ATTENDANT CARE FOR COLLEGE STUDENTS WITH PHYSICAL DISABILITIES USING WHEELCHAIRS: TRANSITIONAL ISSUES AND EXPERIENCES

A THESIS

SUBMITTED TO THE GRADUATE SCHOOL

PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE

OF MASTER OF ARTS

BY

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BALL STATE UNIVERSITY

MUNCIE, INDIANA

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BY

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ABSTRACT

Title: Attendant Care for College Students with Physical Disabilities using Wheelchairs: Transitional Issues and Experiences

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From preschool through the end of high school, accommodation and success rather than self-advocacy and student development are the predominant frameworks for students with physical disabilities. Many students with physical disabilities who use wheelchairs are assisted by their family members with daily life activities such as getting out of bed, showering, eating, dressing, and toileting. For most of these students college is the first time they will have to use his or her own voice. Once in college, the students are responsible for finding their own personal care. Students are challenged with becoming responsible for the process of hiring an attendant for themselves, taking the next step to becoming independent, and being socialized into a new environment. Many factors affect the transition and experiences from high school to college and for students with physical disabilities, that transition may involve attendant care.

The purpose of this study was to explore the transitional attendant care issues and experiences of college students with physical disabilities who use wheelchairs. A phenomenological approach grounded in qualitative methodology was used in this study.
In a mid-sized public doctoral-granting Midwestern institution, twelve participants were interviewed who were undergraduates with a physical disability using a wheelchair and having attendant care.

Seven themes emerged regarding transitional issues for students with attendant care: time management, preparing for attendant care, training attendants, first feelings, accepting responsibility, parental involvement, and financial considerations. Four themes emerged regarding their collegiate experiences: attendant care preferences, relationships with attendants, supportive friends, and characteristics of attendants. Recommendations for future studies, future researchers, student affairs educators, and future college students were provided.

While students with disabilities that use wheelchairs and attendant care have similar experiences with many other students, they also have experiences that are completely different than the average college freshman. It is important to understand the unique challenges this subpopulation of college students has, and what they can do, and not do, to meet those challenges. Students with disabilities that use a wheelchair and will use attendant care need to consider the implications of attendant care and plan ahead prior to coming to college.
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Chapter one provides an overview of the study that explored college students with physical disabilities using wheelchairs and their experiences with attendant care. Also included in this chapter is a statement of purpose, research question, significance of study, assumptions, limitations, definition of terms, and the organization of the project.

**Introduction to Study**

From preschool through the end of high school, accommodation and success, rather than self-advocacy and student development, are the predominant frameworks for students with physical disabilities (McCarthy, 2007). Eleven percent of undergraduate students, or over two million students, have a disability (Martin, 2012). The majority of the disabilities are not physically apparent, however 15 percent of students have an orthopedic, or mobility impairment. Approximately 27 percent of students with disabilities enroll at four-year institutions, compared to the 68 percent of students without disabilities (Barnard-Brak, Sulak, Tate, & Lechtenberger, 2010). Many students with physical disabilities mainly those who use wheelchairs, are assisted by their family members with daily life activities such as getting out of bed, showering, eating, dressing, and toileting. During K-12, students who identify as having
physical disabilities are protected under the Individuals with Disabilities Improvement Act (IDEA, 1997), which guarantees K-12 students with disabilities access to public education, and modifies curriculum tailored for student success. It was reauthorized in 2004.

Sometimes students with disabilities who use wheelchairs have few personal care responsibilities because a parent or guardian handles their personal care needs and all school-related issues. “When most of these students arrive at college it is the first time they have had to find—and use—his or her own voice” (McCarthy, 2007, p. 11). When college starts, the students are responsible for figuring out their own personal care. Students are challenged with becoming responsible for the process of hiring an attendant for themselves, taking the next step to becoming independent, and being socialized into a new environment. These are some of the transitional issues students may have to handle.

“Almost overnight, students move from a system in which someone else such as a parent or teacher managed the ‘disability thing’ to a completely self-directed system” (McCarthy, 2007, p. 12). Students have to assume personal responsibility when they come to college. “Colleges are not required to provide personal care assistance, and their responses will run the gamut from being completely hands-off the process, to providing assistants, to providing help in hiring an attendant” (Tiedemann, 2012, p. 69). This experience can be unsettling to transition from one day being a person with a physical disability whose personal care needs come from family, to being a first-year college student and having to take responsibility for their personal care needs through the process of hiring someone they do not know (attendant) to help them with this process. “Larry
Markle, director of Disabled Student Development at Ball State University, said ‘Directing personal care is the biggest hurdle.’ Students should begin planning for their personal care needs when they start visiting campuses” (p. 69). Students needing attendant care need to know the options that are available to them. They should ask about the ways to find people who can help them with their personal care needs, and to see what the disability office on that campus has to offer.

Many factors affect the transition and experiences from high school to college, and for students with physical disabilities that transition may involve attendant care (Tiedemann, 2012). Before coming to college, many students have not had to consider who was going to take care of them because a friend or family member had always been around to assist them. When a student makes the decision to live on a college campus, and have their personal and organizational needs met by personal attendants they need to figure out the services that are available to them on campus. This is essential so that they have a chance succeeding in college. They also need to learn how to be successful in their academic endeavors.

Studying the transitional issues and experiences of college students with physical disabilities who have attendant care and use wheelchairs helps others to better understand how these experiences help develop these students as individuals and shape their collegiate career. The data gathered throughout the study will give insight into this topic.

**Statement of Purpose**

The purpose of this study was to explore the transitional attendant care issues and experiences of college students with physical disabilities who use wheelchairs. Findings
from this study will help others better understand college students with physical disabilities and their experiences with attendant care.

**Research Question**

This study addressed the following research question. How did college students with physical disabilities using wheelchairs describe the issues they encounter and the experiences they had with attendant care as they transitioned into higher education?

**Significance of Study**

For many college students, transitioning from high school to college is a challenging experience. Along with that experience, students with disabilities take on the additional challenge of having to find someone to assist them with their personal care needs, and get adjusted to college life and being a student (Tiedemann, 2012). Students with physical disabilities experience some of the same transitional experiences and needs as those students who do not have physical disabilities (McCarthy, 2007). However, their experiences are sometimes more complex compared to others because of the responsibility of having attendants. Personal care is often very essential to their college success in college, and it is something that ought to be discussed before arriving at college. Meeting with staff in the disability services office can sometimes better assist with this part of the transition (Tiedemann, 2012). Attendant care can add stress and it can influence their academic and social integration into higher education. For these students, managing their own attendant care is a learning process; it takes place gradually and sometimes haltingly. There are times when their progress will be stop and go, some days things will go great with an attendant and then an issue arises and they may have to
terminate the employment of that person. There will be moments of success and failure (McCarthy, 2007). The more knowledge there is about this transitioning process for students, the better their experiences will be understood.

Assumptions

Many assumptions were made prior to this study about the potential participants and their responses to questions that they would be asked. The researcher assumed that:

- Students with physical disabilities in wheelchairs would be willing to share their stories about the individuals who have helped them with attendant care while in college.
- Getting these individuals to share their stories might be a challenge given the highly personal nature of the topic.
- I assumed that some of the stories would describe how these individuals were very helpful to them, and some of the stories would be negative experiences.
- For many of the students it was the first time to have someone outside the family provide attendant care.

These issues with the participants’ transition to college would make the transition difficult for many of them.

Definition of Terms

The following terms are defined for this study.

Attendant care – Paid and unpaid assistance needed by individuals with a physical disability for daily living activities such as bathing, dressing, feeding, and grooming (Texas State Council for Developmental Disabilities, 2005-2012).
Personal care – The occupation of attending to the physical needs of people who are disabled or otherwise unable to take care of themselves, including tasks such as bathing, management of bodily functions, and cooking (The Free Dictionary, 2012).

K-12 – Kindergarten through twelfth grade (Dictionary.com, 2012).

Wheelchair user – A person who uses a wheelchair, especially because of physical disability (Oxford Dictionaries, 2013).

Home Care Agency (Agency) – A home care agency is an agency that provides care workers to help you at home. The agency might be a private company or a charity. The agency can be employed by the council to provide you with services, or you can employ the agency's staff yourself from your own resources or using Direct Payments (FirstStop, 2013).

**Organization of the Project**

This study is structured into five chapters. Chapter two is a review of related literature concerning the transitional issues and experiences that students with physical disabilities in wheelchairs face during their collegiate career. Chapter three includes a description of project and methodology. Chapter four presents the findings in the study. Chapter five provides a discussion of the topic, conclusions, limitations, and recommendations for further research. A list of references and appendices are included at the end of the paper.
CHAPTER TWO

REVIEW OF RELATED LITERATURE

Imagine waking up at 7:30 am in the morning with someone whom you do not know very well standing in your room informing you they are here to help you prepare for your day, by helping you shower, get dressed, and doing anything else you may need before departing to class. This brief imagery to some is uncomfortable, but for others it is a part or their everyday routine. Some college students with physical disabilities, who use wheelchairs and have attendant care in college, go through this ritual daily. Many people do not know this is something that routinely takes place in the life of someone who has limited mobility. The study examined the attendant care issues and experiences of college students with physical disabilities who use wheelchairs. The following literature review is divided into three sections, theoretical foundation, students with disabilities in wheelchairs, and attendant care.

Theoretical Foundation

Chickering and Reisser

Students’ experiences grant different types of personal development during their collegiate career. Chickering and Reisser (1993) identified seven vectors a map to help determine identity related issues during the collegiate experience. The seven vectors, originally proposed as major constellations of development during adolescence and early
adulthood, apply to adults as well. These vectors have allowed college and university educators to view the educational process more clearly. The seven vectors are as follows: 1. developing competence, 2. managing emotions, 3. moving through autonomy toward interdependence, 4. developing mature interpersonal relationships, 5. establishing identity, 6. developing purpose, and 7. developing integrity. Like all college students, students with physical disabilities transition through these vectors. Vectors one, three, four and five may be the more applicable to students with physical disabilities.

**Vector 1: Developing Competence.** There are three types of competence that are developed during college, intellectual, physical and manual skills, and interpersonal (Chickering & Reisser, 1993). Entering college students with disabilities are already perceived to be at a higher risk to drop out than their nondisabled peers, so reaching intellectual competence can sometimes be a challenge for them (Marmiseishvili & Koch, 2011). Physical or manual skills differ for students with physical disabilities. When physical and manual skills can mean athletic and artistic achievement, fitness, gaining strength and self-discipline (Chickering & Reisser, 1993), those are not always physically possible for students with physical disabilities. Challenges may arise for when students have a physical disability trying to be interpersonally competent. Students should be able to state their disability, and/or be able to discuss disability-related accommodations with their professors, and other faculty/staff member (Hadley, 2011).

Because of preconceived perceptions placed on students with physical disabilities as it relates to intellectual competence. They may have to work harder than students without disabilities. For many students with physical disability they may never become
physically competent. The inability to self-advocate, because it is not something that had to be done prior to college, can prevent them from becoming fully interpersonally competent in college.

**Vector 3: Moving through Autonomy toward Interdependence.** Students come to college exploring their new autonomy, and searching for realistic purposes and meaningful achievements (Chickering & Reisser, 1993). For a student with a physical disability using a wheelchair, autonomy may look different than for students without physical disabilities. The challenges of autonomy arise for this population of students when they realize that their personal care is now one of their primary responsibilities, whereas in K-12 most often their parent/guardian and family members handled that aspect of their lives. Disability service staffs unanimously agree that one of the largest obstacles for students with physical disabilities who live on a college campus is the unfamiliarity with obtaining and directing their personal care (Tiedemann, 2012).

