whose role it is to cure what is defined as pathological or not normal” (p.19). Additionally, Wilson cites John Holland (1995), a general practitioner, who writes about the “unbearable impotence doctors feel in the presence of their patients' pain” (p. 19). Holland suggests that, “in defense, doctors may attempt to deny reality and climb onto a pedestal labelled ‘Excellent Carer’... by busying themselves with excessive care, their patients are left feeling incompetent and powerless, while the doctors welcome the feeling that they are all-powerful” (p.19-20).

In order to illustrate this phenomenon, Wilson refers to the example of Beth, an individual with multiple sclerosis. When her treating neurologist asked Beth whether she had noticed any changes in functioning, she noted that her bowels were not moving as regularly as

they use to. The physician recommended the insertion of a colostomy system in order to regulate these functions.

Wilson notes that Beth's irregular functioning had not disturbed her, but it had disturbed her physician. The physician had needed to ease his intolerable helplessness in the face of the incurable MS. He had needed to gain control, if not over the MS then at least over Beth's bowel movements. Restoring what seemed like control had been his way of dealing with the anxiety provoked by the unpredictable and the unknown. However, the physician's action also carries the message that people with disabilities are not accepted for what they are. In the medical model, individuals with disabilities have to be "normalized" (Wilson, 2003). Further, while medical advances are appreciated by many people with disabilities, emotional investment in such advances sometimes lead to disappointment and eventually anger toward the medical profession (Wilson, 2003).

Finally, Wilson cites additional scholarship by Marks (1999) that the reason physicians often fail to provide sufficient pain relief is that they cannot believe and therefore cannot empathize with their patients' unbearable pain. According to Marks, this lack of belief "is often due to the lack of external evidence of pain, such as a visible injury" (p. 21). Marks explains further that patients' complaints of pain are often not viewed as credible without evidence of external injury because visible trauma can be cured or treated. Marks contends that the ability to cure provides physicians with a means of stress relief about the suffering the injury has caused. Conversely, when the cause of pain is unknown or untreatable, disbelief is a defense against helplessness (Wilson, 2003).

Smart advocates that disability is caused by a hybrid of interactions between the individual and the physical as well as social aspects of their surrounding environment. According

to Smart, the environmental model supposes the individual's surroundings —both social and physical—can cause, define, or exaggerate disability. “Disability is viewed as . . . a product of a disabling, unresponsive, or insensitive environment" (p.65). Essentially, environments can limit physical access and opportunities for work, education, and social participation (Smart, 2009).

Social Model

According to Wilson (2003), the social model of disability was developed by the disability community in response to the medical model. This approach was grounded in the idea that the social environment should adapt to enable people with disabilities to function as equal members of society. For Wilson “The environment is seen as disabling because it discriminates against certain individuals. [People with disabilities] are seen as united by their shared experience of exclusion and prejudice. Rather than focusing on the impairments that distinguish [people with disabilities] from one another, the social model adopts a cross-disability perspective. Its main concern is to remove disabling environmental barriers and to increase [persons with disabilities] autonomy and choice” (Wilson, 2003,p. 21).

In order to illustrate how environments create disabling barriers, Wilson provides the example of Hanna, a wheelchair user, who was invited to a meeting on the second floor of a building. The building had an elevator to promote second-floor access, however this accommodation was insufficient because the device was not within arms-reach of the wheelchair user.

Wilson cautions that the underlying message Hanna received may have been, “This place is not designed for you. Although we have a lift, it is there for those who can reach the buttons, not for the likes of you, and you don't belong here.”

The social model aims to change attitudes among the non-disabled majority so that inclusion will become the norm and impairment will not always be equated with disability. However, at times it may not be possible to create an environment that can address the needs of all people with disabilities because some people's needs conflict with others; for example, some people with visual impairments see better in bright light and others in dim light. In addition, to apply the social model successfully, there must be a recognition, an understanding, and a move to address the collective fear that disability triggers (Wilson, 2003).

Wilson argues that among therapists and other helping professionals, this fear usually manifests itself in the form of countertransference. “Countertransference is the emotional response that the client triggers in the therapist” (p. 23). Countertransference represents any unresolved personal issues, conflicting values, biases and distortions that can significantly affect the clinicians’ capacity to provide competent psychotherapy, or any other professional help (Wilson, 2003).

To conclude her discussion of the social model, Wilson examines a set of factors which she calls secondary gains of disability. This is the tendency of some people with disabilities to develop a high degree of dependency and accept diminished autonomy. In order to illustrate this behavior, Wilson refers to the story of Helen who retired from law enforcement due to functional losses resulting from an arthritis diagnosis. Helen states: “This morning when I passed the bus stop and saw all these people waiting for the bus in the wind and rain I was glad I don't have to do it anymore. I like it that the ambulance comes to pick me up from home” (Wilson, 2003, p. 22).

Wilson contends that Helen was most likely speaking about the comfort she derived from her forced dependency — her loss of physical ability had been followed by loss of the will to

“fight it” out there. According to Wilson, statements such as Helen’s “highlight the thin and often unclear line that separates real needs from the seduction of dependency” (p. 22). As long as the focus of disability continues to be shifted away from the individual with the disability onto society's attitudes, values and actions, it is inevitable that the traits in Helen's somewhat regressive comment will tend to be ignored, because they may weaken the cause (Wilson, 2003).

Analytical Model

The discussion of secondary gains or adaptations like those illustrated by the case of Helen, represent a move toward an examination of the internal experience of disability. While the medical and social models focus on the reduction of disabling symptoms, the analytical model progresses as a continuous experience, which undergoes cyclical phases of progression and regression as a defense against what is perceived as unbearable adversity. According to Wilson, “mental health is not just an outcome of the individual's developmental history, it also relates to the specific context in which the person lives.” Wilson further contends that this phenomenon, “cannot be understood in isolation, emotional distress, and dependency can be understood in terms of context, relationships and meanings” (Wilson, 2003, p. 23).

The analytical model assumes that human beings are self-regulating systems, where each person comprises a hierarchy of subsystems that interact via the brain with the larger social system. Wilson refers to the scholarship of Taylor (1994), which indicates that under this model “psychoanalytic intervention may favorably influence health not only by enhancing the regulatory capacity of the person's psyche, but also by modifying the reciprocal feedback it has with other subsystems” (Wilson, 2003, p. 23).

Wilson utilizes the idea of body image to demonstrate the significance of the analytical model. Body image is the degree to which an individual perceives that he or she deviates from

the acceptable physical norms in a culture. Wilson argues that, “Damage to the body, which is a source of self-identity and self-regard, can cause severe emotional upheaval, loss of identity and a diminished sense of self-worth” (p. 23). Difficulty with body image may not only affect the individual with the disability but also the helping professionals with whom they interact, through a process of countertransference (Wilson, 2003).

Relational Model

Wilson builds upon the analytical framework to advance the fourth model of disability—the relational model. The relational model points out the link between experiences, both internal and external, of individuals who perceive themselves as having a disability and the effects that disability can have on people without disabilities. Particular attention is given to the struggle against dependency and the stages by which people with disabilities achieve autonomy, a separate identity and a positive self-image. The concerns and difficulties experienced by individuals with disabilities are, of course, as varied and diverse as those of people without disabilities. However, there are factors that can be seen as disability specific. One such factor is the time of life at which disablement occurs, which can significantly influence the individual's adjustment process, self-perception and the way he or she is perceived by others. Therefore, the model initially differentiates between congenital (present from birth) and acquired disability (Wilson, 2003).

The relational model has four components: (1) the developmental process from an object relations perspective; (2) the perception of self; (3) identity, autonomy and separation; and, (4) the perception of disability as an eternal transition in the construct of adolescence (Wilson, 2003, p. 24).

Although the existing developmental models focus little on the role that disability plays on the development process, object relations theory does provide a useful adaptive framework. This approach views child development as an outcome of the relational environment experienced by a child. According to Wilson, “the emphasis on interaction between people and their environment provides a positive scope for understanding the developmental process of people with disabilities” (Wilson, 2003, p. 28).

Wilson notes that the developmental processes outlined by early psychoanalysts such as Freud (1911) were based on internal developmental markers that are propelled by increasingly complex biological needs. Freud was not concerned with the effect that culture would have on the maturation process. According to Wilson, “any developmental theory that is based, as are Freud's psychosexual stages, on the link between control over bodily functions and emotional maturity fails to address the way in which emotional maturity is achieved when body functioning is impaired. Under Freud's psychoanalytic theory, a lack of bowel control or an inability to feed oneself will prevent the individual from reaching maturity” (Wilson, 2003, p. 25).

Conversely Wilson notes the great majority of people with disabilities achieve emotional maturity despite physical dependency. According to Wilson, “The growing power of the disability movement and the personal achievements of individuals with disabilities present a challenge to any theory that links physical functioning with emotional maturity” (p. 25). Rather, Wilson argues that emotional maturity consists of two factors: (1) the person's awareness of his or her condition in the context of everyday life; and (2) the degree to which the individual assumes responsibility for his or her own well-being, as compared to those without disabilities (Wilson, 2003, p. 25).

Klein (1932, 1965) built upon Freud's concept of drives. She emphasized the early mother—child relationship and believed that aggression rather than sex was the primary instinct. Klein attached great importance to the child's relationship with the mother's breast, which as the primary object is alternately viewed as either ideal or persecutory. By implication, difficulty with feeding, sensing or touching, such as might be experienced by a child with a disability, may influence the child's perceptions of the mother. According to Klein the child's sense of self as good or bad is related to the predominance of good and bad objects in its internal object world. Thus a breast that is perceived as predominantly bad due to difficulty adapting to the child's impairment will affect the latter's self-esteem (Wilson, 2003).

Klein argued that when a child with a disability has difficulty with breast- or bottle-feeding, the caregiver's frustration about her lack of success nursing the child may be transmitted to the child, thus intensifying its feeling of negativity. Wilson notes that Klein's study of early interactions between child and primary caregiver is supported by more recent research that indicates the presence of a disability may have an effect on these interactions. Consequently, Wilson contends that the earlier research of Klein provides some insight into the roots of emotional problems associated with some congenital disabilities (Wilson, 2003).

Wilson continues to provide justification for an object relations framework of development by citing the scholarship of Fairbairn (1952, 1956), which deals with the formation of satisfying and unsatisfying personal relationships as a function of personality development. Fairbairn conceptualized the non-satisfying object as having two sides: one that frustrates and one that tempts. Because the infant is unable to tolerate the situation, the non-satisfying object is split into two parts: an exciting object and a frustrating object. Both of these objects are repressed, eventually causing a splitting of the unitary ego. In applying Fairbairn's theory,

Wilson contends that, “we would not expect there to be differences in personality structure between people with disabilities and people without them, unless their disabilities prevented them from deriving satisfaction from their caregivers during childhood” (p. 26). In other words, only if a caregiver reacts differently to a child because the child has a disability, for example by overcompensating or by coldness and avoidance, would conflict be expected to occur. Defense mechanisms such as splits in the object and splits in the ego are necessary only because of negative experiences imposed on the individual by an external object (Wilson, 2003).

When the child has a disability, according to Wilson, a false self may develop under the following circumstances: when the nature of the impairment makes it difficult for the caregiver to adapt adequately by addressing the child’s immediate needs; or when the caregiver’s reaction to the child is influenced by the disability. An example of this latter situation would be if the caregiver experiences a sense of repulsion, embarrassment or hopelessness as a result of the child having a disability. Wilson notes that, “At times the disability itself or the medical treatment involved can represent a significant environmental impingement, which may result in the child withdrawing psychologically, becoming isolated and hiding its true self (Wilson, 2003, p. 27).

Wilson expands upon this notion of caregiver adjustment by examining a possible consequence of maladaptation, “hate in countertransference.” A concept first discussed by Winnicott (1975), this phenomenon refers to the tendency of caregivers and therapists sometimes to hate their children and clients respectively. Central to this concept is the ability to accept, rather than repress, objective feelings of hate. The fundamental premise of hate in countertransference is that “without objective hate there can be no objective love” (p. 27).

When applied to the development of a child with a disability, difficulty may occur when the caregiver overcompensates for natural feelings of objective hate. Wilson contends that this

can cause the child to lack the capacity to love. Further Wilson argues that, “the guilt associated with the hate felt towards the vulnerable child and reluctance to express the feeling can lead to the child exhibiting inappropriate responses” (Wilson, 2003, p. 27).

An example of an inappropriate response in this context may be the individual with an intellectual disability who expresses an uninhibited love for everyone he meets or everything he does without being able to meaningfully discriminate preference for one activity or person over another (Wilson, 2003).

To conclude her discussion of the developmental process component in the relational model, Wilson examines the degree to which children develop a sense of autonomy as a function of adapting to their environment. Wilson refers to the scholarship of Margaret Mahler in which Mahler hypothesized that such adaptation is modeled for the child by the mother. Mahler describes human development as, “A process whereby the child will eventually function on its own and not be helplessly dependent on the mother, but at the same time will retain an interpersonal tie to the mother” (p. 28). Mahler suggests that, “the separation/individuation process is particularly complicated for infants with a disability due to their physical need for extra help and support. When the physical need for help remains almost unchanged, it may be difficult for both the mother and infant to forge a distinct sense of identity” (p 28). Wilson cautions that, “some mothers of children with disabilities feel guilty about not preventing their child's predicament, and therefore tend to discourage attempts at separation and independence” (Wilson, 2003, p. 28).

Building upon the idea of separation, Wilson introduces the second component in the relational model which is the individual's perception of self. Wilson addresses self-perceptions from two perspectives: the perceptions of those with congenital disabilities, and those who have

acquired a disability since birth as a result of illness or injury. The relational model maintains that an impaired body is not necessarily experienced by the person with a disability as damaged or deformed. Rather as a product of object relations and attachment theories, disability under the relational model is perceived and constructed as a function of the cumulative experiences within an environment. Consequently, according to Wilson, “much of the available literature suggests that most people with a congenital disability perceive their body as a whole, integrated object rather than as incomplete” (Wilson, 2003, p. 28).

Conversely, the onset of disability forces those with newly acquired disabilities out of the nondisabled world to face the task of bridging the gap between their present reality and their pre-expulsion, pre-disability experience. A unique combination of factors affects the self-perception of all people with newly acquired disabilities, including their belief system, pre-disability experiences, self-esteem and the nature of their medical condition. There may also be external factors, such as reaction of their social group and the level of accommodation within the physical environment, which may also affect the rate of adjustment and overall self-perceptions of these individuals.

Wilson demonstrates the differences in perception among those with congenital and acquired disabilities by noting that a comparison of dreams reported in therapy indicates that people with a congenital disability rarely dream about their disability, while people who have acquired a disability later in life often refer to their dream life as a pre-disability space. Wilson notes that in such cases the individual psyche has yet to integrate the disability reality. Wilson concludes that people with newly acquired disabilities have to struggle to piece together the fragments of their past and their present in order to retain some stability and maintain continuity with their sense of self.

People with acquired disabilities and those with congenital impairments may experience feelings of envy, rage and a sense of loss. According to Wilson, such emotions stem from the individual's perception of themselves as different, due to their impaired body or their disabling social and physical environment. Further, Wilson asserts that, "The world in which the members of both groups live is not yet ready to accept and embrace their differences, therefore, everyday functioning is studded with attitudinal and physical obstacles that exacerbate their sense of alienation" (Wilson, 2003, p. 32).

Building upon the concept of self-perception, Wilson begins to address the adjustment to disability by introducing the third component of the relational model. In this phase the individual with a disability continues to develop their identity, seeks autonomy and works to achieve separation from parents and caregivers. According to Wilson, "although most disabilities are visible, accepting oneself as having a disability is often the final stage of a long process of gaining self-knowledge and making relational adjustment" (p. 34). Wilson contends further that this acceptance process is often hampered by society's fear of disability and the measures taken to mitigate their effects (Wilson, 2003).

Wilson notes that most children with disabilities experience life from a different perspective from that of their parents and siblings. However, Wilson asserts that it is not always clear who "their own" kind is. There is rarely an available role model to look up to and identify with, so children with disabilities are constantly reminded that they are different. Regardless of how much their family and relations accept and love them, being a stranger without peers or a reference group can hinder the development of their identity and sense of self (Wilson, 2003).

Additionally, Wilson suggests that for some individuals with disabilities it is difficult to reconcile their identity as a member of the disability community even as adults. Wilson

references the scholarship of Rhoda Okin (1999), an individual with childhood onset of polio. Okin describes how for 30 years she tried to disguise the effects of her disability. Further, Okin writes about the process of admitting the impact that functional limitations from polio have on her life. She states, “I am bicultural. I live in two worlds — the nondisabled majority and my minority group's world of the disability community” (p. 33). Okin explains further that discovering her own peer group within the community of people with disabilities brought her a sense of relief. She cautions that “The community of persons with disability has an open enrolment — anyone can join at any time by acquiring a disability. The irony here stems from the assumption that most people do not want to join the community of persons with disabilities but it is a one-way ticket, that is, people with disabilities are not welcome to join the community of people without disabilities” (Wilson, 2003, p 33).