All students seek autonomy, personal responsibility, and to be viewed as someone who is independent. Finding and directing personal care is a way to demonstrate autonomy and use one’s own voice (McCarthy, 2007), and show progress on the path toward interdependence. There are many steps that lead to gaining independence, and for a student with a physical disability some of those steps may be especially challenging, (e.g., having to terminate employment for an attendant for the first time, calling an agency and notifying them of issues going on with attendants, explaining to an attendant when they feel they are not doing their job properly). For some students these responsibilities
appear simple, but for students with physical disabilities who have not had to advocate for themselves, can be challenging.

**Vector 4: Developing Mature Interpersonal Relationships.** Collegiate relationships often have a profound impact on students’ lives (Chickering & Reisser, 1993). The college environment for students with disabilities does not include the same level of academic support that is often experienced in high school settings (Hadley, 2011). For some of these students this is the first time they have been around others who also have physical disabilities. Building and establishing relationships with others who have physical disabilities can be a developmental experience, just as building relationships with nondisabled students. Being able to articulate to others about their attendant care, and seeing how others react to that part of their life, plays a part in building those relationships.

Experiencing difference among people is a step toward developing mature interpersonal relationships. Students who have physical disabilities are sometimes uncomfortable with peers who have disabilities different from their own (Fichten, Robillard, Judd, & Amsel, 1989). That uncomfortable feeling can put a strain on building relationships with others. These students also have to build some type of relationship with their attendants. Being able to build and maintain personal relationships with attendants and peers is a step to building interpersonal relationships.

**Vector 5: Establishing Identity.** Becoming an adult involves developing competencies, emotions and values, confidence in standing alone and bonding with others, and moving beyond intolerance toward openness and self-esteem (Chickering &
Reisser, 1993). Defining one’s true self is a path that all people must take. Achieving competence in this vector may be different for a student who has a physical disability using a wheelchair. Many outcomes can effect this vector, depending on how long a person has been using a wheelchair, how long they have had a disability, what the transition to college was like, and how they socially integrated. Discovering one’s identity is a learning process which is done gradually over time with moments of success and failure (McCarthy, 2007).

Accepting the idea that someone has to help you with your personal care needs may be hard to grapple with. Self-determination is a key skill that can be developed as students with disabilities learn how to self-advocate (Gil, 2007). A large part of establishing identity for students with disabilities is self-advocacy. Self-advocacy means that a student understands his or her disability, is aware of the strengths as of the weaknesses resulting from the functional limitation imposed by the disability, and is able to articulate their need for physical assistance (Lynch & Gussel, 1996). Some students fully accept and embrace their physical disabilities, however there are some people who struggle with that part of their identity.

**Tinto**

Tinto (1993) developed a theory of institutional departure, which explains the longitudinal process of college students leaving from institutions of higher education while capturing the complexity of behaviors that underlie that phenomenon. College students should positively separate transition, and incorporate collegiate values as they become integrated into the academic and social systems at a college or university.
During the transitional period students depart from their high school community and family and transition to college. Transition to college entails a plethora of experiences, including social and academic transitions as two of the major factors in the lives of students with physical disabilities using wheelchairs. As students transition to college, they begin to incorporate the values and norms of the college they are attending.

**Social transition.** “Colleges like other human communities are highly interdependent, interactive systems in which events in any one part may be felt in other parts of the system” (Tinto, 1993, p. 108). College is a place where students go to find themselves and they see if they have what it takes to master academics and fit in the social scene. Mamiseishvili and Koch (2011) suggested living on campus provides more opportunities for students to be engaged in academic and social activities and interact with faculty and students; this results in a higher likelihood of persistence to graduate. Socially integrating on a college campus is a major aspect of the collegiate experience. For some students with disabilities college is the first time they are around other students who have disabilities. To be successful they have to adjust socially to that environment.

**Academic transition.** “Research on academic success in post-secondary education focused specifically on the impact of previous school performance (i.e., high school marks) and/or standardized measures of cognitive abilities” (Parker, Summerfeldt, Hogan, & Majeski, 2003, p. 164). For students with physical disabilities, high school education sometimes is different than for those not having a disability.

The public school system is governed by the Individuals with Disabilities Education Improvement Act (IDEA, 2004), which focuses on the success of
students with disabilities. IDEA is mandated to provide services deemed necessary by the individual education program (IEP) team to assist the student in meetings with success in the educational environment. (Gil, 2007, p. 12) IEPs no longer exist in college. It becomes the students’ responsibility to academically perform (Eckes & Ochoa, 2005). If students want to receive academic accommodations, they must first self-identify with the disability services office, and then self-advocate for the needed accommodations (Gil, 2007).

When a disability has been verified, the institution must reasonably accommodate the student (Eckes & Ochoa, 2005). Students must take personal responsibility to self-advocate for reasonable accommodations. If they do not do this, their academic needs may not be met. The accommodations the students require vary depending on the circumstances. There could be a need for scribes, assisted technology, and note takers, just to name a few. Without proper accommodations, the academic transition will be difficult.

**Students with Physical Disabilities who use Wheelchairs**

College students, as having physical disabilities and using wheelchairs have specific personal and academic needs. In 2008, the United States Government Accountability Office (2009) reported that students with disabilities represented 11 percent of all postsecondary students, and that the populations has continued to grow over the last decade. Of the students with disabilities, 57 percent were women, 67 percent were White, while Hispanic/Latino, Black/African Americans, and Asians represented a smaller number. Students with disabilities attended two-year schools at a higher rate than
their peers. People with disabilities complete college at significantly lower rate than those people without disabilities (Barber, 2012). However, “Wheelchair users are unique among students with disabilities because of the physical barriers in the university environment” (Paul, 1998, p. 1). This section of the paper discusses laws in place to protect these students and their needs. This will provide insight into the lives of these students and their college experiences. Students with disabilities in higher education face a different situation regarding their rights and responsibilities then they did during their elementary and secondary education (United States Government Accountability Office, 2009).

Section 504 and American Disabilities Act

Section 504 of the Rehabilitation Act of 1973 covers college students with disabilities. Section 504 prohibits entities that receive federal financial assistance, including institutions of higher education, from discriminating against otherwise qualified individuals with disabilities (United States Government Accountability Office, 2009). This act contributed to the increasing numbers of students with disabilities who entered post-secondary education (Lynch & Gussel, 1996). Subpart E of Section 504 addressed the rights of people with disabilities in federally funded institutions of postsecondary education, including both public and private institutions receiving federal grants and contracts, and institutions whose students received federal aid.

The Americans with Disabilities Act (ADA, 1990), was signed into law in 1990 and extended the mandate for nondiscrimination on the basis of disability to the private sector and the nonfederal public sector (Lynch & Gussel, 1996). The ADA defined a
person with a disability as someone who has a physical or mental impairment that substantially limits one or more major life activities. The American with Disabilities Act Amendments of 2009 extended the protections of the American with Disabilities Act of 1990 to a larger number of individuals (Mamiseishvili & Koch, 2011).

The accommodations that schools provide can include academic adjustments such as extended time on tests, auxiliary aids, or services such as note takers. Schools have to provide reasonable accommodations that are tailored to students’ individual needs, which allows for equal access to higher education (United States Government Accountability Office, 2009). Those are just a few of the basic accommodations that an institution can provide to students with disabilities. Some schools offer more enhanced services. Enhanced services could include having specialized and trained professionals, disability screenings, assessments, counseling, and tutoring. Some schools offer comprehensive accommodations, which include full participation of the students in campus life.

**Transitioning to College**

The first year of college is an important time for students because students create the foundation for their subsequent experiences (Woosley & Miller, 2009). Students often express concerns over the transitional process, citing worries about interpersonal relationships, adjustment time, homesickness, and academic stress as potential obstacles that arise when getting comfortable with their institution. All students enter college with various characteristics – gender, race, academic, aptitude academic achievement, family socioeconomic background, and parent educational levels – and they all have different levels of initial commitment to an institution (Elkins, Braxton & James, 2000). The
experiences most beneficial for students with physical disabilities in wheelchairs include enhanced academic and classroom experiences, a healthy and stable residential experience, and finding the right attendant care (Padgett et al., 2012).

Persistence to the second year is important to colleges and universities because approximately three-fourths of all dropouts leave at some point during their first year (Elkins et al., 2000). Institutions have a variety of interventions aimed at the initial phases of transitions, both during the summer before college begins and during the first few weeks of the semester (Woosley & Miller, 2009). Orientation programs are crucial to a student’s transition and should not be limited to a day or so at the beginning of the first semester, instead continuing throughout the freshman year (Elkins et al., 2000). There are many factors that help students with physical disabilities ease into their transition from high school to college; acknowledging strengths and areas of needs, learning about the disability services office, participating in precollege academics, taking responsibility for one’s own education, and self-advocating are just a few (Connor, 2012).

**Attendant Care**

The transition from high school to college can be overwhelming and confusing for many students. For students with disabilities it is important to understand and articulate their needs relating to their disabilities. If this does not happen, it can often to lead to issues that can arise throughout the transitional process.

Students with disabilities often encounter barriers that can impede their ability to access, participate in, and complete higher education. Among these barriers are unawareness of the availability of academic support and reasonable
accommodations, lack of skills in self-advocacy and self-determination, financial problems associated with paying for education in addition to disability-related expenses, inconsistencies in provision of educational supports. (Mamiseishvili & Koch, 2011, p. 93)

These barriers can alter a student’s transition to college in multiple ways. Trying to figure out how they will be able to afford attendant care, having to accept responsibilities for themselves when before college their family did that, and being aware of the resources available on campus, are all ways that transitional issues can affect students.

Attendant care is defined as paid and unpaid assistance needed by individuals with a physical disability for daily living activities such as bathing, dressing, feeding, and grooming (Texas State Council for Developmental Disabilities, 2005-2012). Some students with severe physical disabilities require attendant care throughout their lives. Learning to be an effective consumer by setting up and maintaining attendant care has an impact on the students’ well being as well as their academic success (Simon, 1977).

Students have to take initiative when it comes to attendant care. The student is the primary person in control of decisions regarding their personal attendant care; they should learn to exhibit the qualities of an effective personal manager (Birdwell & Fonosch, 1980).

A major issue with attendant care is that often students do not know what needs to be done in order to for them to receive the care they need. “To improve chances for success in attaining independent living . . . the role of the attendant is necessary” (Atkins, Meyer, & Smith, 1982). Tiedemann (2012) discussed how students have to figure out
when they will need an attendant because the job is tailored around their schedule; the students need to know where they can go to locate an attendant to assist them. Some students have Medicaid that takes care of the cost; some have Vocational Rehabilitation, which pays for their care. Finding a source of attendant care is something that some students do not think about. Students can place ads in the local and school newspapers informing others that they are looking for attendants, they can ask a friend if they would be willing to help them, or they can find care through agencies in the surrounding area.

**Summary**

This literature review provides an overview of the theoretical foundation, which focused on Chickering and Reisser’s theory of educational identity and Tinto’s theory of institutional departure, which concentrated on social and academic transition. Students with physical disabilities using wheelchairs receive certain accommodations that they are allowed by federal law. Lastly, attendant care provides necessary assistance with personal care during the college years.
CHAPTER THREE

METHODOLOGY

Chapter three outlines the methodology used in this study to explore the transitional attendant care needs and experiences of students with physical disabilities using wheelchairs. This chapter also contains a statement of purpose, research question, design of the study, data collection procedures, data analysis, and a summary.