According to the relational model, parents must strike a balance between encouraging autonomy and independence, while providing the necessary care and support. Wilson observes that both children with disabilities and their parents may retain the idea that the effects of disability will decrease with age, as if the impairment is a delayed developmental milestone. Wilson recognizes that raising a child with a disability during infancy is not unlike raising a child without a disability. In either case the child is completely dependent upon a caregiver. However, differentiation occurs when the need for dependency gradually decreases with the typical child during early adolescence (Wilson, 2003).

When parent and child realize that the functional limitations of the disability do not subside with age, both parties are forced to reconcile long-held dreams with present realities. In other words, parents have coped to address the specific needs of their children but now are facing

a larger systemic issue. Therefore, Wilson notes that many parents and individuals with disabilities need professional emotional support at this point (Wilson, 2003).

Wilson suggests that these parents are confronted with the question of whether they are destined to be the eternal caregiver of their children or whether these individuals with disabilities should be left to find their own way as with any other emerging adult. Wilson encourages parents to think about their love for and care of their children, as well as the resentment and anger about the effect that the children have had on their lives (Wilson, 2003).

Some parents defend themselves against uncertainty, guilt and anxiety by treating the young people with disabilities as though they will remain forever in a child-like state. Wilson offers several examples such as the 29-year-old female who was not allowed to style her hair and was left sexually ignorant for “her own protection.” This indicates the emotional complexity of the environment in which many young people with disabilities are struggling for autonomy,” according to Wilson.

The fourth and final component of the relational model is the conceptualization of disability as an eternal transition within the construct of adolescence. The theoretical framework of the relational model utilizes the concept of adolescence to understand the process of transition and change. Adolescence is the transitional period in which the dependent child is expected to prepare to become an independent adult. It is a period in which freedom, autonomy and responsibility are exercised and tested in preparation for mature adulthood.

According to Wilson, “The concept of adolescence, which is used in understanding the maturation process of people without disabilities, may offer a way of understanding this aspect of the experience of a person with a disability. Wilson suggests that, “for people who have been disabled since birth or early infancy there may not have been an event to trigger regression or

arrested development. Yet such people are often perceived by themselves and others as being stuck in adolescence, either never experiencing full adulthood or only having occasional short sorties into adulthood before regressing back” (Wilson, 2003, p. 34). Wilson contends that this framework may yield an insight into the adaptive process that people with disabilities go through.

Four Tasks of Adolescent Development

Wilson provides a set of four tasks she contends characteristic of adolescent development and suggests how these activities may evolve for individuals with disabilities and their families. These four tasks include: (1) disengaging from parental figures, (2) dealing with the desire to change the unchangeable, (3) ensuring continuity with the past, and (4) consolidating gender identity and sexual preferences.

According to Wilson, “Adolescence is an in-between state that is often seen as the second individuation process. It is a transitional time in which young people prepare to embrace the autonomy and responsibility of adulthood and to let go of the security, familiarity and dependency of childhood. For young people without disabilities, autonomy is a natural outcome of completion of the difficult tasks of adolescence. For some people with disabilities, however, the challenge of completing these tasks may at times seem insurmountable” (Wilson, 2003, p. 36).

The first task of Wilson’s taxonomy is to disengage from parental figures, both as love objects and as authority figures, and to accept ownership of one’s body and responsibility for one’s actions. This task has two stages. Stage one: disengagement from the parental figure. In addition to the separation difficulties experienced by many youngsters without disabilities, those with disabilities are faced with confusion and ambivalence about the practical process of

disengaging. Typical youngsters are expected to spend unsupervised time learning how to negotiate their own place in the world by measuring their strength against that of peers, as well as communicating, developing relationships and exploring their sexuality. Most people with disabilities are rarely left unsupervised, either by their parents, their caregivers or other professionals. Without some degree of privacy it is difficult to develop peer relationships and put social skills to the test. Deprived of 'behind the bike shed' experiences, whether real or metaphorical, people with disabilities do not have the opportunity to experiment, explore their sexuality or exchange information. Due to their limited peer-group contact they are usually more dependent on and have a more involved and intense relationship with their parents and supporting individuals than do people without disabilities (Wilson, 2003).

Wilson encourages therapists and other professionals to identify and familiarize themselves with the factors that are contributing to their clients' difficulty with disengaging from parental authority figures, especially restrictions on interpersonal relationships. The parents of adolescents with disabilities may be torn between a desire to protect the latter and compensate for the impairment, and a desire for them to find a place in the world. The success of the disengagement process depends to a large degree on the extent to which parents are able to resolve this conflict. Even adult clients can be affected by unresolved parental guilt, shame or anger. Additionally, Wilson notes that beyond formal therapy, disability management programs and other informal practical help can play an important part in enabling the task of disengagement (Wilson, 2003).

The second stage of the disengagement task involves accepting ownership of the body and the psychological reactions to it. This stage for the adolescent is the culmination of the period of growth, during which their bodies have been subject to constant physiological change.

At times they may have felt out of control, which may have challenged their sense of ownership of and responsibility for their bodies. However, once the changes slow down and the body reaches equilibrium they are ready for this ownership and responsibility (Wilson, 2003).

Wilson's second task of adolescence is dealing with the desire to change the unchangeable. Wilson cautions that, "It is questionable whether this task can or should ever be fully completed. Who decides what is and what is not changeable? Is the wish to undergo orthopedic or cosmetic surgery in order to improve the functioning or appearance of the body an indication of an incomplete task of adolescence? Is the wish to change the attitudes of others part of this task? Rather than letting go of the wish to change, it might be better to develop the capacity to engage in an ongoing evaluation of wishes and aspirations" (p. 38).

To illustrate this phenomenon Wilson refers to the example of Christopher Reeve, who from the time of his spinal cord injury from a horseback riding accident until the time of his passing, was constantly looking for treatments that would allow him to walk again. Wilson questions whether Reeve's desire to "find a cure" arose from being unwilling to reevaluate aspirations based upon residual functioning, or the reluctance to let go of a coping mechanism based in denial, which Reeve had developed because the situation was otherwise unbearable for him (Wilson, 2003).

Wilson also acknowledges that there may be some instances where individuals with disabilities may be unwilling to accept their diagnoses and they attempt to conceal any physical manifestations of the disability. Such is the case with individuals who refuse to utilize assistive devices while in the view of others. In these situations, Wilson encourages professionals to work with the individual to evaluate the consequences of retaining possibly unrealistic hopes against

the value of forfeiting these wishes and investing emotional energy in opportunities that are available within the present circumstance (Wilson, 2003).

The third task of Wilson's model of adolescent development is ensuring continuity with the past. Wilson notes that there is a somewhat paradoxical element to this task, which is about holding on to something that is no more. A ritualistic structure such as mourning can offer a useful framework for maintaining continuity with the past. A difficult but essential part of the maturation process is developing a willingness to acknowledge pain and sadness while letting go of unfulfilled hopes and desires. Developing the ability to recognize the past as part of oneself while at the same time living in the present and looking forward to the future can prove a challenge to some people with disabilities and those affected by their disability, such as their parents. It is a balance between becoming stuck in the past, and severing links with it altogether. Wilson provides the example of an individual who turned away from the flow of his life in the present because he could not let go of his desire to walk. Likewise, parents who reject their child with a disability as a defense against the pain of not having their wished-for child are trying to sever links with the past (Wilson, 2003, p. 38).

The fourth and final task in Wilson's framework of adolescence is the consolidation of gender identity and sexual preference. The process of sexual development in a physical sense is fundamentally the same whether an individual has a disability or not. According to Wilson,

The main stumbling block for people with disabilities is the way in which they are perceived and related to by others, either as asexual beings or as oddities. However, even when they are accepted as ordinary sexual beings, individuals with disabilities are faced with a mass of practical obstacles to exploring their sexuality and forming sexual relationships (Wilson, 2003, p. 39).

Wilson contends that, “The reason for the lack of experimentation and risk taking amongst some people with disabilities could be the result of internalizing the perceptions of and attitudes towards their sexuality presented by their parents, the media and other sources” (Wilson, 2003, p. 39). Further, Wilson suggests that professionals should help individuals to raise their awareness of the role of physical and emotional courage and of the possibility of challenging authority and exploring relationships and sexuality (Wilson 2003).

Wilson concludes that, regardless of an individual’s chronological age, he or she may still be struggling with unfinished tasks of adolescence, which can cause confusion about identity and self-image. Wilson’s four tasks of adolescence offer a useful framework for facilitating the maturation process. People who were born with an impairment may never have had the encouragement to grow up and reach adulthood, while people who have acquired a disability later in life may find themselves regressing into adolescence because they had not been prepared for life as an adult with the disability (Wilson, 2003, p. 40).

With this understanding, it is now possible to understand that individuals with disabilities have methods by which they are able to provide meaningful contributions to the workforce and to society generally. Socially oriented models postulate that the effects of disability can be minimized with modifications to the physical and social environments (Smart, 2009). It is from this framework that employers and other professionals began to see tangible action items that if achieved, may facilitate the inclusion of people with disabilities in the workforce, as well as other aspects of society.

In most of these latter definitions, severe physical disability is characterized by functional limitations to the extent that the individual is unable to perform ADLs and IADLs on his or her own and needs personal/human assistance (PA) to accomplish those tasks (Hoenig et al., 2003;

Kaye, Chapman, Newcomer, & Harrington, 2006; LaPlante, Kaye, Kang, & Harrington, 2004). Kennedy et al. (1997) noted that “people with ADL limitations, and in particular those needing assistance, are considered to have fairly severe disabilities” (p. 1). Guralnik (2006) more specifically defined severe physical disability as when “the individual needs help with three or more of the six ADLs (eating, dressing, bathing, transferring, using the toilet, and walking across a small room)” (p. 162). This definition of severe physical disability, with the emphasis on the need for personal assistance, is generally supported throughout the disability and health care literature (Desai & Lentzner, 2001; Jans & Stoddard, 1999; Philip, Armstrong, Coyle, Chadwick, & Machado, 1998; Rathouz et al., 1998; US Department of Education, 2005).

Numbers of Individuals with Severe Physical Disabilities

In 2005, there was an estimated 291.1 million people in the U.S., of which 54.4 million (18.7%) claimed a disability. The number of people with severe physical disabilities (those who needed personal assistance with three or more ADLs and/or IADLs) aged 15 and older stood at more than 6.3 million individuals (Brault, 2008). Persons with severe physical disabilities thus comprised nearly 12 percent of all individuals with disabilities in the United States during 2005.

In comparison, in 2002, 51.2 million people (18.1%) of the U.S. population of 282.8 million had a disability, with 5.1 million needing assistance with three or more ADLs and/or IADLs (Steinmetz, 2006). Between 2003 and 2005, the overall number and percent of individuals with disabilities increased, as did the number of individuals with severe physical disabilities requiring personal assistance - from 5.1 to 6.3 million (Brault, 2008; Steinmetz, 2006). With the advent of better medical care and pervasive assistive technologies, the numbers and percentages of people living with severe physical disabilities is increasing and it is likely this trend will continue in the foreseeable future (Hedrick et al., 2010).

Kennedy, LaPlante, and Kaye (1997), estimated that the population of individuals needing assistance in the performance of one or more ADLs included 90,000 high school and college-aged individuals with disabilities (15 to 24 years of age). The latter group of young people is at great risk of experiencing significantly lower educational achievement and decades of unemployment as individuals with substantially limiting physical impairments (Hedrick, 2008).

Further, the United States Census Bureau (American Community Survey) defines physical disability as the "condition of an individual who is substantially limited in one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying" (p.155). The survey additionally specifies a self-care disability as the "condition of an individual who has difficulty dressing, bathing, or getting around inside the home because of a physical, mental, or emotional condition lasting six months or more" (Rehabilitation Research and Training Center on Disability Statistics and Demographics, 2009).

According to the 2007 American Community Survey, of the 1,731,991 individuals aged 18 to 34 reporting a physical disability in the United States, only 209,089 reported being enrolled in college or graduate school (12.1%). That same survey reports that among 606,411 individuals who reported having a disability that limits their ability to perform self-care activities, only 52,912 (8.7%) report being enrolled in college or graduate school (Rehabilitation Research and Training Center on Disability Statistics and Demographics, 2009).

Use of Personal Assistance

Verbrugge and colleagues noted that individuals "rarely allow disablement to take its course without efforts to retard or stop the process...Personal and equipment assistance reduce task demand...They operate at the immediate periphery of the individual...Both kinds of

assistance aim to solve problems” (Verbrugge & Rennert, 1997, p. 384). In other words, individuals with severe physical disabilities work diligently to offset their functional limitations, and because of their extensive needs, solve these difficulties through heavy reliance on personal and technological assistance. Those with the most severe physical disabilities may use a variety of assistive technologies, but rely substantially on personalized, human assistance to perform everyday tasks.

According to Hoenig et al. (2003), personal assistance services (PAS) refers to human help provided to individuals in specific activities that are generally obligatory for bodily maintenance and for living in the community, comprising the activities of daily living (ADLs, including bathing, dressing, transferring from a bed or chair, toileting, and eating) and the instrumental activities of daily living (IADLs, such as taking medications and shopping for groceries). PAS include all help, whether hands-on, standby, or supervisory, whether paid or unpaid (p. 99).

A number of experts have noted that assistive technology (AT) can often augment, but not replace, human help for these individuals (Agree et al., 2005; Hoenig et al., 2003; Kaye et al., 2006; Kennedy, LaPlante, & Kaye, 1997; LaPlante et al., 2004). What is often not noted in the literature is that for individuals with severe physical disabilities, access to PAS is often necessary 24 hours a day, seven days a week, 365 days a year. Consider personal care, for example: In addition to the normal daytime activities, during sleeping hours, assistance for essential needs such as turning while in bed or arranging pillows and bedding are required. In the event of illness or emergency, assistance must be available and reliable. If the required PAS is not available when it is needed, the individual and/or the student will not be able to live successfully in that environment. For tasks common to academic activities, such as turning book pages, opening

doors, reaching for items, and turning on/off lights, assistance must be available when it is needed, or again the individual and/or the student will not be able to pursue a postsecondary education.

LaPlante et al. (2004) noted that PAS occur across a continuum or hierarchy of expanding needs; the need for PAS increase as the ability to perform ADL and IADL activities decreases. As noted by Newcomer, Kang, LaPlante, and Kaye (2005, p. 205), “rates of unmet need increased as the number of ADL limitations increased.” When there is not enough personal or technical assistance, the needs of a person with a severe physical disability go unmet, and may cause a cascade of secondary health complications, such as discomfort, weight loss, dehydration, falls, and burns (LaPlante et al., 2004), as well as the inability to function in education, employment, and community settings.

These examples lend support to the notion that disability is both dynamic and holistic. There is a dynamic tension between the response to disability by the individual and the response to disability by an external observer. This tension demands a corresponding change in the psychological and social processes that enable them to maintain positive self-esteem and fulfillment of their roles in family and community. This process of continual reassessment and adjustment is called response shift (Nosek, 2012).

During the adjustment process people who hold negative and limiting attitudes toward disability often exert an undue influence and render a disservice to the disabled individual by forcing them to internalize these perceptions. Accordingly, the degree to which individuals and families have developed the capacity to adjust to any new circumstances will determine how they respond to disability.

This response to adversity and the stress that results is referred to as coping. How individuals cope can depend on many factors, including age, gender, personality, experience, intellectual ability, cognitive style, severity of the stress, and how much time has passed since the stressful event. Coping styles have been categorized many different ways according to the focus and the method used: e.g., problem focused or emotion focused, engagement versus disengagement, cognition or behavior, and internalizing or externalizing. Five common psychosocial reactions in coping with disabilities include anxiety, depression, anger, denial, and positive adjustment (Nosek, 2012).

Less positive psychosocial responses to disability often result from institutionalized social exclusion, discrimination, stigma, and devaluation of people with disabilities. However, the grassroots independent living movement has brought to light the importance of peer role modeling and peer counseling. According to Nosek, “By talking with others who face similar or even greater disability-related barriers and psychosocial challenges, individuals can gain confidence and new ideas about coping strategies, daily functioning, self-image, and more effective ways of relating to other people and the world around them” (Nosek, 2012, p. 119). This contention about the utility of having informal support with common experiences is affirmed by the research of Allison (2007) and the case study of Jim (Appendix 1).

The holistic and dynamic nature of disability management is supported by the concept of phenomenology in counseling and psychotherapy literature. This methodology for studying the lived experience “provides a view of human history that does not focus on past events but motivates individuals to look forward to ‘authentic experiences’ that are yet to come”(Corey, 2009). This approach presumes that human beings exist within the world and should consider themselves interactive participants in the world in which they live. The extent to which human

beings attribute meaning to daily activities is, according to Corey, an indicator of their views about mortality. Those who engage in superficial conversation are behaving as if life on earth is infinite. An evaluation of moods and feelings about the world will determine the authenticity of the lived experience. The degree to which humans live authentically is a function of whether they have been able to formulate their own expectations in life rather than primarily constructing their outlook around the expectations of others. After such an analysis humans may be more able to self-actualize or be who they want to be (Corey, 2009).

The recognition of a phenomenological approach to disability management is embodied in life care planning. A life care plan is a dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized, concise plan for current and future needs with associated costs for individuals who have experienced catastrophic injury or have chronic health care needs (Allison, 2007).

Allison (2007) conducted a qualitative study of seven individuals with varying levels of spinal cord injury to consider how accurately each participant's individualized life care plan projected his or her current need for personal assistance and consultation with general and specialty physicians. Further, researchers were interested in understanding the lived experiences of study participants and in exploring emerging themes that may have relevance to the life care planning process. In addition to collecting data relevant to personal assistance and physician consultations, the interview process was designed to gather information regarding outcomes and other factors that may impact these two categories of the life care plan. Each of the case studies revealed areas where life care plan projections were both consistent and inconsistent with current needs as reported by the participants (Allison, 2007).

In this study, each of the seven participants was asked to discuss the activities within their typical routines that require assistance from other individuals. The researchers clearly stated that, initially, only the activities for which the participant is actually receiving assistance should be identified. This question yielded three data points: (1) a list of the specific activities that require assistance, (2) the amount of time necessary to thoroughly and safely complete the activity, and (3) the provider of this assistance. The specific activities requiring personal assistance are not identified in the life care plan, but this specificity was necessary in order to prompt participants to reflect upon and accurately report their needs. Although the question, "How many hours of personal assistance do you require each week?" may appear to be straightforward, it is actually very complex. Accurate responses required participants to recall the specific activities that they are unable to complete independently and to report how long it takes to complete each task with assistance (Allison, 2007).

Personal assistance was defined as any form of help needed to complete a specified activity. This ranged from minimal stand-by assistance to total assistance in activities of daily living such as bathing, grooming, dressing, eating, and other tasks. In addition, assistance needed in transportation, community outings, worksites, and other settings were explored with each participant. In order to make the analysis of this data more informative, researchers prompted participants to consider the personal care required within each of the following categories: grooming and bathing tasks, household activities, community outings, and other activities (Allison, 2007).

Grooming and bathing tasks included activities such as dressing, hair styling, trimming nails and facial hair, and personal hygiene. Household tasks included activities such as cleaning, doing laundry, cooking, paying bills, and sorting mail. Community outings included activities

such as provision of transportation to and from shopping areas, social activities, and other events outside of the home. Other tasks, such as taking medications or making appointments, comprised the fourth category (Allison, 2007).

Four of the seven subjects who utilized personal assistance at the time of the interview were then asked to report whether they are receiving the amount of personal assistance that they truly need. The researchers utilized a skip pattern based upon participant responses. For example, if a participant responded affirmatively, the researchers continued to other areas of the interview. For those stating they were not receiving the amount of weekly personal assistance that is necessary, a probe was added that asked participants to describe the activities requiring additional assistance and to estimate the additional amount of time necessary to complete the task. For each task, participants were asked to discuss why this additional assistance is necessary and why it is not currently received. Activities were explored within the four primary task areas established earlier (i.e., grooming and bathing tasks, household activities, community outings, and other activities).

Additional probes included questions regarding service utilization access, transportation needs, vocational status, social activities and community participation, acquisition of information about services and tools that may enhance independence, and others as appropriate. According to Allison, "Discussion regarding personal assistance was an essential element of the investigation because it facilitated a greater understanding of participant experience. Although adequate funding, availability of healthcare professionals, and other factors may prevent individuals from accessing needed assistance, the necessity for such care may exist" (p.156). Therefore, the perspective of the participant and possible barriers to needed assistance should be taken into

account when considering responses in relation to assessing quality of life measures as a component of life care plan development (Allison, 2007).

In her analysis of emerging themes from the case study of Jim (Appendix 1) Allison notes, “it appears as though periodic meetings with a case manager could have been of value soon after discharge from the rehabilitation facility and in the years since” (Allison, 2007, p.157). Jim stated that he would have benefited from having additional guidance in recruiting, selecting, and training attendants. In addition, while in college a case manager may have been able to suggest assistive technologies, campus and community services, and other resources that could have enhanced his educational experience. Later, a case manager may have assisted with tasks such as locating qualified attendants, coordinating preventative health care, and providing informational resources regarding spinal cord injury. Jim successfully earned academic degrees, operated a retail business, and managed his attendant care, but case management support may have introduced him to additional tools and resources that would have been of value.

Funding of Personal Assistance Services in the United States

Stumbo et al. (2009) recognized the important role public benefit programs play in the maintenance of services. Moreover, these researchers realized that disparities in funding among states will create another inequity barrier for students with significant disabilities. Individuals with disabilities who require personal assistance have a number of potential options available to them for the underwriting of such services. Individuals may, depending upon their state of residence, receive financial underwriting via Medicaid or vocational rehabilitation. However, funding for personal assistance services constitutes a necessary but insufficient condition for successful matriculation (Stumbo et al., 2009).

Two large Medicaid programs provide long-term services and supports to persons with intellectual and developmental disabilities. The Medicaid Intermediate Care Facility for the Developmentally Disabled (ICF/DD) program was first authorized in 1971. This program provided the first Medicaid long-term services and supports benefit specifically for persons with intellectual and developmental disabilities. In 1981, the Medicaid Home and Community Based Services (HCBS) program was authorized as an alternative to the institutional standards of the ICF/DD program. The HCBS program provided a community complement to the ICF/DD program at a time of accelerating commitments within states to develop community and family supports. Reflecting those commitments, between June 1982 and June 2005, the number of people receiving paid support while living in community homes of three or fewer persons with intellectual and developmental disabilities increased from 15,700 to 184,000, and the number in settings with four-six residents with intellectual and developmental disabilities increased from 17,500 to 107,100 persons. In contrast, the number of persons with intellectual and developmental disabilities in public and private institutions of 16 or more residents decreased from about 180,100 to about 67,000 (Lakin et al., 2008).

Medicaid HCBS played a significant role in financing the substantial shifts from institutional to community supports. Between June 30, 1992, and June 30, 2005, the number of HCBS recipients with intellectual and developmental disabilities increased from about 62,500 in June 1992 to about 443,600 in June 2005. During the same period, the number of ICF/DD residents decreased from 146,300 in June 1992 to 101,800 in June 2005 (Lakin et al., 2008).

The Rehabilitation Act of 1973 (P.L. 94-112) established federal-state public Vocational Rehabilitation (VR) programs. Under the Act, VR services are defined as, “ any services described in an individualized plan for employment necessary to assist an individual with a

disability in preparing for, securing, retaining, or regaining an employment outcome that is consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individual” (Rehabilitation Act of 1973, 2012).

An Individualized Plan for Employment (IPE) is a cooperatively developed plan for achieving an employment goal by identifying the types and number of services that will be provided. The IPE contains six mandatory components. The first is a description of the specific employment outcome that is chosen by the eligible individual that is consistent with the unique strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the eligible individual, and, to the maximum extent appropriate, result in employment in an integrated setting.

The second component of the IPE contains a description of specific vocational rehabilitation services that are needed to achieve the employment outcome. These include, as appropriate, the provision of assistive technology devices and assistive technology services, and personal assistance services, including training in the management of such services. These should be provided in the most integrated setting that is appropriate for the service involved and is consistent with the informed choice of the eligible individual; and timelines for the achievement of the employment outcome and for the initiation of the services.

The third component of the IPE is a description of the entity chosen by the eligible individual or, as appropriate, the individual’s representative, that will provide the vocational rehabilitation services, and the methods used to procure such services. The fourth component is a description of criteria to evaluate progress toward achievement of the employment outcome. The fifth component of the IPE contains a detailed statement regarding the terms and conditions of the IPE, including, as appropriate, information describing the responsibilities of the state

rehabilitation agency; the responsibilities that the eligible individual will assume in relation to the employment outcome of the individual; if applicable, the participation of the eligible individual in paying for the costs of the plan; and the responsibility of the eligible individual with regard to applying for and securing comparable benefits. Comparable benefits analysis means prior to providing most vocational rehabilitation services to an individual the state agency will determine whether comparable services and benefits are available under any other program (Rehabilitation Act of 1973, 2006). After comparable benefits are secured, a statement regarding the responsibilities of other entities as the result of such agreements is required.

The sixth component of the IPE is a statement of projected need for post-employment services, if the need for such services is anticipated by the counselor or eligible individual (Rehabilitation Act of 1973, 2012).

One of the many services subsidized under the federal-state rehabilitation program for qualified consumers is vocational training. Such services include the provision of personal and vocational adjustment services, books, tools, and other training materials, except that no training services provided at an institution of higher education shall be paid for with vocational rehabilitation funds unless maximum efforts have been made by the designated State unit and the individual to secure grant assistance, in whole or in part, from other sources to pay for such training (Rehabilitation Act of 1973, 2012). Maximum effort means completing public student aid applications both through the U.S. Department of Education, as well as any state administered education grant programs. Federal student loans are not considered a comparable benefit for purposes of determining eligibility for tuition assistance from state VR agencies. Also excluded are scholarships and other merit-based awards (Rehabilitation Act of 1973, 2006).

State VR agencies may also provide therapeutic treatment necessary to correct or substantially modify a physical or mental condition that constitutes a substantial impediment to employment, but is of such a nature that correction or modification may reasonably be expected to eliminate or reduce an impediment to employment within a reasonable length of time. These services are also only authorized to the extent that financial support is not readily available from a source, such as through health insurance of the individual or through comparable services and benefits (Rehabilitation Act of 1973, 2012).

State VR agencies may also provide maintenance for additional costs incurred while participating in an assessment for determining eligibility and vocational rehabilitation needs or while receiving services under an IPE. This can include on-the-job or other related personal assistance services provided while an individual is receiving other services from vocational rehabilitation (Rehabilitation Act of 1973, 2012).

To take advantage of VR agency funding, students must know the communities into which they are moving. They must understand the local personal assistance labor force and know how to most effectively communicate with them. In some college/university communities, local independent living centers provide valuable assistance in helping students learn how to most effectively and efficiently access prospective personal assistants in those communities. However, in the end, students who require personal assistance are unlikely to enroll at a postsecondary institution away from home if they perceive themselves as lacking the knowledge and skills necessary to effectively recruit, screen, interview, hire, train, schedule, manage, and dismiss personal assistance personnel (Stumbo et al., 2009).

Funding for personal assistance services remains a critical issue for many people with severe physical disabilities. Additional research is needed about the inconsistencies that exist in

state and federal waiver-based funding policies, programs, and outcomes. For example, Medicaid consumer directed personal assistance services (CDPAS) is a growing and promising trend that affords Medicaid beneficiaries control over hiring, scheduling, training and paying for personal care attendants.

“Home or community-based services” means services furnished under the state's Medicaid plan, and furnished under a waiver granted by the Centers for Medicare Medicaid Services (CMS) (Home and Community-Based Waiver Services, 2014). These services may include any or all of the following as defined by individual state Medicaid agencies and approved by CMS: (1) Case management services; (2) Homemaker services; (3) Home health aide services; (4) Personal care services; (5) Adult day health services; (6) Habilitation services.; (7) Respite care services; (8) Day treatment or other partial hospitalization services, psychosocial rehabilitation services and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness; (9) Other services requested by the agency and approved by CMS as cost effective and necessary to avoid institutionalization.

The extent to which variations and gaps exist in the availability of CDPAS affect the ability of persons with severe physical disabilities to attend postsecondary education and enjoy fruitful and meaningful careers is a significant policy barrier nationally (Stumbo et al., 2009). Of the \$84.5 billion spent on what the CMS terms as Long-Term Services and Supports (LTSS) between 1993 and 2003, only 23% was expended for HCBS programs, with the remaining 77% still dedicated to institution-based care (Lakin, Prouty, & Coucouvanis, 2005).

Lakin et al. (2008), examined expenditures for a random sample of 1,421 adult Home and Community Based Services (HCBS) and Intermediate Care Facility for the Developmentally Disabled (ICF/DD) recipients in four states. Investigation revealed variations in expenditures for

individuals with different characteristics and service needs and, controlling for (1) individual characteristics, (2) residential setting type, (3) Medicaid program (ICF/DD or HCBS), and (4) state of residence, the annual average per-person Medicaid expenditures for HCBS recipients were less than those for ICF/DD residents (\$61,770 and \$128,275, respectively). HCBS recipients had less severe disability (intellectual, physical, health service needs) than ICF/DD residents. Controlling for these differences, and for congregate settings, HCBS recipients were less costly than ICF/DD recipients, but this distinction accounted for only 3.3% of variation in expenditures. Persons living with families receiving HCBS (\$25,072) and in host families (including foster, companion, or shared living arrangements; \$44,112) had the lowest Medicaid expenditures (Lakin et al., 2008).

A persistent argument against providing equal funding for HCBS and ICF/MR services is that states do not have the necessary resources to fund these services. For example, as reported in the annual report of the Alabama Medicaid Agency, as of FY 2009, the Alabama Agency was still demonstrating a strong preference for institution-based services. The Alabama Agency reported that of the 26,145 licensed nursing facility beds in Alabama, 63% were used by Medicaid-eligible individuals at a cost of more than \$50,735 annually per patient. In other words, for every Medicaid dollar spent on long-term care services in Alabama \$0.90 is devoted to institutional based care and \$0.10 is directed toward HCBS.

By contrast, under the HCBS model, assuming that a recipient is granted the maximum number of billable hours allowed in the jurisdiction (30 hours weekly), at the standard rate of \$8 dollars per hour, the cost to the AL Agency to staff that recipient at home would be \$12,480 annually (Alabama Medicaid Agency, 2010). The 90% ratio in favor of institutional care is supported by current state regulations. Under Alabama Administrative Code (Medicaid) Rule

No. 560-X-22-.06, long-term care providers are allowed to utilize a formula that guarantees providers will be reimbursed at 87% of total possible occupancy regardless of their actual census (Chappelle, 2010).

As a result of these funding disparities, it is challenging to implement a program for students with significant disabilities in higher education when there is little public support for the notion of creating these programs in the community generally. However, for individuals with significant disabilities, supported access to higher education is essential to obtaining opportunities in the primary labor market (Hagner, 2000).

Hagner explores the theoretical and empirical work in labor economics and the sociology of work relating to the segmentation of the labor market into a primary and a secondary sector and examines the implications for vocational rehabilitation. Demand-side and supply-side factors associated with the development of segmented labor markets and movement of workers from the secondary to the primary sector are reviewed. Transition into primary sector employment is explored as an important aspect of career development for individuals with disabilities. Recommendations for working toward this goal are offered for job development, job analysis, and job training and support (Hagner, 2000).

Hagner recognizes the majority of positions held by individuals with disabilities are confined to a relatively narrow portion of the overall labor market. Citing earlier research of Walls and Fullmer (1997), which found that among 103,417 successfully rehabilitated individuals, the top five occupations held by consumers of all disability types achieving competitive employment through the state-federal VR system were janitor, chef/cook, attendant, porter/cleaner, and kitchen worker. Together, these five occupations accounted for more than 20% of all rehabilitants. Although the number of jobs in these occupations is growing, they are

primarily low paying and seldom offer benefits. Consequently, Hagner contends that many of the occupations most frequently held by rehabilitated individuals require relatively little training and minimal skill levels. This trend is even more noticeable in the area of supportive employment. To support his assertion, Hagner refers to research by Banks and Kregel (1991), which found that about 87% of VR supported employees worked in only two types of work fields: food service (48.7%) and custodial (35.4%). Hagner cites additional research (Meisenheimer, 1998), which points to these occupations as being two of the lowest paid jobs in the economy (Hagner, 2000).

According to the author, this discrepancy may be rooted in the fact that there is an emphasis in rehabilitation counseling on one-time job placement for consumers and the relatively small amount of time typically devoted to career development assistance. Hagner contends that existing research has demonstrated that the VR program needed to address career development for individuals with disabilities through a sequence of stages, beginning with exploration and advancing through establishment and maintenance phases. However, he supports additional scholarship, but cautions: "If clients do not complete exploration tasks satisfactorily, they may become fixed in secondary labor market positions with little future" (Hagner, 2000).