Statement of Purpose

The purpose of this study was to explore the transitional attendant care issues and experiences of college students with physical disabilities who use wheelchairs. Findings from this study will help others better understand college students with physical disabilities and their experiences with attendant care.

Research Question

This study addressed the following research question. How did college students with physical disabilities using wheelchairs describe the issues they encounter and the experiences they had with attendant care as they transitioned into higher education?

Design of Study

Qualitative methodology was chosen for this study because it seeks to answer questions that stress how social experience is created and gives meaning
(Denzin & Lincoln, 2005). “The best-known representatives of qualitative research studies that embody the characteristics are those that employ the techniques of participant observation and in-depth interviewing” (Bogdan & Biklen, 2006, p. 2). This methodology was chosen because the researcher believes the transitional experiences of students with disabilities using wheelchairs and who use attendant care have voices that need to be heard. This is done best through in-depth questioning and an analysis of their individual experiences.

Phenomenology was the chosen approach used to guide this study. “A phenomenological study describes the common meaning for several individuals of their lived experiences of a concept or phenomenon” (Creswell, 2013, p. 76). Phenomenology focuses on describing a common experience that all participants share. The participants identify with the same phenomenon, in this case a college student with a physical disability using a wheelchair and having attendant care.

To gain in-depth and detailed answers about the participants’ transitions and experiences, personal interviews were conducted. A semi-structured protocol was used. This type of interviewing focuses on the participants’ experience, the interviewers questions are aimed at cognitive clarification of the participants, experiences (Kvale & Brinkmann, 2009). Through this type of interviewing the researcher is able to identify similarities. “The researcher relies on the participants’ views as an inside emic perspective and reports them in verbatim quotes” (Creswell, 2013, p. 92).

Setting
The institution used in this study was a mid-sized public doctoral-granting institution located in the Midwest, which primarily serves undergraduate students along with some graduates (Carnegie Foundation, n.d.). The institution provides a disability services office to meet the needs of all students who identify as having a disability. There are also modified rooms (e.g., bedroom doors controlled by clickers, proxy cards to enter the residential hallway, accessible showers, and motion censored sinks) provided in the residence halls so the rooms are accessible to students with disabilities. Many physical features of the buildings make it easily accessible to students with mobility limitations. To protect the confidentiality of the participants and the institution, the names and locations mentioned in the interviews were exchanged with pseudonyms during the transcription process.

**Population**

Students who participated in this study self-identified as being an undergraduate with a physical disability using a wheelchair and having attendant care. The population was comprised of participants ranging from age 18 and 26. The participants had a variety of academic statuses (i.e., freshman, sophomore, junior, senior). Many were diagnosed with some sort of birth defect or bone disorder, which is why they used a wheelchair. Participants are not required to live on campus. No other delimiters (e.g., gender, disability type) were used.

**Sample**

The study group consisted of the first 12 students who agreed to participate in the study and fit the inclusion/exclusion criteria. Recruiting of participants continued until
phenomenological saturation was reached (Creswell, 2013). All participants identified as being an undergraduate with at least one physical disability, used a wheelchair, and utilized attendant care.

**Data Collection Procedures**

A semi-structured interview protocol was used to assist with the data collection process (Appendix A). The research questions were used to help build a basis for the interview protocol. The protocol had two major sections, transitional issues, and experiences the student had with attendant care. The participants were asked to be candid and share as much about their personal experiences and transitions as they felt comfortable. The interview environments were held in mutually agreed upon places by both the researcher and the participants. Participants were notified at the beginning of the interview that they would be asked some questions that were personal and sensitive in nature. They were assured of confidentiality, no one beyond the researcher would know of their individual responses.

It is difficult for able-bodied persons to imagine instances where strangers would ask them to reveal normally private information about their health, bodies, or personal habits. A request of this nature would not be unusual for persons with physical disabilities (Braithwaite, 1991). Since some participants may have been hesitant to talk about such sensitive issues, structuring was used to explain the purpose of the interview, and why the participants’ responses would be beneficial to the study (Kvale, 1996). However, due to the personal nature of some of the questions, this study contained some sensitive research where there were potential consequences or implications directly for
the participants in the research or for the class of individual represented by the research (Dickson-Swift, James, & Liamputtong, 2008). The participants were reassured that no one other than the researcher would have access to the recorded interview and transcriptions. The researcher also explained that a pseudonym would be given to participants to protect their identity, in hopes to prepare them to open-up and engage in the interview.

A panel of experts experienced in the topic or qualitative research methodology reviewed the proposed interview guide (Davis, 1992). The panel consisted of disability services educators and faculty members skilled in qualitative research. A pilot test was conducted by the researcher to refine and further develop the interview protocol, help frame questions, collect background information, and adapt research procedures (Creswell, 2013). Revisions were made to the interview protocol per the suggestions of the members the panel, and the pilot test. At the beginning of the interview casual conversation was held to make the participant feel at ease and comfortable about the interview. Here are a few of the questions in the interview protocol. What does your attendant do for you? Please describe the tasks that he/she assists you with. Do you feel like you were you prepared for all of the issues you encountered related to attendant care in college?

Respondents were notified of their rights through an informed consent document which was reviewed with each participant prior to the start of their interview. The Institutional Review Board at the university reviewed and approved the data collection
process. Data were collected during the fall semester of 2012 and spring semester of 2013.

Purposive sampling used with the snowball sampling techniques were used to gather participants. Snowball sampling is asking a person who was interviewed if they could recommend anyone else who may meet the criteria to participate in the study (Bogdan & Biklen, 2006). The data were gathered through personal interviews with students who had physical disabilities, using wheelchairs and had attendant care. The director of the disability services office forwarded an e-mail, to the members of the target population. The e-mail clearly stated that the participants were free to participate in this study, but their participation would have no influence on the services provided to them through the disability services office. Interviews were held until phenomenological saturation was reached.

At the beginning of each interview, the participants were notified that their participation was voluntary and that their identity would be confidential. Interviews did not have a set time limit, but were 30-60 minutes in length, and were held until all questions from the interview protocol were asked. Participants were informed before the interview began that the researcher wanted to audio record the interview. Their permission was requested before recording took place.

Data Analysis

Each interview was transcribed and verified after the interview was conducted. Transcriptions were verified by reviewing the transcripts against the audio recordings. The researcher did all transcriptions. Coding of the transcripts involved aggregating the
text into small categories of information; clusters of meanings were developed from significant statements and placed into themes (Creswell, 2013). This analysis technique results in systematic procedures that move from a narrow unit, on to detailed descriptions. The transcriptions were cleaned by removing non-essential stutters, pauses, and/or filler words (Cameron, 2001). The descriptions were gathered and themes were identified and summarized to answer the research question, how the individuals described the issues and experiences with attendant care as they transitioned into higher education. Memoing was done throughout the process to help process the data. Memos are personal thoughts or reflections added to or placed at the end of a set of notes (Bogdan & Biklen, 2007). Thick description was used to explain not just the behavior, but its context as well, so that the phenomenon could be made meaningful to an outsider (Geertz, 1973).

**Summary**

The study explored the transitional attendant care issues and experiences of college students with physical disabilities using wheelchairs. The study was held at a midsized, public, doctoral-granting institution, in the Midwest. The transitional issues and experiences of attendant care for these students were examined to better understand the experiences that college students with physical disabilities using wheelchairs have throughout their collegiate career. Data were gathered during personal interviews with each participant. The data were collected during the fall semester 2012 and spring semester of 2013.
CHAPTER FOUR
FINDINGS

Chapter four presents the findings from the study which examined the transitional issues and experiences of students with physical disabilities using wheelchairs and had attendant care. The chapter begins with a summary of the study, followed by a detailed presentation of the findings. Each participant was labeled with a pseudonym, along with any other identifying names and locations mentioned in the interviews. The interviews focused on two major topics, the transitional issues for students with attendant care and the collegiate experiences with attendant care. The chapter concludes with a summary of the data collected.

Summary of the Project

This study examined the transitional issues and experiences of students with physical disabilities using wheelchairs who had attendant care. Related experiences were studied to better understand the transitional issues and experiences of students who utilized attendant care. Data were gathered through 12 personal interviews with undergraduates who identified as having a physical disability, using a wheelchair, and who had attendant care. The participants were interviewed during the fall semester of 2012 and the spring semester of 2013. During the coding process common themes were gathered from the responses. They were organized and reduced into broader themes
regarding the two categories addressed by the research question: transitional issues related to attendant care, and collegiate experiences students had with attendant care.

**Demographic Characteristics**

The first 12 students who agreed to participate in this study comprised the sample. The recruitment of participants continued until phenomenological saturation was reached. All 12 students had a physical disability and used wheelchairs. Eight of the participants were male, and four were female. The majority of the participants were of Caucasian descent, one student was of African American descent, and another was of Pakistani descent. Participants’ ages ranged from 18 to 26.

Though each subject attended the same institution, the demographic characteristics of each individual varied.

- **Chad** – A 26-year-old senior who transferred from a community college to the university his sophomore year. Chad was diagnosed with Muscular Dystrophy at age 15 and had used a wheelchair since age 16. He lived on campus in a residence hall.

- **Jane** – A 22-year-old junior. Jane was diagnosed with Cerebral Palsy and had used a wheelchair since she was a child. She lived in a residence hall.

- **Jim-Bob** – A 25-year-old sophomore who transferred from a community college to the university his sophomore year. Jim-Bob was diagnosed with Muscular Dystrophy as a child and had used a wheelchair since he was two years old. He lived on campus in a residence hall.
• Skylar – A 23-year-old fifth-year senior. Skylar was diagnosed with Cerebral Palsy at eight months and had used a wheelchair since age three. She lived on campus in a residence hall.

• Rebecca – A 19-year-old sophomore who received a spinal cord injury at age four, which is why she started using a wheelchair. She lived on campus during her freshman year; then due to improper physical care chose to commute from home for a semester. This year she returned back to campus as a first semester sophomore where she lived in a residence hall.

• Charles – A 21-year-old junior who had used a wheelchair since he was a child. He has lived on campus throughout his collegiate career. He left college for a semester due to health issues but returned and lived in a residence hall.

• Biz – A 21-year-old senior who was diagnosed with Osteogenesis Imperfecta (brittle bone disease) as a child. He has used a wheelchair since a very young age. He lived in a residence hall.

• Sparky – A 22-year-old who self-identified as a super senior. He lived on campus his freshman year, and he left college for a semester due to health concerns. He returned back to campus once he was better, and lived on campus for a few more years. Recently he decided to move off campus with his fiancé.

• Colton – A 19-year-old sophomore, who was diagnosed with Muscular Dystrophy at an early age. He had used a wheelchair since childhood. He lived in a residence hall.
• James – A 21-year-old junior who was diagnosed with Muscular Dystrophy as a child. At age 16 he broke his leg and had used a wheelchair since then. He lived in a residence hall.

• Samantha – A 22-year-old fifth-year senior who was diagnosed with Muscular Dystrophy during childhood. She had used a wheelchair since ten. She lived in a residence hall.

• Steve – A 23-year-old junior who had a rare bone disorder, which left him using a wheelchair. Over the years the bone disorder got worse and he was extremely limited mobility. He lived in a residence hall.

Findings

Each participant’s interview provided useful information for this study. The participants who shared a relationship with the researcher were very comfortable sharing their experiences and were more likely to provide in-depth information as it related to their personal care. The students who the researcher did not personally know sometimes hesitated with responses, or gave brief answers to questions related to their personal care. All participants were willing to discuss their stories but their level of comfort controlled how much they were willing to share with the researcher.