Hagner discusses the characteristics of both primary and secondary labor markets as they are defined in existing literature. Dual sector labor market theory holds that the labor market is not a single arena but is segmented into two tiers or sectors. In the upper or primary sector, workers enjoy relatively high wages, fringe benefits, satisfactory working conditions, and employment security. Primary sector workers have reasonably equitable workplace policies, and workers receive raises and promotions, or they move to more desirable jobs with another

company as their skills and knowledge increase. Additionally, primary sector jobs tend to offer some degree of worker autonomy (Hagner, 2000).

In the secondary sector, wages are low, benefits are minimal or nonexistent, work conditions are less desirable, lay-offs and periods of unemployment are more probable, and supervision styles and work rules can be somewhat more harsh or arbitrary. Workers seldom experience any degree of autonomy. Secondary jobs also tend to be concentrated in the least prestigious occupations in the economy, such as those uncharitably referred to as "food and filth" jobs. The rate of turnover in these jobs tends to be high (Hagner, 2000).

Consequently, the critical feature of labor market segmentation is that workers in the secondary sector tend to become stuck in that sector after a time, unable to bridge the gap and rise into the primary sector even as they continue to gain work experience. According to dual market theory, a barrier to movement is built into the structure of the labor market, making it difficult for long-term secondary workers to advance to the primary sector (Hagner, 2000).

The absence of potential for advancement can prove problematic in achieving the fundamental goals of the vocational rehabilitation process. According to the author, the central aims of vocational rehabilitation are for consumers to achieve self-sufficiency and be able to support themselves through earned income. From this perspective, terminal placement of a consumer in a secondary sector job is problematic in several respects: Wages in the secondary sector are not high enough to allow an individual to dispense with the need for additional unearned income, and secondary jobs provide fewer benefits, are less safe, and offer less employer support and less job security. According to dual labor market theorists, secondary sector workers can expect little job-related training, few transferrable skills, and more difficulty advancing beyond the beginning stages of career development (Hagner, 2000)

Personal Assistance Services (PAS) in Postsecondary Education (PSE)

A number of factors surrounding PAS in PSE have led to its almost total exclusion in the American research literature. As reported in this research, a relatively small number of individuals are affected compared to those with other disabilities enrolling in higher education (such as individuals with learning disabilities or less-severe physical disabilities). In addition, this group has comparatively higher resource-intensive needs per person than other groups of people with disabilities. From the perspective of the PSE institution, meeting the very resource-intensive needs of a small minority of students is difficult to justify given the increasing numbers of students with disabilities entering higher education and whose needs can be met more simply through computer technology or physical and environmental accessibility (Stodden, Roberts, Picklesimer, Jackson, & Chang, 2006; Turner, Revell, Strobel, & McDonough, 2003). And finally, there is no legal mandate to provide personal assistance services in postsecondary education similar to the requirements for secondary education (US Department of Education, 2005; US Department of Education, 2007). However, it is clear that postsecondary education degrees are essential for all individuals to obtain and retain competitive employment especially in the primary labor market (Diab & Johnston, 2004; Stodden & Dowrick, 1999; Stodden & Conway, 2003; Stodden, Dowrick, Anderson, Heyer, & Acosta, 2005; Stodden et al., 2005; Stodden et al., 2006) and this may be especially true for individuals with severe physical disabilities (Brault, 2008; Steinmetz, 2006).

Legal Mandates

The Individuals with Disabilities Education Act (IDEA, P.L. 101-476) requires that state and local elementary and secondary agencies that accept federal funding must provide personal services and aides, including PAS personnel, as warranted, to ensure that students with

disabilities are afforded a free appropriate public education. Under the Act, “Supplementary aids and services means aids, services, and other supports that are provided in regular education classes, other education-related settings, and in extracurricular and nonacademic settings, to enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate” (Supplementary Aids and Services, 2006).

Further the student’s Individualized Education Program (IEP) team must consider as part of its annual plan development or modification process, whether the student requires any supplementary aids and services. The IEP document must contain:

A statement of the special education and related services and supplementary aids and services, based on peer-reviewed research to the extent practicable, to be provided to the child, or on behalf of the child, and a statement of the program modifications or supports for school personnel that will be provided to enable the child: (i) To advance appropriately toward attaining the annual goals; (ii) To be involved in and make progress in the general education curriculum in accordance with paragraph (a)(1) of this section, and to participate in extracurricular and other nonacademic activities; and (iii) To be educated and participate with other children with disabilities and nondisabled children in the activities described in this section. (Definition of Individualized Education Program, 2007)

In determining the nature and scope of support needed, technical assistance literature indicates that the provision of one-to-one instructional or health care assistance may be considered as a supplementary aid or service so long as this assistance is required for the student to receive a free and appropriate public education. Normally, secondary schools are responsible

for hiring, training, and supervising personal assistants for high school students with assessed needs and the student and his/her parents are not usually involved in that process.

On the other hand, postsecondary institutions are not legally required to provide similar services with regard to PAS (US Department of Education, 2005; US Department of Education, 2007). While the Department has made it clear that postsecondary institutions cannot discriminate against individuals with disabilities due to Section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act (ADA), personal assistants are not mandated. These acts do specify that PSE institutions must provide appropriate auxiliary aids (such as videotext displays and assistive listening systems) and academic adjustments (such as priority registration and reduced course load) to students with disabilities who show such a need; however, PAS are not included.

An issue that is often misunderstood by PSE officials and students is the provision of personal aids and services (Stumbo et al., 2009). Personal aids and services, including help in bathing, dressing, or other personal care, are not required to be provided by postsecondary institutions. The Section 504 regulation states: Recipients [postsecondary institutions that receive federal funding] need not provide attendants, individually prescribed devices, readers for personal use or study, or other devices or services of a personal nature. Title II of the ADA similarly states that personal services are not required (US Department of Education, 2005). (Ahlström & Wadensten, 2010; Kelly, 2010; Kyung, Fox, & White, 2006; Misra, Orslene, & Walls, 2010; Wadensten & Ahlström, 2009a; Wadensten & Ahlström, 2009b)

Federal regulations associated with the ADA (Personal Devices and Services, 1991a: Personal Devices and Services, 1991b) specifically state that public entities and public accommodations, meaning public and private postsecondary institutions, are not required to

“provide attendants, individually prescribed devices, readers for personal use or study, or other devices or services of a personal nature including assistance in eating, toileting, or dressing.” In addition, both the Department of Justice’s regulations (Communications, 1994), and the Department of Treasury’s regulations (Communications, 1991) have similar provisions reading: “The agency need not provide individually prescribed devices, readers for personal use or study, or other devices of a personal nature.” Specifically and definitively, personal care needs are the responsibility of the student. Personal assistance services in higher education may become an enormous barrier for entering and being successful in the PSE environment and in future career endeavors (Stumbo et al., 2009).

To assess the level of personal assistance support services provided to students with severe physical disabilities by postsecondary institutions, Hedrick and colleagues (2012) conducted a national survey of members of the Association of Higher Education and Disability via an online distribution. Of the 326 respondents with usable responses, 36 (14.1%) stated that some level of personal assistance services was provided to students with severe physical disabilities, ranging from providing emergency services (25 or 69.4%) to providing residential services with in-house personal assistants (4 or 11.1%). Personal assistance support to students with severe physical disabilities were more likely to be provided at master's, comprehensive, and research universities and less likely to be provided at bachelor's, associate's, and trade/technical schools. The education institutions that provided personal assistant support were more likely to be able to identify students with severe physical disabilities who were negatively impacted by the lack of personal assistance support, were more satisfied with their personal assistance support services, had longer tenure in disability support services, and had greater numbers of part-time staff (Hedrick et al., 2012). When exploring the services offered to students with severe physical

disabilities and the extent and flexibility of those services, the phrase “comprehensive service program” is often used.

The Comprehensive Service Program (CSP)

Key to a truly comprehensive program is flexibility in the delivery of services for the individual student. An institution can outline its services to show the prospective student what he or she can expect in the way of services. However, the extent to which a cadre of services cannot accommodate the unique needs of individual students detracts from the comprehensiveness in the overall scope of services. It is not valid to determine comprehensiveness based on a list of services, or on the sheer number or kinds of different services provided. The definition of comprehensiveness of program services will also vary based on the differing kinds of disabilities served. An extensive program of services on a particular campus may totally serve the orthopedically disabled student but may only minimally serve the needs of the deaf or hard-of-hearing student (Kloepping, 1978).

A further complication in defining the comprehensive service program (CSP) surfaces with the issue of fostering dependence. One of the early guides for establishing program services for the disabled in higher education contains the following statements: "The college or university need not provide the student with a disability with an easy life. Acts of favoritism are unnecessary and contrary to sound rehabilitation principles. Modifications should be made, to insure fair opportunity for people with disabilities to obtain a college education equal to that offered the able-bodied student." (Kloepping, 1978) Today, a far greater number and degree of services are required to be labeled a minimum services program (Kloepping, 1978).

The CSP embodies some basic operational assumptions or principles:

- The availability of qualified staff.
- Services based on needs.
- Individualized approach to service delivery (flexibility).
- Ease of access (centralized facility).
- Optional utilization of services (Kloepping, 1978).

For a student with a significant physical disability, the need for well-trained staff becomes essential. The provision of medically-related services, interpreters for the deaf, adapted physical education, career counseling, and attendant-care services, among others, requires in-depth knowledge of disabilities and resources to meet multiple needs. The use of student, staff and peer advocates, both for people with and without disabilities, is also a highly desirable staffing requirement (Kloepping, 1978).

Services in the comprehensive program can be divided into two general categories. The first is the centralized program that is provided by a dedicated program for students with disabilities. The second is the decentralized program, where university resources and services are available to the disabled student either directly or as a result of coordination/liaison activities through the disabled student [sic] program. Assuming a population of students with disabilities who represent a variety of disability categories, such as deaf, blind, orthopedic, congenital, or developmental, the Kloepping paper contained a list of support services that has been labeled as comprehensive. The program objectives and evaluation criteria are outlined in Appendix 2 and include, for example, Classroom Assistance, Admissions, Housing, and so forth. (Kloepping, 1978).

Along with the programmatic components of the CSP model, Kloepping calls for the collection of longitudinal data on current and former students. He suggests that academic data such as GPA and other progress measures be monitored by academic terms. Further, Kloepping suggested graduation be examined by type of credential received. Kloepping also proposed that

data be collected on graduates who have obtained successful employment. Lastly, Kloepping recognized the need to determine the rate at which graduates are progressing from, “dependent to independent living” status. He defined these particular evaluation criteria as dependence upon SSI, welfare and other transfer payments (see XIV in Appendix 2).

The CSP model, long established, has proven useful. However, in recent years, the CSP model has become more focused on routinely providing services for the greatest number of students rather than experimenting with how it can improve on its process. This is evidenced by the fact that, to date, the markers for evaluation set forth by Kloepping have been tested on a very limited basis. An institution that was recognized by Kloepping for successfully implementing the comprehensive approach was the University of Illinois. According to Kloepping, “One of the earliest and most successful programs in serving the disabled student in the postsecondary setting has been the University of Illinois at Champaign-Urbana. Their Rehabilitation-Education Center provides a wide range of direct services to the disabled student and may represent one of the most centralized programs of service for the disabled in higher education” (Kloepping, 1978,p. 59). However, as late as 2009, the leadership in disability services at Illinois [Stumbo et al.], cited a lack of outcomes-based research on the efficacy of the comprehensive program.

The iteration of the CSP model adopted by the University of Illinois is predicated on the practice of gradually transferring responsibility from staff to the students. The model, however, acknowledges that maximal independence for some will be living more independently at Nugent Hall and Beckwith Support Services (the University’s transitional living environment), rather than moving into another university or community residence. The model also hypothesizes that if transitional training in personal assistance management began at home during the last one to two

years of high school, the intercept (percentage of responsibility) would be higher and independent living could occur earlier (Hedrick, 2008).

The curricular component of the CSP model, referred to as the Transitional Disability Management Program (TDMP), is a highly individualized educational program designed to improve the disability management knowledge and skills of enrolled students. Effective disability management results in students achieving their highest level of independence in every aspect of their lives. It involves Beckwith students taking personal responsibility and acquiring the knowledge to find the resources they need to make positive life choices (Hedrick, 2008).

The TDMP is a comprehensive training program designed to help students: (1) improve their knowledge of disability laws and resources; (2) improve their skills in advocating for access and reasonable accommodations; (3) maximize their independence in the performance of ADLs; (4) improve their physical and/or functional capacity; (5) improve their social integration into the campus and community; (6) acquire knowledge and skills necessary to benefit maximally from the use of assistive technology (AT); (7) acquire the knowledge and skills necessary for independent personal assistance management; (8) successfully transition to internships and/or permanent employment following graduation; and (9) improve skills at advocating for and finding accessible housing post-graduation (Hedrick, 2008,p.7).

During each year of their stay at Beckwith, students are given the opportunity to participate in the TDMP. Students work with University staff, one-on-one, to determine the areas in which they would like to increase their knowledge and skills. The students and disability specialist then collaborate in the creation of customized individual goals and a work plan for their achievement. The goals may relate to their career aspirations, knowledge of disability laws, ability to effectively advocate for themselves, health and wellness, ability to use new AT or to

more effectively perform or manage the performance of certain ADLs, supervise their PA staff, or post-graduate objectives. Students meet with the disability specialist at the beginning of each semester to discuss objectives for that semester. Monthly meetings are scheduled to determine progress, and end-of-the-semester evaluations are performed to determine what progress was made (Hedrick, 2008).

The TDMP may include specific instructional modules and/or activities related to the following content areas (Hedrick, 2008):

- Disability laws and resources.
- Americans with Disabilities Act of 1990.
- Air Carrier Access Act.
- Section 504 of the Rehabilitation Act.
- Fair Housing Act.
- Advocacy for access and reasonable accommodation.
- Laws, regulations, and standards.
- Strategies for generating willing compliance.
- Physical and/or functional capacity.
- Physical exercise, recreation, and sport.
- Social integration within the campus and the community.
- Extra-curricular activities.
- Student organizations.
- Activities of daily living.
- Management strategies.
- Assistive technology.
- Products and resources for enhanced independent living.
- Personal assistant management. Recruitment, interviewing, training, hiring, disciplining, and evaluation of personal assistant staff.
- Problem-solving, conflict resolution, and communication.
- Career assistance.
- Career goal setting.
- Resume preparation, job searching skills, application and interviewing skills.
- Disability disclosure and self-advocacy.
- Accessible housing post-graduation and housing options including lease agreements.

Based upon longitudinal data collected by the University of Illinois, which has been operating this program for nearly 35 years, for "students at the University of Illinois with the most severe physical disabilities, graduation outcome benchmarking was performed in 2005 for

residents who required assistance in the performance of activities of daily living. A total of 151 students were identified as having resided at Beckwith Hall [the university's transitional living environment]. Of that number, a remarkable 87% were found to have earned Illinois degrees. With regard to employment outcomes of students with severe physical disabilities, 60% since 1995 obtained professional employment following graduation while 32% entered graduate school” (Collins, Hedrick, & Stumbo, 2007,p. 38). Thus, only 8% of these students did not enter the workforce or continue their education after earning their baccalaureate degree.

These employment outcomes were subsequently corroborated by the University's Office for Planning and Budgeting, which found that “58.3% of former Beckwith Hall residents who graduated between 1986 and 2000 to be employed one year following graduation” (Collins, Hedrick, & Stumbo, 2007).

The learning objectives included within the Illinois curriculum are rooted in the seminal document offered by Kloepping (1978) entitled, “Short and Long-Range Planning for a Comprehensive Service System.” These objectives are theoretically supported in part by the scholarship of Wilson (2003) and her work deriving the relational model of disability. Elements of the relational framework are also embedded in the research of Benz and colleagues (2000) detailing factors that affect positive graduation and employment outcomes for individuals transitioning from high school. Concurrently this theoretical orientation has also served for what had been highlighted as evidence-based practices for successful transition by Test and Cease-Cook (2012). Consequently, a remarkable degree of success demonstrated by graduates of the Illinois program should serve notice as to the applicability of the indicators first articulated by Test to the arena of postsecondary education.

The work of Kloepping was originally presented during a conference entitled, *The Disabled Student on American Campuses: Services and the State of the Art: a National Conference Held at Wright State University* in 1977. The current leadership of the Office of Disability Services recognizes the impact that the seminal work has on the department's philosophy. According to Tom Webb, current director of the Office of Disability Services at Wright State University, [our model] "is proof of a culture of inclusion that touches faculty, staff and students with equal strength." Further, Webb has a firm commitment to staying among the nation's leaders in higher education for students with significant disabilities; "There is so much potential here that most universities could never tap into because they don't have the culture that we do," said Webb. "We need to continue to innovate beyond what we've been doing traditionally. We're already on the right track, but this office... this university historically has laid the tracks for others. We must keep pushing to do that" (Bauguess, 2014).