Transitional Issues for Students with Attendant Care

The participants in the study had many specific experiences as it related to their transitions to college as a student with a physical disability using a wheelchair and having attendant care. These participants had not only transitioning into college, but they were in a transitional process as it related to having a physical disability as a college student. The
mutual transitions that were discussed by the participants included time management, preparing for attendant care, training attendants, first feelings, accepting responsibility, parental involvement, and financial considerations.

Time management. Each participant discussed how time management played a factor in his or her transition from high school to college. While the experiences varied for each student, though, they all had different schedules when they arrive at college, and they all had some sort of experience related to time management. Some of those issues revolved around working with their attendants, getting to class on time, and scheduling when they would use the restroom and have a shower.

For Jim-Bob the transition to using attendant care was a large adjustment. He had never had attendant care and was use to having family members help him. Because his family members had helped him for so long they were able to accomplish tasks more quickly than his attendants. Jim-Bob stated,

At first it was a lot slower than being at home with someone that had done it repeatedly for twenty years . . . I had to deal with the fact that I would basically have to plan my day around it . . . I feel like I spend most of my day sitting in my room waiting for my attendants to come in. If they are there and I’m not there within 10 minutes, they can just leave and I’m screwed out of them not showing up until the next one which is usually hours later.

Jane had similar experiences.

I have to wait for my aides to come, so I’ve had to train my bladder to go when my aides come so that I don’t have any issues. . . . I have to shower whenever it
works for them. . . . At midnight after working on a paper like everyone else could shower . . . I have to wait to shower in the morning if I feel gross. I have to do it whenever I have the time allotted to do it so that was different. Whenever I was at home I could just be like “Hey Mom! Can I have a shower, “or” can I change my clothes.”

Being put on a routine schedule with their attendants was something that many of the participants had to get used to. It was hard to transition from an environment where your parents or family members were constantly available to help when you needed it.

Participants had to start relying on the schedules of their attendants. Going to the bathroom when they wanted was not an option, everything had to be scheduled.

Participants also had mixed feelings about the flexibility of the aides from an agency. An agency is a place that provides care workers to help people at home. Skylar said,

Freshman year it was all done on a time schedule, I didn’t have very many friends that were here that I could ask for help so that was a main thing . . . I have someone coming at this time, I need to know what I need to have done. I had to time out when I would eat and when I would drink so I would know when I would be able to go to the bathroom because I couldn’t just run at any given time to get my Mom.

Biz and Steve used both an agency and private care and they had a lot to say about their experience with agencies. Private care is when the students find someone outside of an agency to assist them with their personal care needs. Steve said,
With Agency A . . . you have to do everything on their schedule, so I would get up even on my days that I didn’t have class. I would get up at like seven in the morning and I was just ticked off all the time because of it . . . one of my friends has a night aide . . . after they leave from their shift, they would wake me up get me out of bed and then go to their next client, it was always a constant rush.

Biz stated,

You have to live your life on a schedule . . . Agency A didn’t provide any assistance after midnight unless you have an all night aide, and so I have to go to bed by a certain time and that didn’t seem fair to me. I felt like I was missing out on stuff and even on weekends.

However, one participant expressed that at home he learned how to live a scheduled life. Chad is the only person who spoke of life prior to college being so structured.

At home it is more of a . . . straightforward schedule. My parents’ work and coming home and getting ready for the next day and stuff, everything had to be at a more precise schedule. Here it is more open, you know more open to changing. My aide everyday has a different schedule . . . he lives off campus, having someone that doesn’t live with me helps me kind of make the schedule more open.

Chad’s experience was unique, he came to college with the ability to make his own schedule by getting private care, instead of going through an agency where more than likely he would have been put on a strict schedule like he had at home. Not only do these
students have to learn to manage time with their classes and other outside extracurricular activities, they also have to learn to schedule personal parts of their lives, like for example going to the bathroom, or taking a shower. Time management plays a large role in their lives as college students.

**Preparing for attendant care.** Very few of the participants were prepared for what to expect about attendant care, and they felt that they were unprepared before coming to college. A couple of them had a person assigned to assist them during high school, and a few more had attendants during the summer. Samantha discussed what her care was like during K-12.

I had an aide go around all day with me, get my books, help me use the bathroom, help me get food, and basically everything that I needed . . . it was the same person from third grade until when I graduated.

Biz also had additional help in K-12. He said, “At school they followed me around, they helped me take notes, go to the bathroom.” Chad spoke of having someone helping him put his books away during breaks, helping him get food, and grabbing things he could not reach.

Jane and Sparky had attendant care while at home during the summers per their parents’ request. Jane said “My parents made me have attendant care just so we could get it set up my senior year of high school, like during the summer.” For Sparky he had attendant care during the summer since the sixth grade. Even though they had those experiences prior to coming to college, they still felt like they were not prepared and had very little knowledge of what attendant care would be like in college. Chad said,
The unknowing part made me really uncomfortable. . . . When I first got here I didn’t know anybody really . . . it was just different, like a different world pretty much. . . . It’s just the unknowing part I wasn’t prepared for, but it kind of helped me too. . . . You know it made me more specific on what I need help with, and it makes me understand myself as a person.

He felt that not being prepared to take care of himself in college helped him figure out how to articulate what he did need help with when it came to his disability. Biz stated, “I really didn’t know much.” He even took a class in high school about transitioning from high school to college for a disabled person, even that was not helpful to him once he actually arrived at college. Like both Biz and Chad, Samantha who had some form of attendant care from elementary through high school, said, “I didn’t know how it worked at all or how complicated it would be.”

The other participants said they also received little to no advice about what to expect; they were not prepared to handle attendant care issues that would occur once they got to college. Skylar said, “I didn’t know anything about how it worked. I didn’t know what all it would entail; I didn’t know anything about the hiring process, I didn’t know how to pay for it. I didn’t know a single thing.” Colton said,

I didn’t really know too much. . . . I really didn’t think about it before. . . . I don’t know that I was necessarily prepared, it’s kind of one of those things you don’t know until you get into it . . . I feel like I’m not necessarily always prepared for what’s happening, but I feel like I deal with it.
However, there were two participants who did feel that they were ready for what they would encounter. Jim-Bob said he was ready because,

> I am older and I realize you know that this is going to be my life regardless, so I might as well get used to it. If I had been younger it would have been a lot harder to get used to it, but I think the maturity factor set in, you know, a little bit before I got to school, so I was ready for all of that.

Charles also said the he was not as informed about attendant care but felt he was prepared. “I knew that it existed, I knew that I would need it but I didn’t know a whole tremendous amount about it. . . . It wasn’t as a big of an adjustment as I thought it would be.” Ten of these participants expressed in some way that they did not feel prepared for attendant care as they entered college. Very little information had been given to them to prepare them for what was ahead, and their knowledge on the topic of attendants was limited.

**Training attendants.** A few of the participants spoke of their experiences regarding training their attendants. When the participants got new attendants, they had to train them to meet their needs, whether they had been trained by the agency or not. The process varies depending on if they were going through an attendant care agency or if they were using privatized help. The choice to work with an agency gives the assumption that the attendants had some formal training regarding working with people who have limited mobility, and physical disabilities. Choosing to work with someone who does not work for an agency and works privately, there is no a way to ensure they have any training when working with a person with a physical disability.
Skylar explained what happened with her attendant when they arrived the first time. Her mother was with her and she trained the first attendant, but from that point on it was up to Skylar because her mother would not be there. Skylar said,

I had the stomach flu one time, and they sent someone new so I had to train them by myself with stomach flu. It is always really awkward saying like, “do this for me, do that for me,” and sometimes I am a lot more independent than other people. So sometimes they will do too much and sometimes they won’t do enough, so its kind of finding that balance, I’m really good at training now though.

Biz spoke of using attendants from an agency and how they would send a different attendant weekly. “That was kind of weird too because I had to retrain everybody because they have to lift me a certain way, shower me a certain way, that was difficult.” Chad had a very detailed way he trained his aides, years of experience had helped him advocate for himself.

Trying to explain what you need help with, like how specific you need to be or how discrete you need to be, I kind of feel its my job to make sure that the aide is really comfortable. . . . That’s what I try to do from the get go. . . . I said you need to meet me in my room, here are the things I need help with . . . getting up in the morning, putting me in the bed, this is how you lift me up, this is how you put me in my chair, this is how you help me use the restroom . . . you just really have to physically go through everything so that . . . everything is out in the open. Be as
specific as possible is one of the biggest reasons; I think transitioning from home to here helped.

People have certain ways to do personal tasks. Being able to advocate for themselves and say, this is what I like and this is what I don’t like, is really important when working with attendants. Being able to comfortably train the attendant is very important.

**First feelings.** Meeting someone for the first time can be an awkward moment. Meeting someone for the first time that is coming to help you take a shower can be extremely awkward; especially when that person is someone you do not know. Seven of the participants talked about those first interactions that they had with their attendants and how that interaction normally went. Samantha said,

> It was really awkward at first . . . I know I need a lot of help so a lot of personal care like showering and stuff is just really awkward. . . . The first 5-10 minutes are really awkward, like “Hi, I don’t know you, you’re going to help me shower,” that’s awesome.

Jim-Bob, James, and Colton all repeated similar themes regarding first interactions with their attendants. James said, “It was kind of weird when I had an aide help me for the first time. We did things slower than I did at home. It was just frustrating sometimes too.” Jim-Bob said,

> I guess the main this for me is just getting comfortable with the new people doing it, and . . . how slow they are and I know they have to take their time, it takes time for them to get better at it.
Colton stated, “I felt kind of weird about having people help me with stuff that only my parents helped me with before.” When Skylar talked about her initial experience, she took a moment to reflect, and said “It’s definitely awkward at first because you’re like okay, this isn’t my family but they’re going to have to help me in the bathroom, they are going to help me shower, and it’s, it’s definitely humbling.”

Charles, who did not have attendant care before coming to college said, “I thought I would be more apprehensive than I was.” He surprised himself by being more comfortable with the care. He felt that way due to the attendant he had, he was fortunate to get paired with someone whom he really liked, and felt she was a truly good person. Jane had some experience with attendant care prior to coming to college, and she felt that is why her first interactions were a little different compared to those who had no experience with attendant care. She said,

It was a lot less awkward like with showering and stuff, because I was somewhat use to it, so I was a lot more comfortable with having someone else besides my Mom help me shower, than I would have been if I wouldn’t have gotten that experience before.

Each participant handled this new experience differently and most people had that awkward, and uncomfortable feeling at first; they all recognized that was normal. Those who were fortunate to have prior care, and were paired with a really good attendant, understood those factors help ease that part of their transition to attendant care.

**Accepting responsibility.** Taking ownership of one’s actions, and becoming fully responsible for oneself, is something most college students have to learn. Students
realize Mom and Dad are no longer there everyday to get them up for to school, they are not there making sure you go to class, and do homework as assigned. It becomes the students’ responsibility to make sure those things are done. Students with physical disabilities who use wheelchairs experience the same thing, however they have the added responsibility of being able to advocate for themselves when it comes to their disability. They have to assume the responsibility to realize that Mom and Dad will not be able to tell the attendant what is needed, and how the student likes to be put in bed; it is now up to the student to start handling this aspect of his or her life.

Ten of the participants talked about how responsibility factored in to their experience with attendant care. Their responses range from enjoying newfound responsibility, being overwhelmed, being nervous, and still not feeling as though they accepted the responsibility. Sparky realized that he needed to take personal responsibility. “I realized, okay Sparky you got to take some initiative and do this on your own.” While James knew what needed to be done, and he knew that his attendant care depended on him, this knowledge still did not make the process easy.

It was a little nerve wracking at first because I was afraid to make a mistake, to say the wrong things, stuff like that, they are coming to help me . . . It was kind of hard at first to do it on my own because I’ve had my parents helping me my entire life . . . it was just weird, but I’m better at it now. James took a big step when he decided to switch agencies without the help of his parents. He knew that things were not working out well for him with the first agency and he made his own decision to switch agencies. For him that was a big step in accepting
responsibility. Both Biz and Skylar discussed how they knew they needed to be assertive, qualities that prior to college they had not used very often. “I had to be assertive. . . . Managing care is kind of hard. . . you can’t do what you want.” Skylar said,

It was overwhelming at first because I’m a boss to them, so that was weird to me because I am not very assertive and my Mom was like, you’re going to have to be assertive and you’re going to have to be a boss . . . it was weird.

Samantha was not ready to take on the newfound responsibility, but with time she learned to adjust. “It was really scary at first but now it’s fine.” Chad thought about the responsibility as just being the first step to many he would have to take in life.

It was a good feeling and you know obviously when you get out of college, find your own job, live on your own, you are going to have to do that anyway. I felt good about it, I just needed to realize what I needed help with, and just to voice that. Don’t be scared to say what you need help with, always ask questions. . . . It helped me to be more mature, and to be successful in college.

Colton felt he already had some personal responsibility. “I kind of tried to be as independent as possible . . . It’s still an adjustment.” Rebecca was the only participant to express that she had no major responsibility over her attendant care. Her parents still managed her care, and the agency made it easy on her as far as taking responsibility for her care. Though everyone knew it was imperative that they accept responsibility, some had no problem accepting the responsibility while others struggled at first. Accepting responsibility does not always come easy.
Parental involvement. Each participant mentioned that prior to their arrival their closest family members, parents and siblings, helped them with their personal care. The level of parental involvement varied after the student started to attend college. Chad spoke about his parents’ involvement as he started thinking of attending college. Chad had used a wheelchair since he was 15.

My parents didn’t really know a lot services I could use or anything like that so I think at the very beginning, I took it upon myself to find out information. . . . I need to have more focus on it than my parents . . . I had everything under control so they never really had any worries or anything. It was me looking for everything.

Skylar talked about her Mom’s involvement when it came to her attendant care the first night in college. “My Mom stayed with me the first night to make sure I was able to speak for myself. She kind of wanted to see . . . who was going to be there.” As time went on Skylar expressed that her Mom played a minor role in her attendant care. She knew who was helping Skylar, but she no longer helped with training the attendants.

Many of the participants said that their parents were the ones that picked the first agency they worked with. Over time the participants talked less about their parents having such a major role, and the majority of them took the lead when it came to their attendant care.

Financial considerations. Prior to coming to college the participants had to figure out how their attendant care was paid for. There were a few options that were available to these students: Medicaid, Medicaid Waiver, Vocational Rehabilitation (Voc Rehab), or their parents paying the bill. These forms of payment can be combined or one
source can fund all of the costs for attendant care. Each financial resource has different requirements in order for students to receive the government assistance. The majority of the participants used one of these sources, and a few of them had a combination of the resources.

Charles spoke about how his Dad had financially prepared for this transition for a long time.

Dad is very thorough, he got me on the Medicaid wait list about 10 years before I would need it, specifically because . . . the list is so long. He is forward thinking and he knew that . . . the time I got to college I would need that, so he took care of it.

Chad and Skylar used Voc Rehab and they explained how it was utilized.

They pay my aides through direct deposit . . . I interview them myself and I decide who is going to be used, then I tell them my vocational rehabilitation counselor . . . and the aide and my counselor need to work together to get things filled out and ready for next semester.

Skylar explained what the student has to do to be eligible for Voc Rehab.

They will assign you a specific hour rate per week . . . They’ll say you have this many hours to pay people. How do want to pay them, and you can go through an agency, you can have private, or you can do both.

Colton and Jane used a combination of both Medicaid and Medicaid waiver. Colton talked about getting enough hours for his attendant care through Medicaid. He had a hard time making sure Medicaid provided him with enough hours and ended up adding Voc
Rehab to help cover the cost of his care. “I have 24 hour attendant care but I only got approved by Medicaid for 16 hours so it is kind of last minute thing to try and rush around to get Voc Rehab.” Rebecca mentioned that her parents’ paid for her attendant care; and James stated his attendant care was paid for partially by his parents and partially by Voc Rehab.

**Collegiate Experiences with Attendant Care**

The participants also spoke during the interviews of many of their collegiate experiences as relating to attendant care. They were new to the college life and their experiences with attendant care started from their initial transition from high school to college. The mutual collegiate experiences that were discussed by the participants included attendant care preference, relationships with attendants, supportive friends, and characteristics of attendants. The experiences they had in these areas helped shape their overall experiences as college students.

**Attendant care preference.** When it came to locating attendant care, each participant chose different options in securing care. Some chose to use the attendant care agency because it better suited their needs, while others chose to use private care and hired their own people. One participant, Skylar, used both private and agency attendant care.

As I got older, I became more involved on campus and I realized I couldn’t function on the schedule that Agency A wanted. Because with Agency A the latest that they will send somebody out is 10:00 pm and I knew that wasn’t going
to fly. . . . Sophomore year I hired my first full time out-of-agency person. . . .

About junior year I started training my friends to help me.

Skylar also explained the difference between attendant care through an agency versus having private care.

An attendant care agency hires their own people to work, and they send people to be your attendant. Private care you pick the people that you want to be your attendants and you tell them what hours to come.

The choice to go through both an agency and private care was one that is very unique to Skylar. Because of her campus involvements, she knew that she would need an attendant later than what was offered by the agency.

The disability services director provided a list of students who showed interest in assisting students who needed attendant care. Chad and Steve chose their attendants from that list. Steve said,

The director of disability services gave me a list of students that . . . said they are interested in helping students with disabilities, as an attendant. I thought for me that it would be more comfortable to have someone with a flexible schedule like me and we are all going to school here too, and can easily work with my schedule. . . . They are all around my age so you can kind of build a relationship with them easier than someone that is older. . . . So I just got the list and found someone on there interested in helping me.

Chad also spoke about the process he used in choosing an attendant from the list provided to him.
He gave me a list of some students that may want to be a part of helping students with disabilities in wheelchairs. . . . I pretty much call them and then say “Hey I’m looking for attendant care this upcoming semester. Is there anytime we could meet,” and then I would tell them basically go through a dry run of what I would need help with.

Jane chose an agency because she felt that was the best option for her. Jane had a very realistic view of attendant care.

There’s no really awesome place for an attendant care because you are depending on people to be there. Things happen and people are people and you have to work around people. It’s not like you can just be like, “Oh I need to use the bathroom, let me pick up someone random to help me.” You are depending on people to help you do these things so you kind of have to work around them, so there is really no reliable attendant care place.

Biz and Rebecca had unique stories about their choice for attendant care. They originally started out using an agency for attendant care but due to different experiences they decided to leave the agency and go another route. Biz ended up being taken advantage of by his attendants as they constantly showed up late, smelled like smoke, and sometimes were drunk. There was a time when the attendants were coming so late that he was unable to use the bathroom for hours, which lead to him contracting a urinary tract infection. Biz had taken a class in high school about attendant care and shared what he learned. “Their philosophy was that true, student care that is random is probably not as reliable.” This was one of the main reasons he decided to go with an agency over
student care, but after many not so good experiences, he decided that student care would be the best option for him.

    I feel like once you get to know people you kind of get to see what they are willing to do and what they’re not. So I would recommend student care but sometimes it can’t be done in cases where you need care 24 hours.

Biz regretted his decision to not go with student care from the start. Since he had used students as his attendants, he had no problems. Rebecca had a very similar story, her attendants were constantly late, and were not doing a good job helping take care of her. Eventually it led to her getting sick, and having to leave school. She was very discouraged.

    I started commuting from home. . . . I didn’t like commuting so I took the semester off to figure out if I really wanted to come back to campus to live. . . . Having such a bad experience the first time really scared me, and my parents. We knew it couldn’t happen again. . . . In the semester I took off, my parents and I spent time trying to find private care that would work best for me. . . . I now have two attendants and it has been working very well for me.

Luckily Rebecca was able to bounce back from such a negative experience. She enjoys having private care now, and it works better for her. Charles received his care strictly through an agency and he made the reason for that clear.

    I hire an agency because I don’t want students. . . . I don’t want to have an attendant take care of me in the bathroom, or shower me, or wipe me after toileting business and then go out and see them working the desk here, or see
them in my core classes that I have tomorrow, where we might be doing a group project together or something. That would be extremely awkward for me and I’m guessing that would be extremely awkward for them, because it is a personal measure of care, so no students.

Participants had a specific reason for their choice of attendant care. Due to certain experiences some of them had to change from their original plan, some participants had switched agencies and others had stayed with the same one from the beginning. Attendant care choice was all about personal preference and what worked best for each individual person.

**Relationships with attendants.** For students who had attendants help them with personal care needs, it was normal for them to build relationships with the attendants. All of the participants spoke of having a friendly relationship with their attendants. Many of the students considered their attendants to be their friends. However, two participants considered the relationship as strictly business, and another two people mentioned that their attendants seemed like family. These relationships with their attendants brought about both positive and negative experiences based on the relationships.

Among the participants who said that their relationship was more of a professional relationship, Rebecca described her relationship with her attendants as “caring, professional, and reliable.” She viewed the attendants as employees. “They aren’t close to me as a family or a friend. They are a caring person doing a job.” James made it clear he preferred a more business like relationship.
I don’t care about their personal lives . . . I’m one of those people that like boom, boom, boom I have to get everything done so I can go . . . I’m one of those people that tries to make sure people don’t see I have aides that help me . . . for me an aide is there to work, not to play, they are there to help me.

The business relationship seemed to work well for both James and Rebecca. Colton and Samantha had mixed feelings, some of their attendants were friends but others they have a business relationship with. Colton said “some of them are kind of friends, others . . . I just deal with them.” Samantha had similar thoughts about her relationships with her attendants.

Some of them I have actually become close with, we’re friends kind of . . . we don’t hang out outside of them helping me, but we talk. We are friends on Facebook, its not completely professional. I have a couple of like older nurses that come and help me at night. . . . They have to help me, but we’re not like friends.

It seemed that the attendants who were younger were viewed as more of a friend compared to older attendants where the relationship was more business like.

There were two participants who were extremely close to their attendants, so the relationship was more like family. Charles had an attendant that was with him for three years straight and he called her “the gold standard of attendants.”

Shirley was in her 50s . . . she literally was like my second mother . . . . Or like my person away from home who was not my mother but as close to my mother as I could get.
Because her age was so close to his mothers, Charles thinks that was why he felt that way about her. His relationships with other attendants were not like that one. Skylar had a very similar situation with her attendants.

Some of them are acquaintances. . . . I had an attendant I got really close to. She has since left, but she’s like my second Mom here. Two of my attendants actually are like my best friends; one of them actually worked for the agency, hated it, quit and came to work for me privately. The other one, her sister has what I have, Cerebral Palsy so she kind of grew up around it. So I’d say some of them are friends.

Those two had attendants who became more like their family, than friends. The other six participants viewed their attendants as friends and not a business relationship. Steve mentioned,

They help me a lot. Sometimes we hang out, outside of helping me and its kind of fun that you get to know someone and become friends with them. . . . We hang out together, we do things together, that kind of thing its more than a business relationship.