Summary

In this chapter, relevant literature was highlighted that helps to define four models of disability, the characteristics of people with those disabilities in the United States and the methods that such individuals employ to mitigate the effects of those disabilities. Specifically, the benefits of using personal verses technological assistance were discussed. Typical funding methodologies for personal assistance services were also discussed. An examination of differences in service provision between secondary and postsecondary educational settings was also provided, including legal responsibilities of each type of institution to offer such support. Finally, the framework of the Comprehensive Service Program (CSP) was outlined along with brief discussion of some program outcomes. Also, literature was examined that supports the CSP model and its continued impact on current philosophy in disability service provision.

CHAPTER III. RESEARCH DESIGN

Chapter two presented relevant literature that supported the implementation of the Comprehensive Service Program (CSP) in higher education settings for students with severe physical disabilities. This chapter presents the design of the study and includes a discussion of the sources of data, instrumentation, data collection and analysis procedures, and a chapter summary.

Source of Data

The sample for this study was drawn from alumni with disabilities at Wright State University, a medium-sized public university in Dayton, Ohio. Forty-three individuals were contacted to participate in the study. This investigation was conducted in accordance with the approved Auburn University Protocol for Research with Human Subjects. Further, the researcher submitted a Request for Participation of Faculty, Staff or Students in Research Approved by Another Institution (see Appendix 6), securing the cooperation of Wright State University, which owns the courses and degree completion data. With this application, permission was granted to collect data.

Since 1970, the University has developed a program for students with developmental and/or physical disabilities. Services offered include academic support as required by The Americans with Disabilities Act of 1990 and Section 504 of the Rehabilitation Act of 1973. In addition, the University also provides independent living and physical support services that are geared towards providing incumbent students with the skills needed to succeed at the university

and beyond. The Office of Disability Services assists approximately 300 student consumers in a fiscal year.

Individuals were invited to participate in this study if they: (1) had completed the University's personal assistant management course (ED 1020); and (2) successfully completed an undergraduate degree. The Wright State University Offices of Institutional Research and Disability Services compiled a sample of individuals who satisfy the participation criteria.

The objectives of the personal assistant management course are to provide the student with the opportunity to become knowledgeable in:

1. Recruiting, interviewing, screening, hiring, training, scheduling, problem solving, paying for, and managing personal care assistants.
2. Communication skills.
3. Problem solving skills.
4. Resources available for funding personal assistance.
5. Resources for disability-related needs, supplies, and equipment.
6. Resources for accessible transportation & driver evaluation programs (Denny, 2015; See Appendix 4 for complete syllabus).

Students typically enroll in this course during their first term on campus, as successful completion is a corequisite for students to access University provided personal assistant services.

This approach was chosen in order to solicit only those individuals who participated in the program that included the disability management curriculum, thereby most effectively identifying the impact of skill training on self-sufficiency.

Instrumentation

The researcher-developed survey instrument for this study was an 11 item objective questionnaire entitled *Physical Support Services Program Follow-Up of Functional Independence* (Appendix 3). Core areas examined on the questionnaire included the subjects' living arrangements, method of Activities of Daily Living provision and employment or training status. The instrument was developed in part based on an earlier pilot assessment also constructed by the researcher in 2011-12. Content and face validity were established by a panel of experts, which included the Director of the Office of Disability Services at Wright State University, a professor of rehabilitation, and a research methodologist. This allowed for development of the 10 objective questions. The panel of experts reported no difficulty in understanding the content and usability of the instrument.

The panel suggested that an item should be included that addressed the specific disability management courses completed by participants, for a total of 11 questions.

Data Collection Procedures

The instrument was distributed electronically to participants using the Qualtrics delivery platform. This method was appropriate given its low cost and the characteristics of the population under study. Most individuals with significant physical disabilities find it less cumbersome to have materials in electronic format for ease of use with various types of assistive technology and general autonomy in the survey completion process. Scholarship by Mitchell, Chmnecki, CyBulski and MarkesIch (2006) while dated, recognized the potential held by web-based instruments when surveying populations of people with disabilities. These researchers acknowledged that, "Respondents with different impairments may prefer Web administration

because they can complete the interview privately at their convenience” (Mitchell, Ciemnecki, CyBulski, & Markesich, 2006, p.36).

These investigators further noted "Depending on the number of [assessments] completed by this mode, Web surveys can be less expensive than [telephone interviews] because they eliminate interviewer labor hours for data collection" (p. 36). However, these authors concurrently cautioned, researchers need to be cognizant of web accessibility standards for people with disabilities and their potential need for assistive technology during questionnaire completion.

Beyond general architectural guidelines, Mitchell et al. recommended that, instruments be constructed while taking into consideration, "two broad categories of barriers: (1) stamina, and (2) cognitive barriers. The term "stamina challenges" refers to both physical and mental fatigue. Cognitive challenges include, but are not limited to, emotional disturbance, difficulty processing questions and responses, lack of complete or specific knowledge, and confusion about the purpose of the questionnaire" (p. 6). In this study, however, the population were recent college graduates who were assumed to be of sufficient intellect to comprehend the purpose of the instrument and are most likely to complete assessments if administered electronically (Andres, 2012).

Data Analysis Procedures

After dissemination of the instrument, the researcher screened the 43 returned questionnaires and 17 (39.5%) had usable data. Descriptive statistics were calculated to identify the extent to which functional independence is indicated by disability management curriculum completion. Frequency and percent were calculated for each of the six characteristics of

functional independence (current living arrangement, activities of daily living (ADL), level of assistance by sources, gainful activity, income sources and health insurance).

The researcher purchased a license for the Statistical Package for the Social Sciences (SPSS) version 23. An aggregation procedure was performed in order to group responses that were generated by the item addressing specific courses completed. This procedure resulted in the development of disability management course completion patterns. This allowed for observation of completion patterns for all seven courses across the sample.

Summary

This Chapter outlined the research design for examining the extent to which participating in a degree program that includes disability management coursework facilitates self-sufficiency after graduation. Sampling methods and the process of developing an instrument that addresses the research questions were discussed. Descriptions of data collection and analyses were included.

CHAPTER 4. RESULTS

In chapter three the research design that addressed the research questions was presented. This chapter presents the results of the survey. Results are reported by research question. As noted in the previous chapter, the *Physical Support Services Program Follow-Up of Functional Independence* included 11 objective items that queried participants as to their living arrangements, method of Activities of Daily Living provision and employment or training status.

This study posed the following question: “To what extent do individuals, who completed a degree that included coursework in disability management, practice six characteristics of self-sufficiency at a single time point after graduation?” Seventeen of the 43 individuals surveyed submitted usable questionnaires for a 39.5% return rate. An examination of descriptive statistics in relation to each of the characteristics is discussed below.

As shown in Table 1, with respect to living situation, of the 17 respondents, 11 reported living in the community either with or without supports. In addition, six respondents answered that they were living with a family member or legal guardian. Lastly, none of the respondents indicated that they were residing in a group home or other care facility at the time of the survey

Table 1

Frequency and Percent of Current Living Arrangement

<u>Response</u>	<u>f</u>	<u>Percent</u>
With family member, caregiver or legal guardian	6	35.3
In group home or other care facility	0	0
In the community with or without supports	11	64.7
Total (N)	17	100

As table 2 indicates, 13 of the 17 respondents reported that in the above referenced living situation, they are responsible for planning and budgeting for expenses. The remaining four respondents answered that someone else is responsible for these activities.

Table 2

Frequency and Percent of Planning and Budgeting

<u>Response</u>	<u>f</u>	<u>Percent</u>
I am responsible for planning and budgeting for expenses	13	76.5
Someone else is responsible for the budget and expenses	4	23.5
Total (N)	17	100

Table 3 illustrates that 11 of the 17 respondents reported that they require maximum assistance or can complete 15% or less of their ADLs independently. Five participants responded that they needed a moderate to minimal level of assistance when completing daily living tasks.

The remaining respondent indicated that they could complete these activities independently either with or without modification or use of assistive technology.

Table 3

Frequency and Percent Related to Level of Assistance Needed with Activities of Daily Living (ADLs)

<u>Response</u>	<u>f</u>	<u>Percent</u>
Maximum assist (can complete 15% or less)	11	64.7
Moderate to minimal assist (can complete 85%)	5	29.4
Modified/independent (can complete 100% with or without AT)	1	5.9
Total (N)	17	100

Table 4 shows that of the 16 respondents who reported needing some level of assistance to complete their ADLs, 12 indicated that such assistance is provided by a paid caregiver, either by a public program or with private funds. Three participants indicated assistance is provided by family members. Lastly, one individual reported that this assistance is carried out by friends or volunteer support.

Table 4

Frequency and Percent of ADL Assistance Source

<u>Response</u>	<u>f</u>	<u>Percent</u>
Family member(s)	3	17.8
Paid caregiver(s)	12	70.6
Friend(s) or volunteer support	1	6.3
Total (N)	16	100

Concerning respondents' employment or training status, two participants indicated that they are employed full-time. Nine individuals indicated that they are employed, but at less than full-time. An additional three participants noted that they have returned to an education or training program. Also three individuals reported that they were neither in school nor employed at the time of the survey. Table 5 reports frequency and percent of employment and education.

Table 5

Frequency and Percent of Current Employment and Education Status

<u>Response</u>	<u>f</u>	<u>Percent</u>
I am employed full-time	2	11.8
I am employed less than full-time	9	52.9
I am <u>not</u> employed	3	17.6
I have returned to school or other training program	3	17.6
Total (N)	17	100

Table 6 shows employment characteristics. Of the 11 individuals who reported being employed at the time of the survey, five indicated that their employment is aligned with their degree or major field of study. The remaining six participants indicated that they are working outside their degree scope or major field of study.

Table 6

Frequency and Percent of Current Employment Characteristics

<u>Response</u>	<u>f</u>	<u>Percent</u>
My job responsibilities are aligned with my degree or major field of study	5	29.4
I am working outside my degree or major field of study	6	35.3
Total (N)	11	100

Respondents also were queried about the primary source of their insurance coverage. As shown in table 7, 13 participants indicated that they were enrolled as a beneficiary on a public health insurance program such as Medicare or Medicaid. An additional three individuals responded that they were enrolled as a spouse or dependent on someone else’s policy. The remaining respondent indicated that his/her coverage was provided by an employer.

Table 7

Frequency and Percent of Primary Health Insurance Coverage Source

<u>Response</u>	<u>f</u>	<u>Percent</u>
Employer-provided	1	5.9
On someone else’s policy as spouse or dependent	3	17.6
Public health insurance program such as Medicare or Medicaid	13	76.5
Total (N)	17	100

Table 8 displays the primary source of income as reported by respondents. Ten individuals indicated that their primary source of financial support is transfer payments such as Supplemental Security Income or Social Security Disability benefits. Five individuals indicated that they primarily support themselves with wages from employment. One respondent reported the source of primary support was through proceeds from a settlement or other trust. Another person who had returned to school indicated that primarily he/she was supported through student financial aid.

Table 8

Frequency and Percent of Primary Income Source

<u>Response</u>	<u>f</u>	<u>Percent</u>
Wages from employment	5	29.4
Supplemental Security Income or Social Security Disability benefits	10	58.8
Settlement or other trust	1	5.9
Student financial aid	1	5.9
Total (N)	17	100

Table 9 illustrates current education or training status. Of the three respondents who indicated that they have returned to school or another training program, two reported enrollments in a graduate degree program. One individual indicated pursuing a credential from a vocational or certificate program. None of the participants reported pursuing a second undergraduate degree.

Table 9

Frequency and Percent of Current Education or Training Status

<u>Response</u>	<u>f</u>	<u>Percent</u>
Enrolled in graduate degree program	2	11.8
Enrolled in undergraduate degree program	0	0
Enrolled in a vocational or certificate program	1	5.9
Enrolled in courses as a non-degree student or taking for personal fulfillment	0	0
Total (N)	3	100

Table 10 shows the reported time interval since respondents earned their undergraduate degree. Two individuals were graduated within the last year. Another four individuals earned their degree within the last 3 to 5 years. Ten individuals stated that it had been six years or more since they completed their degree. One individual reported that they received their undergraduate degree from another institution after transferring. None of the participants reported having graduated in the 1 to 3-year timeframe.

Table 10

Frequency and Percent of Time since Earning an Undergraduate Degree

<u>Response</u>	<u>f</u>	<u>Percent</u>
Less than one year	2	11.8
1 to 3 years	0	0
3 to 5 years	4	23.5
6 years or more	10	58.8
I completed my degree at another institution	1	5.9
I have not completed an undergraduate degree	0	0
Total (N)	17	100

The final item on the questionnaire was a semi-structured question which asked respondents to indicate the disability management courses they completed as part of their degree program. Table 11 shows the seven course offerings and the respective number of completers for each course. All 17 respondents completed the managing personal assistants course.

Table 11

Frequency and Percent of Respondents Who Completed Disability Management Courses

<u>Response</u>	<u>Completers</u>	<u>Percent</u>
Adaptive Computer Technology (BME 155/1550)	5	29.4
Career Planning for Individuals with Disabilities (LA 201/2010)	2	11.8
Developing Peer Mentors with Disabilities (ED 1030)	2	11.8
First Year Seminar (UVC 101/1010)	7	41.2
Foundations of Learning (ED 1040)	1	5.9
Managing Personal Assistants (ED 101/1020)	17	100
Physical Fitness for Disabled (HPR 100/KNH 1440)	3	17.6

Table 12 shows the frequency of disability management course completion patterns among the sample. Six participants completed only the managing personal assistants course. The remaining 11 participants completed various combinations of disability management courses in addition to managing personal assistance.

There were eight unique patterns. Four individuals responded that they completed the first year seminar in addition to managing personal assistants. Two individuals reported completing the adaptive computer technology course along with managing personal assistants. Other patterns that received only one unique response are included in Table 12.

Table 12

Frequency and Percent of Disability Management Course Completion Patterns

<u>Course Combination</u>	<u>f</u>	<u>Percent</u>
Managing Personal Assistants	6	35.3
Managing Personal Assistants and First Year Seminar	4	23.5
Managing Personal Assistants and Adaptive Computer Technology	2	11.8
Managing Personal Assistants, Foundations of Learning and Physical Fitness	1	5.9
Managing Personal Assistants, Career Planning and Developing Peer Mentors	1	5.9
Managing Personal Assistants, Adaptive Computer Technology, First Year Seminar and Physical Fitness	1	5.9
Managing Personal Assistants, Adaptive Computer Technology Developing Peer Mentors and First Year Seminar	1	5.9
Managing Personal Assistants, Adaptive Computer Technology, Career Planning, First Year Seminar and Physical Fitness	1	5.9
Total (N)	17	100

Summary

This chapter detailed descriptive statistics relating to whether disability management course completion is indicative of self-sufficiency after graduation. Results were inconclusive as to whether completion of the disability management curriculum facilitated self-sufficiency for this sample.

CHAPTER V. DISCUSSION AND CONCLUSIONS

Chapter four provided an overview of disability management course completion patterns. The chapter also provided a snapshot of individuals' independent living status and economic self-sufficiency after completing an undergraduate degree.

This final chapter will offer a discussion of the significance of these observations for current implementation of the Comprehensive Service Program. Recommendations are also offered for leadership at institutions that offer a disability management curriculum for students with severe physical disabilities as part of their undergraduate degree program. These recommendations are intended to provide information to program administrators so that they can make informed decisions on how their programs should respond to the observations presented in this study.

Limitations of the Results

Wright State University estimates a total population of 450 graduates has completed the disability management curriculum over the past 15 years. A sample size of 17 in this study is less than representative of a population of this magnitude. Consequently, any analysis beyond the compilation of descriptive statistics was unwarranted.

A Shift in Strategy

Recall from chapter two that Wilson (2003) draws the comparison between disability acceptance in the relational model and adolescent development. She characterizes this particularly for individuals with congenital disabilities as brief sorties into adulthood and adult responsibility but typically always regressing to behaviors that are typically seen in adolescents.

With this framework, it is incumbent upon disability service professionals to shift their mindset from providing accommodations to total disability management.

To that end, institutions that follow the comprehensive services approach need to include within their eligibility and preservice process a mechanism where the perspective of student strengths, interests and abilities are explored while also conducting a life care analytical approach similar to what is suggested by Alison (2007), with an aim to answer the question of how much assistance will be required to meet an individual's level of care. Disability service professionals will then be able to guide students through a major selection process that will lend the student the earning capacity commensurate with the cost of care either with or without work incentives. This will allow prospective students and their supports to decide whether completing a four-year degree is beneficial for the student.