Biz considered his attendants as friends that he looked up to; he felt they truly cared about him.

I hold them to a higher respect. I considered them kind of my role models, when I need advice I talk to them, stuff like that, and especially people I have had for a long time because they know me.
As the relationships with the attendants varied, so did the participants’ experiences with them. Everything you do can bring a positive or negative experience depending on the situation. All of the participants had at least one negative and positive experience to share. Several of the experiences were chosen to demonstrate more insight into these participants’ lives. Chad spoke about an experience where the actions of his attendant surprised him, and made him thankful for his attendant.

One time me and my friends wanted to get off campus and I couldn’t, they couldn’t lift me in their vehicle so I called my aide and he said, well I will drive you there and back. . . . He understood that I needed help, that I want to hangout with people and he’s not like I’m just here to help you, I’m not here to make your social life easier, so that really sticks out to me.

Samantha had a similar experience where there was something that she wanted to do but the times didn’t match with when her attendant was supposed to come.

Our hall council had a little dance and I was going to need help right before it. . . . I don’t normally have someone on that day but . . . one of them said she would come help me and we switched times. It’s easier once we get to know each other because, if they need to switch times because of something, they can just ask me and the other way around.

Jane overall had more positive experiences than negative, and she explained what makes those experiences so positive for her.

My experiences with attendants have been pretty awesome because my attendants are willing to work with me and I am willing to work with them. I can text them
if I ever like have an emergency and they will try to make it work. I can call the attendant care office, like “Yep I need help because I am stuck,” and they will try to get someone as soon as they can.

Where there were positive experiences, there also were negative experiences. Charles used a urinal and a normal task for his night attendant was to empty the urinal before he/she left for the night. One particular night things did not go as planned when his attendant left to empty his urinal in the bathroom.

She came back and she said both of the accessible bathrooms at the time were occupied. I didn’t want to be a bad aide to you, and not do what you told me to do, so don’t drink out of the water fountain.

She had emptied his urinal into the water fountain. He asked her what about the other people in the hall that may drink out of the fountain. Her reply amazed him. “They are not my clients, you are, and I don’t care about them and what they don’t know can’t hurt them.”

Jim-Bob had a situation where his aide was not friendly and her actions actually led to him getting hurt.

She was getting me out of bed one morning and the pump to pump my Hoyer that lifts me up in the air, my foot got stuck under the pump and she pumped it anyway and broke my toe. When my toe broke I started yelling . . . her response was “well why was your foot there.”

After that incident he never used that aide again. Steve had an experience where his attendant was over two hours late. Because of that, he missed a test, a class, and was
stuck in bed for a few hours because he had no way to get out. The night before they had made plans that she would be there to wake him up before she left for her second job. At some point there was a miscommunication on her end, which led to her termination.

**Supportive friends.** A number of the participants spoke of having friends who were there for them when their aides were not, and friends who understood and were not bothered by their attendant care. The participants’ spoke about how having friends who were very supportive of them, and how they were thankful to have those people in their lives. James told a story about when his chair started malfunctioning and he was not near his building. “I was in the McGraw building and my chair was malfunctioning. It wasn’t working, and so it shut down. I had one of my fraternity brothers come over, and he pushed me back to my room.”

Skylar’s friends wanted her to be able to hang out later in the night, so they started offering to help her get ready for bed.

Billy came to me and said, “Why do you go to bed so early?” I was like, “I really don’t.” . . . At the time I had the agency come at 10 and help me get ready for bed. “I really don’t, I just kind of lay there,” and he’s like “I can do that, that’s not hard” . . . and he started helping me.

Biz’s relationship with his friends went further than he expected. He had a less than desirable experience with agency care and his friends started offering to help take care of him.
I just decided to ask my friends if they would like to get paid to be my aide. I told them you will get paid for five hours a day, you don’t have to be there the whole time, but I just need you to be ready to come over whenever I call you.

Sparky had a very unique conversation with a professor who had mistaken his friend for his attendant.

I had a professor . . . that came up to me and saw my friend helping me. He said “Well is this your friend/attendant or whatever,” and he said, “Well do you get paid to do this,” the professor asked him that. He was like “Well sir to be honest with you I am doing this because I met Sparky freshman year and he is a cool kid. I’ve always stayed in contact with him, and there is nothing that I wouldn’t be comfortable helping him with. I’ve helped him off the floor of his shower when his attendants hadn’t shown up; I’ve helped him go to the bathroom in an inaccessible spot. I’ve helped him, but you know I do that out of the goodness of my heart and not the fact that I’m getting paid to be his attendant.” He was not getting paid to be my attendant he was just my friend.

**Characteristics of attendants.** Many of the participants spoke about various characteristics of the attendants they had during their collegiate career. Many of the females preferred to have female attendants. They were not opposed to males helping them as long as it was not in the shower, or to use the bathroom. A few of the females expressed that they were comfortable with their Dad or other male family members assisting them, and had even had male friends help them when absolutely necessary. The male participants had mixed responses. Some of them only preferred males to help them
with showering and toileting, and some preferred females. It just depended on the person and exactly what the attendant would be doing. There were some male participants who didn’t care who helped them as long as they were getting the services they needed.

Some of the stereotypes the participants had were based on other people’s perceptions about the attendants as well as their own. Biz said what he thought about some of the attendants. “Aides were kind of shady, like plenty of them have been banned from campus so obviously they don’t do their background checks very well.” Colton had an interesting viewpoint,

The people . . . are kind of annoying to me, strange, or just different . . . the kind of people I wouldn’t normally get along with. . . . I kind of feel like people just assume that I’m always hanging around them . . . some of the people aren’t necessarily who I want to be seen with I guess. They are people that I wouldn’t normally be around. . . . I feel like people kind of think something about me just because I am around this person.

James said,

I know a lot of these aides come from backgrounds that are not as stable as mine and they’ve got really good hearts. I know people that have the stereotypes, I have aides that have like weird tattoos and stuff like that, backgrounds where you can see their home environment is not the best but their hearts are always in the right place. I just want people to know that even though they have a tough life and stuff like that, their only job is to help people in chairs and stuff like that, I just want to get that stereotype out because these people truly have big hearts, if
they are willing to help me. . . . I mean there are some pretty private issues, they help me go to the bathroom, and help me go take a shower, a lot of people I don’t know if they could do that. These people they’ve got guts and they’ve just got a really good heart. I want people to know their hearts are in the right place even if they may come from troubled backgrounds.

**Summary of the Chapter**

The participants interviewed for this study described specific aspects of their transition to college, and their overall collegiate experiences as students who had physical disabilities using wheelchairs and utilizing attendant care. Aspects of their transition included time management, preparing for attendant care, training attendants, first feelings, accepting responsibility, parental involvement, and financial considerations. Aspects of their collegiate experience included attendant care preference, relationships with attendants, supportive friends, and characteristics of attendants.
CHAPTER FIVE
DISCUSSION

Chapter five presents a project summary, discussion, limitations, recommendations for future research, and concluding thoughts.

Project Summary

This study examined the transitional issues and experiences of students with physical disabilities who used wheelchairs and had attendant care. The theoretical framework for this study was rooted in Chickering and Reisser’s (1993) work on educational identity and Tinto’s (1993) work on academic and social integration in college. These works were combined with the literature on transitional issues and experiences for college students with physical disabilities who use attendant care. Data were gathered through semi-structured interview with 12 undergraduates who self-identified as having a physical disability, using a wheelchair, and using attendant care. Common themes were gathered from the responses, and these themes were organized and analyzed in response to the research question. The transitional issue themes that emerged from the data collection were time management, preparing for attendant care, training attendants, first feelings, accepting responsibility, parental involvement, and financial considerations. The themes related to collegiate experiences with attendant care were
attendant care preference, relationships with attendants, supportive friends, and characteristics of attendants. Interviews were conducted during the fall semester of 2012 and the spring semester of 2013.

**Discussion**

The discussion is organized into two major sections, transitional issues for students with disabilities who had attendant care, and their collegiate experiences with attendant care. The theme of transitional issues for students with attendant care focused on seven subthemes: time management, preparing for attendant care, training attendants, first feelings, accepting responsibility, parental involvement, and financial considerations. The collegiate experiences of these students with attendant care, themes had four subthemes: attendant care preferences, relationships with attendants, supportive friends, and characteristics of attendants.

The theoretical foundation of this study rested with Chickering and Reisser’s (1993) work on educational identity, and Tinto’s (1993) work on academic/social integration and persistence to graduation. Chickering and Reisser’s vectors one, three, four, and five were pinpointed as those closely related to the experience of students with physical disabilities using a wheelchair and attendant care. The students in this study developed intellectual and manual competence skills while in college, however their physical development was delayed. Students began to develop a level of autonomy moving toward interdependence, but because they have to rely on personal care assistance from others, they may not reach autonomy as quickly as others. Students started building interpersonal relationships with their peers as well as with their
attendants, some of those relationships are easier to maintain than others. These students also learned more about themselves during their transition to college and experience with attendant care, therefore helping them to establish their identity.

Tinto’s focus on social and academic transition was demonstrated in the development of students with physical disabilities using wheelchairs and having attendant care. Some students thrived socially despite having attendant care throughout various times of the day and night, others had a harder time achieving social integration. The transition to college is difficult enough for many student, but when transitioning as a student with a physical disability using a wheelchair and having attendant care, the social aspect can be somewhat harder to initially grasp. The same applies with their transition to the academic setting. Since there are no longer Individualized Education Plans that accompany the students, needed accommodations have to be taken care of by individual students. These students are responsible to request reasonable accommodations, if they do not advocate for themselves the academic transition will be difficult.

**Transitional Issues for Students with Disabilities who had Attendant Care**

There are many transitional issues that arise as college students enter college. Transitioning from high school to college can be challenging when you do not know what to expect. The students who participated in this study all had extra physical and academic challenges because they were not only transitioning as a college freshman, they were transitioning as college freshman with a physical disability. The transitional issues they encountered included time management, preparing for attendant care, training
attendants, first feelings, accepting responsibility, parental involvement, and financial considerations.

Attempting to balance and manage time during the first year of college can be a challenging task for most students. For students with physical disabilities balancing their time between academics, social life, and daily living conditions can be stressful and challenging. Students with physical disabilities spend a great deal of time planning what and when their attendants will be able to assist them. For many of them it seems as if they live their life on a schedule tied to their personal attendant. They have to make sure that an attendant is available as needed throughout the day, get to class on time, and find time to spend time with their friends. These students had to adjust to such a major change in their schedule when they arrived at college. Many transitions come with adversities’ and transitions do not always flow as smoothly as imagined.

When something happens in a student’s social life it can also affect their academic life: every part is tied together in some way so when something happens with an attendant, a students academic and/or social life has the possibility of changing. “Colleges like other human communities are highly interdependent, interactive systems in which events in any one part may be felt in other parts of the system” (Tinto, 1993, p. 108). The first year of college is an important time for students because they are creating the foundation for their subsequent experiences (Woosley & Miller, 2009). The average new college student spends time on class-related activities (e.g., attending class, assignments, etc.), daily living activities, (e.g., eating, sleeping, etc.), and engaging in social activities (e.g., hanging out with friends, playing video games, etc.).
Mamiseishvili and Koch (2011) suggested living on campus provides more opportunities for students to be engaged in academic and social activities and interact with faculty and students. All but one participant lived on campus at the time of this study. The experiences most beneficial for students with physical disabilities in wheelchairs include enhanced academic and classroom experiences, a healthy and stable residential experience, and finding the right attendant care (Padgett et al., 2012). This was true for the students who participated in this study.