For example, if it is determined that the individual needs to be in a field with an initial earning capacity in excess of \$100,000 per year in order to cover his/her cost of care, the student may need to be otherwise qualified for admission into a science, engineering, technology or mathematics (STEM) program that is specifically directed to obtaining employment in those fields or other professional specialties, such as law or medicine. If an individual also has a concomitant diagnosis of dyscalculia, a specific learning disability that affects an individual's ability to learn and comprehend arithmetic and elementary mathematics concepts, it can be argued that he/she was unlikely to complete that course of study without a fundamental alteration to the program, thereby rendering the student not otherwise qualified for admission to that particular program. The conclusion might then be that it would be disingenuous for the disability service professionals to recommend enrollment, suggesting instead to explore a vocational certificate or associate degree that would generally keep the prospective student below the

maximum income thresholds for means tested programs that provide care and other self-sufficiency supports. One of the participants in this study provided unsolicited feedback in the form of an email to the researcher, after completing the questionnaire. The viewpoint that this participant articulated provided a useful illustration of the critical decision facing many high school graduates and their families, as they consider the most beneficial postsecondary path. The name of the participant in the scenario below has been changed to preserve anonymity.

The Case of Luke

Luke is an individual with a significant physical disability that caused him to create individualized processes to complete his activities of daily living (ADL) in an independent way. Recall from chapter one that a modified/independent assistance level means that an individual can complete 100% of his/her ADL either with or without the use of assistive technology. Luke has completed several of the disability management courses at Wright State University (WSU) and has earned an undergraduate degree from The Ohio State University in hospitality management after transferring from WSU. He has maintained a part-time job as a concierge for a major international hospitality and entertainment firm since 2009. Luke lives independently in the community near his work with his wife (Michaels, 2016).

He reported his sources of earned and indirect income as follows: (1) \$900 per month from Social Security, and (2) \$1,200 per month from employment. In addition, Luke stated, “I pay next to nothing in healthcare costs because Medicare/Medicaid takes care of 90% of my bills.” He also shared that he receives \$300 per month in Supplemental Nutrition Assistance Program benefits [food stamps]. Including income replacement from means tested programs [SNAP and Medicare/Medicaid], Luke estimated his net income to be \$2,400 per month or \$29,000 annually (Michaels, 2016).

By contrast, Luke stated:

If I work a regular full-time job earning \$50,000 per year, 25% of that will go to taxes (federal, state, local, Medicare), which is about \$12,500 per year. If you add another \$10,000 per year for premiums and co-pays and out-of-pocket expenses for insurance, which is not unusual when you have a disability that takes away \$22,500 of your yearly income. This includes no share of cost for Medicare/Medicaid because my care is minimal to nonexistent for them. This means my yearly take home pay would be \$27,500 and that does not even include transportation to get back-and-forth from my full-time job rather than a part-time one. So at this point I'm at least \$1000 in the hole per year and that's at \$50,000 salary (Michaels, 2016).

Implications for Individuals with Higher Support Needs

Extending the previous example, the consequences of full-time employment for people with high physical support needs is even more worrisome. For example, an individual with a C5-C6 spinal cord injury resulting in quadriplegia is employed as a secondary education teacher prior to her injury. She elects to continue in this same position after rehabilitation. The annual salary for a teacher in her school system with 28 years of experience is \$89,000 per year (Weast, 2014).

An individual with this amount of annual income must utilize federal work incentives that are contained within the Social Security Act in order to have a portion of her income excluded so that she can remain eligible for Medicaid services. Individuals whose income still exceeds the level allowed by the work incentives have the option of reimbursing the administering state for their share of their Medicaid cost. This amount, referred to as the share of

cost, represents the amount by which the individual's income exceeds the average cost of care for a Medicaid beneficiary in that state. State income thresholds are indexed to the cost of living as determined by the federal government. As an example, the threshold for Alabama for FY 2016 was \$27,075, while the threshold for California in 2014 was \$56,000. Assuming that the hypothetical teacher was a resident of California, her share of cost would have been approximately \$33,000 per year or \$2,750 per month in 2014. If it is then assumed that this person's net pay after income taxes was approximately \$60,000 per year, her approximate available income after deducting the share of cost would be \$27,000 per year (Weast, 2014).

This is \$2,000 less than Luke reported as his net income while receiving Social Security supplemented by wages from part-time employment. When the value of his income replacements from SNAP benefits and public health insurance are included, the buying power of his household has increased to be comparable to that of a family who reported an income of approximately \$50,000 per year. It is possible to infer that Luke's circumstances are similar to a majority of participants in this study. Recall from the results reported in chapter four that nine out of seventeen respondents reported being employed but at less than full-time.

These two examples highlight the employment disincentive that exists for people with significant disabilities in the United States. In order to avoid these unintended outcomes, disability service and vocational rehabilitation professionals must work together to ensure that the individual is tracked into career field that matches his/her strengths, interests and abilities, as well as provides a sufficient earning capacity to cover disability costs either with or without supports, allowing the individual to maintain a truly livable wage.

This collaboration will require a paradigm shift by disability service and vocational rehabilitation professionals that will lead to the recommendation that pursuing full-time

employment may not be the most prudent vocational goal when weighed against functional capacity and potential earning power. Consequently, pursuing a bachelor's degree may not be an efficient use of resources when the vocational goal is to obtain part-time employment. Service professionals are in the best position to provide individuals and their support persons with unbiased information so that families can make informed personal and financial decisions when selecting a postsecondary path.

A cooperative effort between university disability service professionals and the vocational rehabilitation agency would help to implement this approach. The vocational rehabilitation agency should conduct a vocational evaluation including a benefit analysis to determine eligibility and Individualized Plan for Employment development process. The results of these evaluations should then be shared with the individual. Individuals should then be encouraged to share findings with their perspective higher education institutions, so that informed choices can be made.

This collaborative approach becomes problematic when an institution such as the one utilized for this study maintains an open enrollment policy. This is an institution that will admit any student who has taken either of the college entrance exams and has a high school diploma. An open admission standard makes it nearly impossible for an institution to deny an applicant with significant disabilities who is not otherwise qualified for admission. Therefore, short of using a competitive enrollment policy, it is incumbent upon disability service program staff to honestly advise prospective students about appropriate majors, taking into consideration the individual's ability to undertake the academic rigor of a program that may provide the student with sufficient earning capacity upon graduation.

A failure to engage in this type of analysis would arguably be at least disingenuous to the student, if not an abdication of the institution's ethical responsibilities. Students might be forced into student loan arrangements and never achieve the earning capacity to repay their obligation when also paying for total costs of their care. Obtaining a job with an annual income below a certain point would not support their needs but still deem them ineligible for means tested programs that would otherwise pay for the cost of care.

While it is the student's choice to engage in a program that may cause long-term debt, institutions are in the best position to advise prospective students and their families of the potential impact of these decisions that are unique to individuals with significant disabilities.

Providing students and their families with information that will allow them to make informed choices about a career path will also serve to enhance the quality of service provided by university-based disability support programs. Institutions may be able to direct resources to individuals with a greater likelihood of completing the program and maintaining competitive employment at a livable wage – a wage that incorporates the unique needs of the particular graduate with a severe disability well into work life and beyond (Halpern, 1993; Hagner, 2000).

Future Research

Replication of this study with a larger sample will likely enable inferences to be drawn regarding the existence and magnitude of relationships between completion of a disability management curriculum as part of an undergraduate degree and its contribution to the independent living status and economic self-sufficiency of graduates. Such investigations need to focus on the combinations of courses that will lead to the most self-sufficient outcomes. Substantiating this information will provide disability service leadership with empirical support for beginning or maintaining a degree of a comprehensive service program. Recall from chapter

two that institutions are not statutorily required to offer such programs. Alternatively, administrators must be able to quantify the return on investment from these programs. This is particularly important in an environment where resources are scarce.

Summary

This chapter provided a discussion of additional limitations that became apparent over the course of the study, principally that the sample size was small and may not be representative of the total population under study. This finding rendered any analysis beyond the calculation of descriptive statistics impossible. Secondly, this chapter included a discussion of the possible significance of these observations for disability service practitioners as well as perspective students with severe physical disabilities and their families. The results presented in chapter four and the subsequent analysis in chapter five provide these stakeholders with information to make informed decisions about how programs continue to evolve and provide services that will allow graduates to be in the best position to secure and maintain employment in the primary labor market following graduation.

Concurrently, these recommendations encourage prospective students and their supports to engage in a critical evaluation to determine the steps required for the individual with a severe disability to maintain a truly livable wage. This may include the realization that university enrollment is not prudent when costs of care, costs of education and required earning capacity are balanced against the strengths, interests and abilities of the individual.

References

- Agree, E. M., & Freedman, V. A. (2003). A comparison of assistive technology and personal care in alleviating disability and unmet need. *Gerontologist, 43*(3), 335.
- Agree, E. M., Freedman, V. A., Cornman, J. C., Wolf, D. A., & Marcotte, J. E. (2005). Reconsidering substitution in long-term care: When does assistive technology take the place of personal care? *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 60*(5), S272-S280. doi:10.1093/geronb/60.5.S272
- Alabama Medicaid Agency. (2010). Annual report 2009. Retrieved from http://www.medicaid.alabama.gov/resources/annual_report_2009.aspx
- Andres, L. (2012). *Designing & doing survey research*. London: Sage.
- Bauguess, S. (2014, Fall). Moving forward by looking back. *Wright State University Magazine, 7-10*. Retrieved from <http://webapp2.wright.edu/web1/community/2014/moving-forward-by-looking-back/>
- Benz, M. R., Lindstrom, L., & Yovanoff, P. (2000). Improving graduation and employment outcomes of students with disabilities: Predictive factors. *Exceptional Children, 66*(4), 509-529.
- Bowe, F. (2000). *Universal design in education: Teaching nontraditional students*. Westport, Conn.: Bergin & Garvey

- Brault, M. W. (2008). *Americans with disabilities: 2005*. (Current Population Reports No. P 70-117). Washington, DC: U.S. Census Bureau. Retrieved from <https://www.census.gov/prod/2008pubs/p70-117.pdf>
- Campbell, D. M. (2004). Assistive technology and universal instructional design: A postsecondary perspective. *Equity & Excellence in Education*, 37(2), 167-173.
- Chappelle, M. (2010). In Roy J. R., Peebles E. M.(Eds.), *Nursing home occupancy-reimbursement rate*. Montgomery, Alabama: Alabama Medicaid Agency.
- Collins, K. D., Hedrick, B. N. & Stumbo, N. J. (2007). Using comprehensive postsecondary transitional support services to enhance the health, independence, and employment success of persons with severe physical and/or psychiatric disabilities: The University of Illinois approach. Retrieved from www.auburn.edu/~emp0006/Illinois_approach_Collins_2007.pdf
- Corey, G. (2009). Existential therapy. *Theory and practice of counseling and psychotherapy* (8th ed., pp. 131-163). Australia ; Belmont, Calif.: Thomson/Brooks/Cole.
- Desai, M. M., & Lentzner, H. R. (2001). Unmet need for personal assistance with activities of daily living among older adults. *Gerontologist*, 41(1), 82.
- Diab, M. E., & Johnston, M. V. (2004). Relationships between level of disability and receipt of preventive health services. *Archives of Physical Medicine and Rehabilitation*, 85(5), 749-757.
- Eckes, S., & Ochoa, T. (2005). Students with disabilities: Transitioning from high school to higher education. *American Secondary Education*, 33, 6-20.

- Freedman, V. A., Agree, E. M., Martin, L. G., & Cornman, J. C. (2006). Trends in the use of assistive technology and personal care for late-life disability, 1992-2001. *Gerontologist*, 46(1), 124-127. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=aph&AN=19936186&site=ehost-live>
- Getzel, E. E. (2008). Addressing the persistence and retention of students with disabilities in higher education: Incorporating key strategies and supports on campus. *Exceptionality*, 16(4), 207-219. doi:10.1080/09362830802412216
- Getzel, E. E., & Thoma, C. A. (2008). Experiences of college students with disabilities and the importance of self-determination in higher education settings. *Career Development for Exceptional Individuals*, 31(2; 2), 77-84. doi:10.1177/0885728808317658
- Gibson, B. E., Brooks, D., DeMatteo, D., & King, A. (2009). Consumer-directed personal assistance and 'care': Perspectives of workers and ventilator users. *Disability & Society*, 24(3), 317-330. doi:10.1080/09687590902789487
- Hagner, D. (2000). Primary and secondary labor markets: Implications for vocational rehabilitation. *Rehabilitation Counseling Bulletin*, 44(1), 22-29. doi:10.1177/003435520004400104
- Halpern, A. S. (1993). Quality of life as a conceptual framework for evaluating transition outcomes. *Exceptional Children*, 59(6), 486-498.

- Hedrick, B. (2008). *The Illinois model for transitional postsecondary personal assistance services*. Unpublished manuscript. Retrieved November 9, 2011, Retrieved from <http://stemmidwest.org/downloads/Review of Strategies for PA Services The Illinois Approach Hedrick .doc>
- Hedrick, B., Stumbo, N. J., Martin, L. G., Nordstrom, D. L., Morrill, J. L., & Martin, J. K. (2010). *Personal assistant services for students with severe physical disabilities in postsecondary education: Results of a national survey*. Unpublished manuscript.
- Hedrick, B., Stumbo, N. J., Martin, L. G., Nordstrom, D. L., Morrill, J. L., & Martin, J. K. (2012). Personal assistant support for students with severe physical disabilities in postsecondary education. *Journal of Postsecondary Education & Disability*, 25(2), 161-177.
- Hoening, H., Taylor Jr., D. H., & Sloan, F. A. (2003). Does assistive technology substitute for personal assistance among the disabled elderly? *American Journal of Public Health*, 93(2), 330-337.
- Jaeger, P. T., & Bowman, C. A. (2005). *Understanding disability : Inclusion, access, diversity, and civil rights*. Westport, Conn.: Praeger Publishers.
- Jans, L., & Stoddard, S. (1999). *Chartbook on women and disability in the united states*. Washington, DC: National Institute on Disability and Rehabilitation Research. Retrieved from <http://www.infouse.com/disabilitydata/womendisability/index.php>

Kaye, H. S., Chapman, S., Newcomer, R. J., & Harrington, C. (2006). The personal assistance workforce: Trends in supply and demand. *Health Affairs*, 25(4), 1113-1120.

doi:10.1377/hlthaff.25.4.1113

Klopping, K. (1978). Short and long-range planning for a comprehensive service system. In P. Marx, & P. L. Hall (Eds.), *Proceedings of the disabled student on American campuses : Services and the state of the art : A national conference held at Wright State University, August 21-25, 1977* (pp. 51-63). Dayton, Ohio: University Publications, Wright State University.

Lakin, K. C., Doljanac, R., Soo-Yong Byun, Stancliffe, R. J., Taub, S., & Chiri, G. (2008).

Factors associate with expenditures for Medicaid home and community based services (HCBS) and intermediate care facilities for persons with mental retardation (ICF/MR) services for persons with intellectual and developmental disabilities. *Intellectual & Developmental Disabilities*, 46(3), 200-214.

Lakin, K. C., Prouty, R., & Coucouvanis, K. (2005). Long-term service and support expenditures for persons with ID/DD within the overall Medicaid program. *Mental Retardation*, 43(1), 68-72.

LaPlante, M. P., Kaye, H. S., Kang, T., & Harrington, C. (2004). Unmet need for personal assistance services: Estimating the shortfall in hours of help and adverse consequences. *Journals of Gerontology*, 59B(2), S98-S108.

- Mackelprang, R. W., & Salsgiver, R. O. (2009). Traditional approaches to disability: Moral and medical models. *Disability: A diversity model approach in human service practice* (2nd ed., pp. 79-108). Chicago: Lyceum Books.
- Michaels, L. R. (2016). In Peebles E. M. (Ed.), *Survey feedback and my story*
- Mitchell, S., Ciemnecki, A., CyBulski, K., & Markesich, J. (2006). *Removing barriers to survey participation for persons with disabilities [white paper]*. Ithaca, New York: Rehabilitation Research and Training Center on Disability Demographics and Statistics. Retrieved from <http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1191&context=edicollect>
- National Council on Disability Federal Advisory Committee on Youth. (2001). *Speak out: Youth and young adults with disabilities*. (NCD white paper). Washington DC: National Council on Disability.
- Nosek, M. A., & Howland, C. A. (1993). Personal assistance services: The hub of the policy wheel for community integration of people with severe physical disabilities. *Policy Studies Journal*, 21(4), 789-800.
- Philip, I., Armstrong, G. K., Coyle, G. G., Chadwick, I., & Machado, A. B. C. (1998). A better way to measure disability in older people. *Age and Ageing*, 27(4), 519-522.
doi:10.1093/ageing/27.4.519
- Pingry, L. N. (2007). *Factors that predict graduation among college students with disabilities* (Ph.D. Dissertation) . (3322735).