The students in this study had to schedule in advance common daily tasks that many people take for granted, like when to go to bed, getting out of bed, using the restroom, and taking a shower after a long day. Scheduling these tasks was not easy for these students. Students in this study reported having to plan ahead when they would eat or drink, because subsequently using the restroom whenever they wanted was not an option. They had to schedule in advance such routine personal tasks with their attendant so that they could be accomplished. It is already difficult enough to transition to college from high school; these students had to plan time for classes, homework time, work, time for yourself, and time for friends. These students not only had to figure out routine transitional issues that all students must face, but they also had to schedule in when their attendants would assist them. Tiedemann (2012) discussed how students with physical disabilities have to figure out when they will need an attendant and then schedule those needs around their attendant’s schedule. If either the student or attendant is late, the student can miss important commitments or the schedule can be off for the remainder of
the day because the agency may not be able to send someone else out to assist the student. Any variation to an established schedule was problematic for these students.

Preparing for attendant care, by someone other than their family members, was something many of these students put off and had not carefully considered as a part of the transition to college. Prior to actually attending college many students were unsure how they would find attendant care. Because parents were their main caretakers prior to college, attendant care was not something the students necessarily though about. It was clear that not until they had made the transition into the university that attendant care would be something they would have to start relying on in place of their parents. Each of them needed some form of physical assistance in college, unfortunately many had not thought through what that assistance would be.

More information about attendant care should be provided to students and their families before they get to college so that they can be better prepared. One of the biggest obstacles for students with physical disabilities who live on a college campus is the unfamiliarity with obtaining and directing their personal care (Tiedemann, 2012). Surprisingly, the majority of the participants had not carefully considered the implication of attendant care prior to coming to college. This realization is intriguing since attendant care is such a large part of their daily lives. The lack of knowledge prompted the idea that there should be something in place prior to arrival at college that can help better inform wheelchair users how their lives will change once in college. In addition to having disability services staff hold workshops throughout their first semester that can help the students prepare for potential attendant care transitions, pre-arrival programs are
crucial to student’s transition, and should not be limited to a day or so to the beginning of the first semester (Elkins et al., 2000). They should continue throughout the course of the freshman year. According to the students in this study many of their parents didn’t really know what to expect when it came to preparing for attendant care. The few students who had knowledge of attendant care appeared to have an easier transition, but they still were not prepared for the multiple issues that attendant care can bring into a person’s life.

While spending time preparing for attendant care is important, it is also important to make sure that the chosen attendants are trained well. The students in this study spoke of how they had to train their attendants to assist them. While the students whose care was provided through an agency did not have to worry as much about training because the agency provided some training, the students who had private care had to spend time training because often the attendants did not know what to do. Training others to help with personal issues means expressing what is expected in relation to their care.

College students with disabilities must be able to self-advocate for their needs by discussing disability-related accommodations with their professors, faculty/staff members, and their attendants (Hadley, 2011). In order for these students to train their attendants they had to self-advocate for their personal care, some of them had never done that before. Self-advocacy means that a student understands his or her abilities and disabilities, is aware of the strengths and weaknesses resulting from the functional limitation imposed by the disability, and is able to articulate their need for physical assistance (Lynch & Gussel, 1996). When working with attendants they had to be able to
say “I need you to do this for me,” or “no, I don’t like that.” The experience of training attendants helped students learn how to advocate for themselves.

The initial interactions students had with their attendants often left them feeling uneasy. Many of the students said they felt weird having someone they did not know help them with personal issues like toileting and showering. These uneasy feelings happened on various occasions throughout the semester, because when working with an agency they were not sure when a new attendant would come to assist them. These apprehensions are completely normal for someone who had their family assist them with personal issues all of their lives. As they moved to a new environment and their parents were no longer there to assist them, the students had to rely on others for help. Most often that help was from someone they did not know. For the most part they had to learn the awkwardness that comes with the initial meetings of new attendants.

Accepting responsibility for the disability was something each person in this study had come to grips with. Accepting responsibility means speaking-up for themselves and adequately explaining their disability and what that meant for them as a student. Accepting responsibility for some of the students was something they looked forward to, other students were unsure if they were ready to do this. Before coming to college many of their parents were primarily responsible for all things related to the disability. The students did not have to speak about their disability, or worry about how they were going to be taken care of; their parents took did that. Once in college the responsibility of self-advocating and explaining what was needed became the student’s responsibility.
Accepting that parents are no longer with them to speak for them, these college students that used a wheelchair had to adjust to college and their personal care on their own because their parents were no longer around to take care of them. Since the student is the primary person in control of decisions regarding their personal attendant care, they should learn to effectively exhibit the qualities of a personal manager (Birdwell & Fonosch, 1980). Some students were more apprehensive accepting this newfound responsibility it can be a challenging transition. After being in college for a while most of the participants felt they had reached a level of autonomy (Chickering & Reisser, 1993) where they could handle their attendant care, and did not need their parents to speak for them anymore. Learning to be an effective consumer by setting up and maintaining attendant care influenced the students’ well-being (Simon, 1977).

Several of the students mentioned that their parents played a major role during their high school career and at the beginning of their collegiate experience. Some students stated their parents did not do much research on what the student would need once in college, other students said their parents did everything for them. The level of parental involvement with the students’ personal care faded after the students transitioned to college. Some parents’ involvement lasted longer than others depending on the experiences the students had with their attendants. Parents of students who did not have the best initial experiences with attendant care were more involved. After their students negative experiences the parents stepped in and had a more active role in their attendant care experience.
As parents send their students away to college many of them worry about their students’ safety. Prior to college many parents of students with physical disabilities are encouraged to be an active advocate for their students (McCarthy, 2007). These parents are concerned about their students’ safety along with the quality of attendant being received. Most colleges do not get involved with employment issues of personal care attendants (Tiedemann, 2012); therefore, parents and students must find the appropriate care often with little guidance from the college. Most often when the student has arrived at college, and their care is set, the parents’ involvement diminishes. This was the case for many of the students in this study. Some of the students still felt they needed their parents’ guidance, while others did fine without parental help. Some students felt their parents were not educated on what they would experience once in college as it related to attendant care.

Students should be made more aware of financial resources that can be used to finance attendant care. A few of the students knew exactly how their attendant care was paid for others did not. There were multiple options of ways to pay for care; it was rare when only one financial resource was used. Vocational Rehabilitation and Medicaid were the two financial resources that were most often used. Using a Medicaid waiver was something many students mentioned as a financial resource, but many were not able to explain exactly what it was. It was clear that most students were not totally sure how their attendant care was paid for, however they understood that several financial resources were helping them.
There are several financial resources available that give college students using wheelchairs the option to attend college, and not have to worry about the extra cost of attendant care. It is important to request information about personal attendants from the college disability office, Vocational Rehabilitation, home health care agencies, and other students with disabilities (Tiedemann, 2012).

**Collegiate Experiences of Students with Disabilities who had Attendant Care**

Students attend college with the hope of getting an education, making lifetime memories, and having a great experience. No two students will have the same experiences and different factors will play into whether their experiences are positive or negative. For students with physical disabilities, a few unique factors contributed to whether their collegiate experiences were positive or negative. Some of these factors included their attendant care preference, relationships with attendants, supportive friends, and characteristics of attendants.

The students who participated in this study discussed the options they had for attendant care. A number of them used attendant care agencies where the attendants were provided for them, and all they needed to do was give the agency their schedule. Others used private care, they either found an attendant through the disability services office on campus, or they sought out an attendant on their own. The choice they made for attendant care was solely based on the students and their needs.

There are many factors that must be considered when decisions are made regarding how attendant care is arranged for. “To improve chances for success in attaining independent living . . . the role of the attendant is necessary” (Atkins et al.,
1982, p. 20). Deciding to use an agency is a more practical path, because the student has less to do to make it happen. However when private care is chosen, students have a larger role to play; the student must recruit potential attendants, interview, hire, train, and develop a schedule for care. A personal care agency takes care of those issues for the student. Finding the right fit is most important for each student. Some of the students had very realistic views about attendant care and each individual’s views affected their overall experiences with attendant care.

Relationships are connections with others that have a profound impact on students’ lives (Chickering & Reisser, 1993). Forming strong relationships with others is good for students who are getting adjusted to college. The way the students in this study viewed their relationship with their attendants varied from person to person. Some viewed their attendants as friends, some wanted a strictly business relationship, and there were a couple who viewed their attendants as members of their family. The nature of the relationship that was formed with the attendant influenced the students’ personal interactions with them. When the students’ spoke of a business relationship with attendants, it was harder for them to think of positive stories about their care, the negative experiences were more common. When the relationship with attendants was viewed as friends and family, the positive experiences were more common than the negative experiences.

Many of the students in this study viewed their attendants as more than just an employee. The students who preferred a business relationship with attendants focused more on the attendant being there to help them, not necessarily to engage in a relationship
with them. The business relationship also impacted the students’ interactions with the attendant. They kept conversation to a minimum when it came to their personal lives, however the conversations about the things they had in common helped them pass the time. Participants who viewed the relationship as more of a friendship, valued the quality time and connection they made with their attendant. The personal relationships with the attendants provided the students with a person whom they felt close too. They shared their common interest, things about their personal lives, which led to the strong connections that many of the participants had with their attendants. They enjoyed being able to call their attendant their friend.

Most new college students do not yet have an established network of friends. It takes time for college students to find the people who they want to build friendships with. For the students in this study many of them were able to build a solid group of friends who had been there for them throughout their collegiate experiences. The relationships these students built were unique because sometimes their friends were also in the role of their attendants.

Transitioning to college and building strong relationships with friends helps students engage in the academic and social settings of college (Astin, 1993), as well as be integrated into their institution. In the college setting, social integration with peers enables students to better cope with the demands of the college environment (Tinto, 1993). Each participant in this study spoke of how their relationship with friends influenced them. The support the students received from their friends was much appreciated because it enriched their lives. For example, many of the students spoke of
having friends who were willing to help them with personal issues liked getting in bed, or even use the bathroom, when their attendants were not available. Having friends helping them with such personal aspects of their lives was something that meant a lot to the students and was greatly appreciated.

When meeting someone for the first time most people make assumptions about that person, based on your previous experiences and interactions with persons like the individual. Sometimes you can tell based on an individual’s demeanor if he/she is having a good day, or for example, if he/she has an accent you may be able to pinpoint where that person was raised. These are personal observations that lead people to make assumptions about others. When meeting a personal care attendant for the first time students also make assumptions about the attendant; sometimes these assumptions led to stereotypes. They tried to assess if this person was going to be someone they would get along with, if they would they have anything in common, and overall if the two would be a good match.

Determining if the attendant you have been partnered with by an attendant care agency is the right fit for you can be a challenge. During the first interaction between student and attendant, it is hard to arrive at the conclusion if the attendant/attendee relationship will be a positive one. It was common that the students in the study had various opinions about the attendants. The participants in this study pointed out stereotypes they had about the attendant; sometimes these stereotypes were discussed with friends. Many of the participants perceived their attendants came from a lower socioeconomic status, and had little formal education. These assumptions sometimes
influenced the relationship between student and attendee. However, even though students recognized that they were stereotyping their attendants, they still appreciated the help provided by attendants.

Most of the participants in this study were not prepared to interact with attendants. Transitional issues related to attendant care appeared when it was time to manage time, prepare for attendant care, train attendants, first feelings, accepting responsibility, deal with parental involvement, and make financial decisions. They struggled with self-advocacy, when they realized that they had to become the captain of their own ship, and they had few crewmembers around to help them. Some of the participants were ready for these experiences because they knew it would be something new and challenging, however others were not prepared. Understanding details about their attendant care, and taking initiative, became something that helped students to take ownership. Relationships with their attendants helped shape their collegiate experiences. When the students have negative experiences, with their attendants, it influences their relationship with their attendants and it may affect their academics and social experiences. The same thing applied to positive experiences.