Rathouz, P. J., Kasper, J. D., Zeger, S. L., Ferrucci, L., Bandeen-Roche, K., Miglioretti, D. L., & Fried, L. P. (1998). Short-term consistency in self-reported physical functioning among elderly women: The women's health and aging study. *American Journal of Epidemiology*, *147*(8), 764-773.

Rehabilitation Research and Training Center on Disability Statistics and Demographics (Ed.). (2009). *Annual disability statistics compendium: 2009*. New York, New York: Rehabilitation Research and Training Center on Disability Statistics and Demographics. Retrieved from <http://www.disabilitycompendium.org/Compendium/index.htm>

Rowell, D., & Connelly, L. B. (2008). Personal assistance, income and employment: The spinal injuries survey instrument (SISI) and its application in a sample of people with quadriplegia. *Spinal Cord*, *46*(6), 417-424. doi:10.1038/sj.sc.3102157.

Schopp, L. H., Clark, M. J., Hagglund, K. J., Mokolke, E. K., Stout, B. J., & Mazurek, M. O. (2007). Evaluation of a consumer-personal assistant training project. *Disability & Rehabilitation*, *29*(5), 403-410. doi:10.1080/09638280600835903.

Smart, J. (2006). Challenges to the biomedical model of disability. *Advances in Medical Psychotherapy & Psychodiagnosis*, *12*.

Smart, J. (2009). *Disability, society, and the individual* (2nd ed.). Austin, Tex.: Pro-ed.

Steinmetz, E. (2006). *Americans with disabilities: 2002*. (Current Population Reports No. P 70-107). Washington, DC: U.S. Census Bureau.

- Stodden, R. A., & Conway, M. A. (2003). Supporting individuals with disabilities in postsecondary education. *American Rehabilitation, 27*(1), 24-33.
- Stodden, R. A., & Dowrick, P. W. (1999). Postsecondary education and employment of adults with disabilities. *American Rehabilitation, 25*(4), 19.
- Stodden, R. A., Dowrick, P. W., Anderson, J., Heyer, K., & Acosta, J. (2005). Postsecondary education across the USA: Experiences of adults with disabilities. *Journal of Vocational Rehabilitation, 22*(1), 41-47.
- Stodden, R. A., Roberts, K. D., Picklesimer, T., Jackson, D., & Chang, C. (2006). An analysis of assistive technology supports and services offered in postsecondary educational institutions. *Journal of Vocational Rehabilitation, 24*(2), 111-120.
- Stout, B. J., Hagglund, K. J., & Clark, M. J. (2008). The challenge of financing and delivering personal assistant services. *Journal of Disability Policy Studies, 19*(1), 44-51.
- Stumbo, N. J., Martin, J. K., & Hedrick, B. N. (2009). Personal assistance for students with severe physical disabilities in post-secondary education: Is it the deal breaker? *Journal of Vocational Rehabilitation, 30*(1), 11-20. doi:10.3233/JVR-2009-0449.
- Test, D. W., & Cease-Cook, J. (2012). Evidence-based secondary transition practices for rehabilitation counselors. *Journal of Rehabilitation, 78*(2), 30-38.
- Tilly, J., Goldenson, S. M., & Kasten, J. (2001). *Long-term care: Consumers, providers, and financing: A chart book.* (). Washington DC: The Urban Institute.

Turner, E., Revell, G., Strobel, W., & McDonough, J. T. (2003). Workplace personal assistance service and assistive technology. *Journal of Vocational Rehabilitation, 18*(2), 107.

US Department of Education. (2005). Auxiliary aids and services for postsecondary students with disabilities. Retrieved from <http://www2.ed.gov/about/offices/list/ocr/docs/auxaids.html>

US Department of Education. (2007). Students with disabilities preparing for postsecondary education: Know your rights and responsibilities. Retrieved from <http://www2.ed.gov/about/offices/list/ocr/transition.html>

Weast, J. (2014, 10/14/2014). Jenny's battle for independence. Retrieved from <https://m.facebook.com/jenny.weast/posts/786221484761051>

Wiener, J. M., & Hanley, R. J. (1989). *Measuring the activities of daily living among the elderly: A guide to national surveys* US Department of Health and Human Services.

Wiener, J. M., Hanley, R. J., Clark, R., & Van Nostrand, J. F. (1990). Measuring the activities of daily living: Comparisons across national surveys. *Journal of Gerontology, 45*(6), S229-37. doi:10.1093/geronj/45.6.S229.

Wilson, S. (2003). A relational model of disability. *Disability, counselling and psychotherapy: Challenges and opportunities* (pp. 19-40). New York: Palgrave Macmillan.

Appendix A

Case Study of Jim

Demographic Information

In April 1984 at the age of 19 years, this male sustained a C5-6 incomplete spinal cord injury as the result of a work-related motor vehicle accident. His life care plan was developed in 1990, 6 years following the onset of injury. Jim (not his real name) is currently 42 years of age and it has been 23 years since the injury occurred; 17 years have passed since his life care plan was developed. He was not married and did not have children at the time of the injury, and this has not changed. Jim was working at the time of the injury, but did not return. He earned a bachelor's degree and master's degree in political science subsequent to the injury and had planned to teach. From 1994 to 2004, he owned and operated a retail business, a video store and newsstand, but over time the business climate changed and problems with employees prompted him to sell it. Currently, he is not planning to return to work. He explained that he is financially secure and does not need to rely upon income earned from working a full-time or part-time job.

Jim shares a house with his parents and is able to access all rooms in the home. Following in the injury, an addition to the home was built to increase the shared living space and the living area, bedroom, den, and bathroom most frequently used by Jim. Exterior ramps to the front and back doors of the home and an elevator to the second floor were installed.

Personal Assistance

Jim privately hires personal attendants for 56 hours each week and his parents supplement with assistance as necessary. He estimates that his parents provide an additional 10-15 hours of

assistance each week with grocery shopping, running errands, and other activities that occur during times when an attendant is not available. Jim requires assistance with nearly all activities of daily living including dressing, showering and personal hygiene, nail care, completing a bowel and bladder program (which requires approximately 30 minutes, four times each day), medication set-up, turning in bed at night (which requires approximately 30 minutes, twice per night) light cooking, and general household chores. Attendants also assist with range of motion and other exercises. When supplies are set-up by an attendant, he is able to accomplish some activities of daily living independently including brushing his teeth and hair, shaving, eating, washing his face, reading, and using a modified computer keyboard. His primary means of locomotion is a power wheelchair, and he is able to operate it independently. In total, Jim estimates that his morning routine requires approximately 2 to 2 1/2 hours each morning and his evening routine requires approximately 1 hour.

Jim manages his own finances, with occasional assistance from his mother who performs all writing tasks on his behalf. Jim works with an accountant to manage his long-term financial plan, make investments, complete annual tax return statements, and manage his employee records. Currently, he coordinates his care among seven attendants, and he stated that this has worked well for him. Because he had control over the hiring process, he works with attendants who are knowledgeable, respectful, and diligent in performing their duties. He has not had any problems with no-shows nor been left without care for an extended period of time. If this were to happen, his parents are nearby and could offer assistance as necessary. While in college, Jim worked with attendants that were provided through a home health care agency, but since then the attendants have been privately hired. A payroll company issues paychecks and tracks information necessary for taxes, and an accountant oversees this process.

The only concern that Jim expressed about the personal assistance that he is currently receiving involves the anticipated loss of his primary attendant and those who are currently working with him. He has had to replace several staff members over the years, and it has been fairly easy to find replacements because the person leaving can generally recommend a suitable colleague. However, he gets along well with his current attendants. Jim believes that his care is sufficient and adequate for his needs at this time. If additional assistance is needed in the future, he has the funds to be able to increase the number of hours of care that he is receiving. Jim explained that he prefers to privately hire attendants because he is able to select them personally and is not expected to commit to a minimum number of hours per week as may be required through an agency.

Jim drives a modified van with a ramp, hand controls, and modified break and gas. The van is also equipped with various switches (e.g., turn signals, power window switches, windshield wipers, etc.) that are easily accessible. Within a few months after his injury, he participated in a driving course and selected customized equipment with the assistance of occupational therapists and others who offered recommendations. He noted that he bought a new van about one year after the injury and replaced it with another new van about 3 years ago. He worked with an occupational therapist and driving specialist in his town to detail the specifications for the modifications. Jim found the local dealer to be very helpful and estimates that he spent an additional \$500-\$750 for the modifications that were necessary. A local mechanic is able to service the van when necessary, and major equipment is under a lifetime warranty through the dealership.

The ability to drive independently was, and remains, very important to Jim. Prior to the injury, he felt that driving allowed him greater independence, opportunities for socializing, and

the ability to engage in leisure activities. Jim continues to feel this way and values the sense of freedom that results from the ability to drive. Because he was 19 years old at the time of the injury, he was preparing to attend college and was looking forward to the experience. Driving allowed him to recapture some of the mobility and independence that the injury had claimed and it gave him another means of socializing with peers. He commented, "Maybe it's because I was a young male, but I didn't want anyone to treat me differently after I was injured. I was set on doing things by myself as much as possible, and I sure didn't want my parents to be wheeling me around town with my friends. I was lucky to have a group of friends who were accepting; they are still my friends now."

Jim is very active in the community and has lived in the same town for most of his life save document e. The town's population is approximately 40,000 and Jim has an extensive social network of friends and family whom he has known for many years. When prompted, he did not identify any current barriers to social or leisure activities, but noted that he does encounter difficulty when trying to shoot pool in some establishments where there is not ample room to maneuver his wheelchair around the tables. He is able to access local grocery stores, drugstores, shopping malls, restaurants, movie theaters, and other retail areas in the community that are open to the general public. When prompted, Jim was not able to identify any public areas that are inaccessible.

Case Management

Jim is not currently receiving any case management support, but did when he was initially discharged from the hospital. Case management support was provided by the hospital and assisted in coordinating services through a statewide nonprofit agency. This agency provided a variety of independent living services including self-care, nutrition, self-advocacy, peer

counseling, health education, and other skills. Jim was involved in the independent living program for approximately 6 weeks and, although he has not done so, he is able to access the facility as a resource at any time. Case management support was terminated upon completion of the independent living program. Jim does not believe that such support would be helpful to him now because he has found ways to compensate for his limitations and knows the resources that are available because he is a long-term resident of his community.

However Jim noted, that soon after injury, he would have benefited from having additional guidance in recruiting, selecting, and training attendants. Jim noted that, initially, he was not sure about what to expect in terms of his own level of independence in the home and community, nor what he would be eventually capable of accomplishing independently, so it was difficult to determine the specific qualities and qualifications of applicants that were necessary. Although Jim ranked health issues as a high concern, his primary source of health related information was the training he received during rehabilitation approximately 23 years ago, even though he has access to the resources available on the Internet. Further, although he denied his need for case management services and has not accessed the rehabilitation facility as a resource, he expressed an interest in learning more about the resources available to individuals with spinal cord injuries. He specifically mentioned his interest in identifying new adaptive equipment, assistive technology, and other resources that directly coincide with the scope of expertise of case managers. It is possible that Jim did not report having a need for periodic case management because he is unfamiliar with the range of services that are available.

Appendix B

Comprehensive Physical Support Program and Evaluation Criteria¹

Program Objectives (Services)	Evaluation Criteria (Service Level)
<p>I. Classroom Assistance</p>	<p>A. Note takers</p> <ol style="list-style-type: none"> 1. All requests for classroom note-taking met 2. Backup system for “no show” 3. Demonstrated independence by student in obtaining note-taking (self-procurement) <p>B. Interpreters</p> <ol style="list-style-type: none"> 1. All requests for interpreters filled 2. Backup system for “no show” 3. System to screen interpreters—to determine competency 4. Project Director aware of available community resources for funding of interpreters <p>C. Examination Assistance</p> <ol style="list-style-type: none"> 1. System to provide assistance for exams 2. Writers 3. Readers 4. System to have exam in braille, large print, or tape <p>D. Readers/ Writers</p> <ol style="list-style-type: none"> 1. Monitoring to insure security of exam – (key in relationship with academic units)

¹ Adapted from: Kloepping, K. (1978). Short and long-range planning for a comprehensive service system. In P. Marx, & P. L. Hall (Eds.), *Proceedings of the disabled student on American campuses: Services and the state of the art: A national conference held at Wright State University, August 21-25, 1977* (pp. 51-63). Dayton, Ohio: University Publications, Wright State University.

<p>II. Blind services</p>	<p>A. Readers Services System to provide peer readers or referral ((recruitment, screening, referral)</p> <p>B. Library Assistance 1. System to provide and /or referral for assistance for on-site library work</p> <p>C. Resource Center 1. Specialized equipment—perceptual and learning aids 2. Taped materials (storage) – tape inaccessible classrooms 3. Time scheduling</p> <p>D. Orientation Materials 1. Map of campus (tactile) or similar general orientation vehicle 2. Written descriptions of physical aspects of campus</p> <p>E. Orientation Training 1. Mobility instruction prior to enrolling on campus 2. Follow-up training (mobility)</p> <p>F. Production of Materials G. Duplication of Materials 1. System to produce braille 2. System to produce tapes 3. Ability to provide materials on short notice 4. System to provide large print 5. Foreign language and specialized technical readers identified</p> <p>G. Duplication of Materials 1. System to reproduce all materials</p>
<p>III. Admissions</p>	<p>A. Early identification 1. System to identify students early 2. Admissions Office liaison 3. Student Health referral 4. Referral (direct) from agency 5. Housing referral</p> <p>B. Correspondence from office 1. Materials to student from program</p>

	<p>2. Pre-entrance service evaluation form (specifically not to be construed to mean a method for screening out prospective students)</p> <p>C. Special admissions slots</p> <p>1. System to provide for waiver of any traditional admission criteria that are irrelevant to admission of a given student</p> <p>D. Special ACT, GRE, etc.</p> <p>1. Provision of special non-timed ACT, GRFE, and other required entrance tests</p>
IV. Registration	<p>A. Runners, assistance with forms</p> <p>1. Assistance in physical aspects of registration (systematic)</p> <p>B. Priority scheduling—to avoid inaccessible classrooms: allow needed time breaks</p> <p>1. System to avoid inaccessible classrooms</p> <p>2. System for priority assignment</p> <p>3. Time scheduling</p> <p>C. Policy making</p> <p>1. Systematic means for input into University Registration Committee or policy making board</p>
V. Counseling	<p>A. Personal adjustment</p> <p>1. Individual one to one counseling</p> <p>2. Peer counseling</p> <p>B. Group</p> <p>1. 1. Peer group support for interaction</p> <p>2. Staff directed</p> <p>C. Academic</p> <p>1. Provide supplemental academic advisement—career –use of peers</p> <p>a. use of available resources (referral)</p> <p>b. knowledge of key college advisors</p> <p>c. advisement on appropriate course- load</p> <p>D. Vocational and career counseling, job</p>

	<p>development, cooperative ed, job advocacy</p> <ol style="list-style-type: none"> 1. Knowledge of placement resources: career and vocational services 2. Augmentation of existing programs <p>E. Disability management</p> <ol style="list-style-type: none"> 1. Learning to deal with the social stigma of disability 2. Learning how and when to ask for assistance <p>F. Sexuality and disability</p> <ol style="list-style-type: none"> 1. Birth control and family planning 2. Dating and contacting others 3. Marriage and the search for the intimate other 4. Disability and sexual alternatives
VI. Housing	<p>A. Accessible on campus</p> <ol style="list-style-type: none"> 1. Availability of on-campus accessible housing <p>B. Accessible off – campus</p> <ol style="list-style-type: none"> 1. Availability of off-campus accessible housing <p>C. Directory or information available on request</p> <p>D. Program of assistance in modifications</p>
VII. Medical Care	<p>A. Preventative medical maintenance</p> <ol style="list-style-type: none"> 1. Program of information and training on preventative care <p>B. ADL-orientation</p> <ol style="list-style-type: none"> 1. Program of information and training on ADL skills <p>C. Medical facilities available</p> <ol style="list-style-type: none"> 1. Information on appropriate facilities <p>D. Identified physicians and other allied health personnel who work effectively with disabled</p> <ol style="list-style-type: none"> 1. Identified competent medical personnel to

	serve students
VIII. Architectural barriers	<p>A. Knowledge of all barriers</p> <ol style="list-style-type: none"> 1. Systematic evaluation of all facilities (based on expert knowledge) <p>B. Program of removal</p> <ol style="list-style-type: none"> 1. Systematic program for removal <p>C. Expertise</p> <ol style="list-style-type: none"> 1. Knowledge of standards (in-depth) 2. Ability to interpret requirements <p>D. Access routes</p> <ol style="list-style-type: none"> 1. available information on access routes <p>E. Liaison activities</p> <ol style="list-style-type: none"> 1. Close working relationship with Physical Plant 2. Single source of coordination 3. Input at planning stages <p>F. Information Sheet</p> <ol style="list-style-type: none"> 1. Available accessibility and environmental information for students (routes, accessibility etc.)
IX. Parking	<p>A. Designated parking</p> <ol style="list-style-type: none"> 1. Provision of designated parking spaces, including widened spaces <p>B. Stickers or permits</p> <ol style="list-style-type: none"> 1. Provisions of special parking privilege/including insignia <p>C. Issuance (control)</p> <ol style="list-style-type: none"> 1. Authority to issue or authorize privilege
X. Attendant Care	<p>A. Program to recruit</p> <ol style="list-style-type: none"> 1. Systematic program to recruit attendants 2. Screening procedures 3. In-service training for employer and

	<p>attendant</p> <p>B. Financial assistance</p> <ol style="list-style-type: none"> 1. Known sources of funding for attendants <p>C. Emergency needs</p> <ol style="list-style-type: none"> 1. System, to provide “back up” service (emergency)
XI. Non-Academic Leisure Time	<p>A. Interpreters for deaf</p> <ol style="list-style-type: none"> 1. Provision of interpreters for deaf at recreational functions <p>B. Architectural considerations</p> <ol style="list-style-type: none"> 1. Information on accessibility aspects of recreational facilities <p>C. Scheduled events/intramurals</p> <ol style="list-style-type: none"> 1. Facilitation of rec/social activities 2. Intramural activities available 3. Intra-university and intercollegiate competition
XII. Adaptive Physical Education	<p>A. Course credit</p> <ol style="list-style-type: none"> 1. Students participate in physical education for credit <p>B. Participation in regular classes</p> <ol style="list-style-type: none"> 1. Participation in regular P.E. program 2. Assistants where needed 3. Medical clearance provided <p>C. Special programs</p> <ol style="list-style-type: none"> 1. Availability of special programs 2. Structured to individual needs 3. Credit available <p>D. Equipment/personnel/facilities</p> <ol style="list-style-type: none"> 1. Availability of trained staff 2. Equipment 3. Adequate facilities
XIII. Attitudinal Climate	<p>A. Educational programs</p> <ol style="list-style-type: none"> 1. Systematic programs to sensitize non-

	<p>disabled</p> <p>2. Utilization of students and student staff</p> <p>B. Organized activities</p> <p>1. Use of n-service training throughout university</p> <p>2. Speaker's Bureau</p> <p>3. Class presentations</p> <p>4. Representation on student and university committees and organizations</p> <p>C. Project involvement in process of effecting attitude change</p>
<p>XIV. Follow-up Data on students</p>	<p>A. Success through semester</p> <p>1. Successful completion of the semester; physically and GPA</p> <p>B. Degree completion</p> <p>1. Quantified data on students who finish degree program</p> <p>1. Bachelor</p> <p>2. Master</p> <p>3. Doctorate</p> <p>C. Employment</p> <p>1. Quantified data on graduates who obtain successful employment</p> <p>D. Movement to independent living/issue of cost to society</p> <p>1. Quantified data on students who have moved from dependent to independent living status (autonomous management of one's affairs)</p> <p>a. Without support (welfare, SSI, etc.</p> <p>b. With support (welfare, SSI, etc.</p>
<p>XV. Mobility Center</p>	<p>A. Maintenance of equipment</p> <p>1. System to provide maintenance and repair of wheelchairs and other specialized equipment</p> <p>B. Emergency services</p> <p>1. System of emergency service and availability of equipment for emergency use</p>

	<p>on loan basis</p> <p>2. System to repair equipment rapidly (minimum “down-time”)</p> <p>C. In-service training</p> <p>1. Established working relationship with community medical supply firm</p> <p>2. Priority service</p> <p>3. Discount prices</p> <p>4. Alternative “life-support” supplies</p>
XVI. Staffing	<p>A. Use of disabled peers</p> <p>1. Disabled peer models available</p> <p>B. Access to role models</p> <p>1. Availability of disabled professional staff models</p> <p>C. In-service training</p> <p>1. Operational in-service training program for all staff</p> <p>D. “Non-closed” view of fully functioning person</p> <p>1. View that disability per son is not necessarily a prerequisite for effective functioning with the disabled student</p>
XVII. Orientation	<p>A. Pre-enrollment orientation program</p> <p>1. Established operational orientation program</p> <p>a. visit to campus prior to enrollment</p> <p>b. personal tour</p> <p>B. Augmentation of all university program</p> <p>1. Operational system to augment all university system</p> <p>C. One – to one orientation preferred procedure</p> <p>1. Provision of one-to-one orientation process</p> <p>D. “Non-closed” view of fully functioning person</p> <p>1. Developed and available materials of significance for in-coming students</p>
XVIII. Equipment	<p>A. Purchase of life-support special equipment</p>

	<ul style="list-style-type: none">1. Funding to purchase or means to ensure purchase of basic needs equipment<ul style="list-style-type: none">a. phonic earb. visual-tekc. swimming pool liftsd. modified transportation (vans) B. Basic tools and supplies- Mobility Center<ul style="list-style-type: none">1. Equipment to provide basic repair and maintenance services C. Rapid Braille Reproduction System<ul style="list-style-type: none">1. System to ensure rapid and inexpensive means to reproduce brailled materials D. Availability of specialized aids on demand or knowledge of resources to obtain<ul style="list-style-type: none">1. Opticon, Thermoform, raised line kits, etc.
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Appendix C

Survey Instrument

Physical Support Services Program Follow-Up of Functional Independence

This questionnaire is designed to identify your level of functional independence at a single time point after completing your undergraduate degree. Your responses will be utilized to shape future curriculum development. Your responses will be strictly confidential. Completion of this questionnaire is voluntary and you may withdraw from participation at any time by closing your browser prior to submitting the questionnaire.

Please select the response that most closely applies to you.

Living Arrangements

1. Which of the following best describes your current living situation?
 - a. With family, caregiver or legal guardian
 - b. In a group home or other care facility
 - c. Independent in the community either with or without supports
2. In this living arrangement, ...
 - a. I am responsible for planning and budgeting for expenses
 - b. Someone else manages the budget and expenses

Method of Activities of Daily Living Provision

3. Which of the following best describes the level of assistance you need with activities of daily living, such as bathing, dressing and gaining access to nutrition? [Note: consider the activity with which you typically require the most assistance]

- a. Maximum assist -- I can complete 15 % or less of the steps required in order to complete these activities with or without the use of assistive technology.
- b. Moderate to minimal assist -- I can complete 85% of the steps required in order to complete these activities with or without the use of assistive technology.
- c. Modified/independent -- I can complete 100% these activities independently either with or without the use of assistive technology.

[if C is selected skip question 4]

4. When you require assistance with activities of daily living as indicated above from whom do you primarily receive that assistance?
- a. Family member(s)
 - b. Paid caregiver(s) whether from a public program or private resources
 - c. Friend(s) or other volunteer

Employment, Training and Benefit Status

5. Which of the following best describes your current employment status?
- a. I am employed full-time.
 - b. I am employed less than full-time.
 - c. I am not employed.
 - d. I have returned to school or other training program.

[if A or B are selected, include question six. If D is selected include question 9]

6. Which of the following best describes your current position?
- a. My job responsibilities are aligned with my degree or major field of study.

- b. I am working outside my degree or major field of study.
7. Which of the following best describes your primary health insurance coverage?
- a. Employer-provided
 - b. On someone else's policy as spouse or dependent
 - c. Public health insurance program such as Medicare or Medicaid
 - d. Student health insurance [included only if returned to school is selected in question five]
8. How would you define your primary income source?
- a. Wages from employment
 - b. Supplemental Security Income or Social Security Disability benefits
 - c. Settlement or other trust
 - d. Student financial aid [included only if returned to school is selected in question five]
9. What best describes your current education or training status?
- a. Enrolled in graduate degree program
 - b. Enrolled in undergraduate bachelors program
 - c. Enrolled in a vocational certificate program
 - d. Enrolled as a non-degree seeking student or taking courses for personal fulfillment

Demographic information

10. How long ago did you complete your undergraduate degree from Wright State University?

- a. Less than one year
- b. 1 to 2 years
- c. 3 to 5 years
- d. 6 years or more
- e. I completed my degree at another institution
- f. I have not completed an undergraduate degree

11. Which disability management courses offered by Wright State University did you successfully complete (check all that apply)?

- Adaptive Computer Technology (BME 155/1550)
- Career Planning for Individuals with Disabilities (LA 201/2010)
- Developing Peer Mentors with Disabilities (ED 1030)
- First Year Seminar (UVC 101/1010)
- Foundations of Learning (ED 1040)
- Managing Personal Assistants (ED 101/1020)
- Physical Fitness for Disabled (HPR 100/KNH 1440)

APPENDIX D
Managing Personal Assistants ED 1020 Syllabus

**MANAGING YOUR PERSONAL ASSISTANCE
FALL SEMESTER 2015
3:30-4:30pm on Tuesdays & Thursdays in Rike 157**

Instructor: Jean Denney
Office: Disability Services, 180 Student Union
Office Hours: By appointment - call (937) 775-5680 to schedule an appointment
Office Phone: (937) 775-5686 (voicemail)
Office email: jean.denney@wright.edu

Course Objectives:

To provide the student with the opportunity to become knowledgeable in:

- Recruiting, interviewing, screening, hiring, training, scheduling, problem solving, paying for, and managing your personal care assistants
- Communication skills
- Problem solving skills
- Resources available for personal assistance (OOD, ODJFS, DOOD, etc.)
- Resources for disability related needs, supplies, and equipment
- Resources for accessible transportation & driver evaluation programs

Course requirements:

The student is expected to:

- Attend class regularly (**only 4 absences permitted**)
- Actively participate in class discussion
- Accomplish assigned readings from class textbooks for the course
- Fulfill all written assignments
-

Evaluation Procedures:

The student will be evaluated on the following:

- Class attendance 90 points (3 points per class)
- Results of examinations 10 points - quiz
100 points - mid term exam due on Thurs, Oct 22, 2015
100 points - final exam due on Thurs, Dec 17, 2015
300 points total

According to the following standards:

<u>Letter Grade</u>			<u>Pass/Fail</u>	
90 - 100 %	=	270-300	=	A
80 - 89%	=	240-270	=	B
70 - 79%	=	210-240	=	C
60 - 69%	=	180-210	=	D
			210-300	P = Passing
			below 180	U = Unsatisfactory

Course Textbook:

Managing Personal Assistants – a consumer guide by the PVA -
<http://mypva.org/images/PersAsst.pdf>. (free)

Course Schedule:

C L A S S	DATE	TOPIC	TEXT READINGS PAGES
1	Tues, Sept 1	Introduction to ED 1020 – Managing your Personal Assistance	
2	Thurs, Sept 3	3 individuals and their stories	
3	Tues, Sept 8	History of the Independent Living Movement	
4	Thurs, Sept 10	What is Consumer Directed Personal Care	1-2
5	Tues, Sept 15	Assessing your PA Needs	3-5, 8-9,54,55
6	Thurs, Sept 17	Managing Your PA Needs – guest speaker	
7	Tues, Sept 22	Developing a PA job description	6-7,57
8	Thurs, Sept 24	Developing a PA job application	18,5-63
9	Tues, Sept 29	Recruiting Pas	13-15
10	Thurs, Oct 1	Interviewing Pas	16-21,58
11	Tues, Oct 6	Screening and selecting Pas	21-23,66
12	Thurs, Oct 8	Hiring PAs & Scheduling Pas	23-26
13	Tues, Oct 13	Training Pas	35-38,65

14	Thurs, Oct 15	Understanding estimates, timesheets, & billing statements – Sarah Mault	11-12,45-48
15	Tues, Oct 20	Accessible Transportation - John of RTA and Cecil of Project Mobility	49-50
16	Thurs, Oct 22	Accessible Transportation- WSU campus shuttle and paratransit TAKE HOME MID TERM EXAM DUE (100 points)-submit in PILOT	MIDTERM DUE
17	Tues, Oct 27	Accessible Transportation – Shannon of Greene CATS	
18	Thurs, Oct 29	Tour of accessible campus housing –Honors, Forest Lane, College Park, Univ Park, & Village	Class activity
19	Tues, Nov 3	Travel Training trip off campus	Class activity
20	Thurs, Nov 5	PA scheduling for Spring Semester (Jan 10 –April 30, 2016)	
21	Tues, Nov 10	Communicating Effectively & Solving PA problems	39-44
22	Thurs, Nov 12	Being a GOOD Manager & Keeping Pas	27-33, 64
23	Tues, Nov 17	Basic Wheelchair Maintenance & Repairs WORKSHOP	
24	Thurs, Nov 19	PA Emergencies	
25	Tues, Nov 24	Developing a PA Back Up Plan	24
26	Thurs, Nov 26	NO CLASS – UNIVERSITY CLOSED – THANKSGIVING BREAK	NO CLASS
27	Tues, Dec 1	OOD PCA program – Whitney Christopherson of RSC PCA	
28	Thurs, Dec 3	Ohio Dept of Job & Family Services (ODJFS) waiver programs	
29	Tues, Dec 8	Dept of Developmental Disabilities(DODD) waiver programs	
30	Thurs, Dec 10	Home Health Care Agencies – Andy & Melissa from Maxim HHC	
31	Tues, Dec 15	Wrap up & course evaluation	
32	Thurs, Dec 17	NO CLASS- TAKE HOME FINAL EXAM DUE (100 points)–submit in PILOT	FINAL EXAM DUE

Appendix E
Information Letter

Dear Wright State University graduate,

I am a doctoral candidate in the Department of Special Education, Rehabilitation, and Counseling at Auburn University. I would like to invite you to participate in my research study to identify your level of functional independence at a single point in time after completing your undergraduate degree. You may participate if you are 19 years of age or over and have successfully completed an undergraduate degree that included the personal assistant management class offered by Wright State University.

Participants will be asked to complete The Physical Support Services Program Follow-Up of Functional Independence. This brief questionnaire contains items relating to your current living arrangement, how you accomplish your activities of daily living, as well as questions related to your employment or training status and healthcare insurance source. It will take approximately 10 min. to complete the questionnaire.

Even though a handful of universities like Wright State have been implementing comprehensive physical support programs for more than 40 years, there is very little data on whether these programs actually increase students' ability to live independently or maintain competitive employment. Consequently it is crucial that graduates be queried to see the extent to which they are able to apply good disability management skills. You may also be aware that such programs are not required to be provided by the program for students with disabilities at an institution of higher education. Therefore it is also vital that outcome data continues to be provided in order to highlight the return on investment. It is hoped that with a robust data, additional universities will be encouraged to initiate comprehensive physical support programs.

If you would like to participate in this study, the questionnaire can be accessed by clicking [here](#). Participation in this study is voluntary and your responses will be confidential. Data will be maintained on the secure portion of the Qualtrics server leased by Auburn University. If you do not wish to complete the questionnaire after beginning it, simply close your browser before submitting and your responses will not be recorded.

The Auburn University Institutional Review Board has approved this document for use from February 4, 2016 to February 3, 2019. Protocol #16-043 EX 1602. The Wright State University Institutional Review Board has subsequently approved this document under Protocol # P 18-024, as of March 4, 2016. If you have any questions regarding this study, please contact me by e-mail at epubbles@auburn.edu or my advisor, Dr. Rebecca Curtis at curtirs@auburn.edu.

Thank you for your consideration,

Sincerely,

Eric M Peebles, M.Ed., CRC

The Auburn University Institutional Review Board has approved this Document for use from 02/04/2016 to 02/03/2019
Protocol # 16-043 EX 1602

Appendix F

Approval Memorandum for Participation of Wright State University Faculty, Staff, or Students in Research Approved by Another Institution



Office of Research and Sponsored Programs
3640 Colonel Glenn Hwy.
Dayton, OH 454-35-0001
(937) 775-2425
FAX (937) 775-3781
email: rsp@wright.edu
www.wright.edu

DATE: March 4, 2016

TO: Eric Peebles, MPA, M.Ed., CRC
Auburn University
Center for Disability Research and Service
215 South Donahue Dr.
Auburn University, AL 36849

FROM: Thomas Koroscil, Chair *TK*
Wright State University Institutional Review Board

SUBJECT: P18-024, Postsecondary Physical Support Programs, Independent Living and
Economic Self-Sufficiency for Individuals with Significant Physical Disabilities

At the recommendation of the WSU IRB Chair, your request was reviewed and
granted. You are free to begin your research as described in your application.