**Delimitations**

The inclusion criteria stated that participants must be a college student who used attendant care, used a wheelchair, had a physical disability, and who was age 18 or older. This was a single site study at a doctoral institution located in the Midwest. The topic involved sensitive aspects of the participants’ daily life; so encouraging participants to open up about their experiences was occasionally difficult. The information gathered
from the 12 participants applies to their experience only and is not the experience of all students who meet the criteria.

**Recommendations**

**Future Studies**

Future studies could engage a larger population of participants who fit the inclusion criteria. Since this study only focused on 12 college students from one institution, having a larger population may produce more information. By expanding the study to a larger population and other institutions the transitions and experiences may be different.

Future studies should ask participants to provide demographic information in addition to the information that will be gathered from the interview. The protocol for this study was revised a number of times to ensure that appropriate question were being asked to gather useful information. By gathering more demographic information about the participants it may help the researchers assess the student’s experiences better. For example, understanding the students distance from home, how long they used a wheelchair, if they had attendant care prior to college, academic classification (i.e., freshman, sophomore, etc.), would help contextualize the study.

A future study could look at the provider side of attendant care, interviewing the attendants about their observations rather than the students. This vantage point would also provide the attendants’ views on the relationship they have with students. If the attendants are also college students, the focus of the study could be how their personal, social, and academic lives are affected by their attending work. A study of this nature
would help inform about the roles of both the student and attendant, which will help others gain a better understanding of the overall experience.

**Researchers**

Future researchers should consider ways to establish trust with the participants so that they are willing to share personal information about their transitional issues and experiences with personal attendants. This can be a difficult task as the information shared is very personal, putting participants at ease is important. When subjects are comfortable with the researcher they tend to give more information and feel a little better about answering the questions.

Future researchers should consider adding more questions about the students’ experiences in college, possibly more in-depth questions about how attendant care plays into their academic experience. More detail about interacting with attendants or a second round of interviews may provide additional information. During a second interview the student go reflect on the content of the first interview, and provide additional information. The inclusion of a focus group may be beneficial to help participants consider common themes.

**Student Affairs Educators**

Student Affairs Educators should understand that students in wheelchairs utilizing attendant care are in many regards similar to other students entering college, however they have somethings that set them apart. It is important to have a clear understanding of what the campus disability services office offers these students. Potentially revising the CAS standards may be a good idea to include a section on attendant care and best
practices of working with students who utilize attendants. Educators should work to gain knowledge about this particular group of students in order to help with their transition to college.

Agencies that provide attendant care services could share with disability services offices their practices so that they can be more informed of what to expect when interacting with attendants in the residents halls. A relationship between agencies and the university would be enabled by better communication between the two. By the disability services offices knowing the different agencies in the area and what they have to offer students, the office can better help students when they start to choose an agency. Making sure updated lists of attendants are provided to the university so that both the disability services and housing offices know who the attendants are would be helpful. By having a understanding of what agencies have to offer, the disability services office would be able to help students prepare a list of interview questions to be used when choosing an agency

**Future College Students**

Future college students with physical disabilities that use wheelchairs should start early researching attendant care options, potentially available to them through college/university disability services offices. Understanding individual needs and being able to articulate them will be helpful when students speak with disability services, as well as choosing what form of attendant care will work best for them. These students need to have a good understanding of what role attendant care will play in their lifes. Preparing a list of potential questions to use to interview attendants and agencies would be helpful. They should work toward accepting personal responsibility for their
disability, so that they can clearly state what they need, and be able to work with their agency and/or attendant about their care. Working toward these things will help prepare students for the transition to the college, thus being more prepared for the experience.

**Concluding Thoughts**

The personal characteristics that students enter college with (Tinto, 1993), and students’ individual levels of initial commitment to an institution (Elkins et al., 2000), influence the transitional issues of all college students. Each student comes to college with a set of personal characteristic and a variety of experiences. While students with disabilities using wheelchairs and attendant care have similar experiences with many other students, they also have a set of experiences that is completely different than the average college freshman. It is important to understand the unique challenges this subpopulation of college students have, and what they can do, and not do, to meet those challenges. Students with disabilities that use a wheelchair and will use attendant care need to consider the implications of attendant care and plan ahead prior to coming to college. Knowing that attendant care will influence their collegiate experience, they need to better understand how to work with attendants. Being able to manage academics expectations, engage in a social life, and use attendant care is a challenge for new college students. Colleges and universities should consider what could be done to help these students with their transitions to college and provide resources to help them be successful.

These students need their stories to be told so that others can gain a better understanding of their experiences. It would help student affairs educators to know their
experiences so they can help these students better transition into college, be responsible for their disability, and self-advocate. Hearing the stories of these students was empowering, many of them were thankful for the opportunity to attend a university. When they successfully transition to their new lives as college students, they are well-able to handle their personal care with more ease. Student affairs professionals should help these students share their stories to help educate others about personal attendant care issues.
REFERENCES


http://www.questia.com/library/1P3-895501411/students-with-disabilities-transitioning-from-high


APPENDIX A

INTERVIEW PROTOCOL
Interview Protocol

A. Introduction

Thank you for agreeing to meet with me today. This study is being conducted to gain a better understanding of the transitional issues and experiences of attendant care when it comes to college students with physical disabilities who use wheelchairs. Your personal experiences are important to this study, so my hope is that you will answer all questions openly and honestly as you possibly can. You are encouraged to share personal experiences and stories through this interview, while the information will be used to better understand the transition and experiences of attendant care for college students with physical disabilities who use wheelchairs.

Before we begin, I would like to inform you of your rights as a research participant. Your identity will be kept confidential and will not be exposed in any published material. Any names mentioned during the course of the interview will be labeled with pseudonyms. You may choose to refrain from answering any of the following questions and you reserved the right to withdraw from this study at any time for any reason.

Furthermore, your answers will be used in drawing conclusions for this study and they may be presented in published material. To ensure I record your answers accurately, I would like to ask your permission to record this interview. The recording will remain exclusively in my possession, and no other person will know you participated in this study.

Do I have your permission to record this interview?
Have you been able to review the Informed Consent Form provided to you earlier? Do you have any questions about this document?

A list of questions has been prepared to help guide our conversation, but please do not hesitate to share any stories or experiences you feel may be relevant. We will talk about your transitional issues and experiences as a student who uses attendant care and has a physical disability and uses a wheelchair.

Would you like me to answer any questions before we begin?

B. Background Information

Directions

I would like to begin by getting a little background information; and having you reflect on your experiences as a student in a wheelchair coming to college.

1. Could you please describe to me your day-to-day care before coming to college?
   • Probe - Who assisted you with your personal needs prior to college?

Thank you, now I want to get more into what you knew about attendant care before coming to college.

2. What did you know about attendant care before coming to college?
   • Probe - Who told you about attendant care?
   • Probe – How was that information helpful to you?

3. At what point did you realize that you would need to find someone to help with your personal care once you were in college?
   • Probe - What was your reaction to this realization?
   • Probe (only if they need help) – For example, sad, angry, comfortable, etc.…
C. Transitional Issues

Directions

Thank you. Now, let’s talk about the transitional issues relating to your attendant care as you entered college. I’d like us to focus on things that changed related to your attendant care when you started college.

4. How did your personal care experiences change once you started college?
I’d like you to think about specific transitional issues you had as it relates to attendant care when you arrived in college.

5. What were some of your transitional issues as it related to attendant care?
   • Probe (only if they need help) – For example, was it different having someone other than your family helping with personal care issues?
   • Probe – Very interesting. Thank you. Can you think of another transitional issue relating to attendant care? (Continue to ask question until there is no response)

6. What was the process for you finding attendant care once you arrived in college? How did you find attendant care?
   • Probe – How did you feel knowing that you were responsibility for your attendant care?

7. How many attendants have you had?
   • Probe – Do these attendants work for the same or different companies?

8. How did you pay for attendant care?

9. Do you feel like you were you prepared for all of the issues you would encounter related to attendant care in college?
• Probe – Why or why not?
• Probe – Did anyone talk to you about what to expect?
  o Probe - Was that helpful?

D. Experiences

Directions

Thank you for sharing, that was very interesting. Now, let’s talk more about some of the experiences with attendant care that you had. Please share as much information as you are comfortable.

Family-related questions

Let’s begin by talking about having an attendant who was not a member of your family.

10. What was it like having someone other than your family member help you with your personal needs?
   • Probe – Describe your initial interaction with having an attendant who was not a member of your family. How did that go?
   • Probe – Was this easy for you, or did you struggle with it?

11. Do you have a preference if your attendants are male or female?
   • Probe – Why does it make a difference to you?

Attendant responsibility question

Thanks. Now let’s talk about what your attendant does for you.

12. What does your attendant do for you? Please describe the tasks that he/she assists you with.
   • Probe – Are there other things your attendant does to help you?
Relationship questions

That was helpful, thanks. Now let’s talk about your relationship with your attendants.

13. What words would you use to describe your relationship with your attendant?
   - Probe (only if needed) – For example, would you call your attendants a family member, friend, employee, etc.? What words would you use to describe your relationship with your attendant?
   - Probe – Why do you use those words to describe your attendants?

14. Did any of your friends ever ask you about your attendant?
   - Probe – How did that go?

15. Does having an attendant affect your social life?
   - Probe – Has your attendant ever helped you to bed early?
     - Probe – Like before 9:00?

16. Do you have a job here on or off campus? How does your job work with your attendant?

Environmental questions

Now I’d like to talk about more environmental related questions, and what role your attendant plays in that.

17. Has your attendant ever had to help you during a fire alarm on or off campus?
   - Probe – What was that experience like?
   - Probe – What would you have done if your attendant wasn’t there?

18. Has there ever been a fire alarm and your attendant had already left you for the night?
   - Probe – What did you do in that situation?
I am sure that you have had some positive and negative experiences with your attendants.

19. Would you say that your experiences with attendants are generally positive or negative?

20. Can you provide a specific example of a positive experience you had with an attendant?
   • Probe – What made that such a positive experience for you?

21. What about a negative experience? Can you provide a specific example of a negative experience you had with an attendant?
   • Probe – What made that such a negative experience for you?

**Negative experience questions**

Thank you, that is a great transition to our next topic. Let’s talk some more about potential negative experiences with attendants.

22. Has your attendant ever been late or not shown up?
   • Probe – If yes, tell me about that? What happened?
   • Probe – Were you ever late to class because of that?

23. Have you ever had an attendant quit on you without notice?
   • Probe – If yes, tell me about that? What happened?
   • Probe – Do you have a list of potential backup attendants?

24. Have you ever had to let an attendant go?
   • Probe – If yes, tell me about that? What happened?

**E. Conclusion**

**Directions**
Thank you for everything that you have shared today, it has truly been helpful. I only have a few more questions for you and that will wrap up our conversation.

25. What is one thing you wish people knew about your experiences with attendant care?

26. Is there anything else you would like to share with me about your experiences related to attendant care?

27. Do you know of anyone else who you think would be willing to share his or her experiences with me?

I would like to thank you very much for taking time to discuss your experiences with me. The conversation that we had will help a great deal in understanding attendant care and the transitional issues and experiences that students with physical disabilities who use wheelchairs face. Please feel free to contact me if you would like to share anything else, or have any questions for me.