

DISABILITY, LEISURE, AND WORK-LIFE BALANCE

BY

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DISSERTATION

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## ABSTRACT

Society is and has always been composed of people of different levels and types of ability. Today, due to legislation and changing attitudes toward disability, the presence of individuals with disabilities is more evident than in decades past. Although their numbers are still considerably lower relative to those of persons without disability, people with disabilities are a part of the American workforce. Like their nondisabled colleagues, they have families, friends, and leisure interests. To date, there has been a paucity of research about the work-life balance of employed people with disabilities. Understanding the work-life needs of these individuals is vital given that the American workforce is aging and the first cohort of jobseekers who have only known life under the Americans with Disabilities Act (ADA) are entering the labor market.

This project was an investigation of the lived experiences of eight men and women with observable mobility impairments who were employed in integrated settings. Through individual interviews and brief worksite visits, I sought to understand the significance of leisure and work in the lives of the participants. Further, I sought to understand how the presence of disability influenced their work and leisure lives, and what beliefs, strategies, and relationships contributed to their quality of life and sense of work-life balance.

The primary theoretical framework for this study was work/family border theory. This theory emphasizes the challenges of moving between the work and non-work domains of one's life and the role of relationships and identities in influencing the ease with which this might be done. Additionally, I utilized the theoretical perspectives of social constructionism and symbolic interactionism to consider the complexities of the disability experience. By engaging in

interpretative phenomenological analysis, I was able to consider both the individual and collective experiences of participants in interpreting the data.

Five major themes emerged from the data; these centered on the importance of identity, work, leisure, relationships, and self-care. Although disability affected all areas of their lives, participants viewed disability as a single attribute or feature; the presence of disability did not define who they were. They spoke of being similar to their nondisabled colleagues and friends, yet spoke of ways in which they were different from others, especially in their youth and as they began to deal with the consequences of aging with disability. They valued work as a way to contribute to society and to connect with other people. Additionally, they identified leisure with family and friends as being important for their physical health and social wellness. Issues of disability identity were noted regarding work and leisure choices, with leisure often providing a space for them to express aspects of themselves that they did not feel were apparent in their vocations. Aging with disability also influenced identity and was associated with a renewed, or in some cases new, desire to connect with other people with disabilities. Maintaining a sense of work-life balance involved consideration of not only work and family issues, but also friends, leisure, and self-care. Further, relationships on and off the job provided support in meeting disability-related needs.

The rich lives described by the participants demonstrated the need to get beyond stereotypical views of what it means to be a person with a disability. The findings indicate the need to view people with disabilities holistically, and as individuals. It is my hope that the suggestions offered as a result of this research will enhance the capacity of employers, nondisabled colleagues, disability service providers, and leisure programmers to address the

unique concerns of people with disabilities across the lifespan and to create more inclusive work and leisure spaces.

*To my parents, Hoke S. and Lillian M. Cook, who instilled in me a belief that I should expect to live a full life. And to my Lord and Savior, Jesus Christ, through whom all things are possible!*

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Depositing of this dissertation marks the completion of the formal process. However, it is as much a beginning as it is an end. I look forward to all I have yet to learn as this journey continues.

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## CHAPTER 1

### INTRODUCTION

#### **Significance of the Study**

People with physical disabilities have endured a long history of social isolation and employment discrimination (Linton, 1998; Longmore, 2003). Belief systems about disability have tended to focus on individual imperfections and the medical aspects of disablement rather than the ways in which physical and attitudinal barriers limit individuals and create disabling experiences (Kaplan, 2006; Linton, 1998). Further, the stigma of disability exists within and across other marginalized groups. For example, Deal (2003) noted that there is a hierarchy of disability even within the disability community. He pointed out that, “The literature suggests that disabled people, like non-disabled people, do not always wish to be associated with other impairment groups for a variety of complex reasons, including competing for scarce allocations of funding/resources, sexual attraction, stigma, etc.” (p. 897). Further, Baynton (2001) asserted that the concept of disability has been used to depict women and racial minorities as inferior to males and whites, causing these other oppressed groups to emphasize their able-bodied status as explanation of why they should be treated fairly. Thus, people with disabilities may face challenges to being accepted not only by those in the dominant culture but also by other persons with disabilities and members of other marginalized groups.

In public policy, disability is defined as an inability to work or maintain gainful employment (Social Security Advisory Board [SSAB], 2003). Although medical advances have resulted in longer lives for people with severe disabilities, and improvements in technology have created work opportunities that are less physically demanding than in the past, this definition

remains unchanged (SSAB, 2003). Moreover, work opportunities for people with disabilities have historically been dictated by the needs of nondisabled members of their local communities and larger society. For example, during the colonial period some people with disabilities worked as indentured servants as towns could refuse citizenship to those who were not able to contribute to their own expenses (Henderson & Bryan, 2004). Similarly, significant numbers of persons with disabilities and women were employed during World War II because so many able-bodied males were taking part in the War; however, after the War, they returned to their former low levels of employment and limited job options (Linton, 1998).

Despite legislation designed to increase workforce participation, such as the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) passed in 1990, the employment rate of people with disabilities has remained at approximately 30% for the past three decades (Krepcio & Cooper, 2008; Longmore, 2003). With such low levels of employment, people with physical disabilities are typically in the minority in their workplaces. Additionally, some individuals with disabilities have lacked opportunities to develop important social skills due to physical limitations, making it more difficult for them to take part in social activities. Further, architectural and attitudinal barriers often preclude their participation. This is especially true for those with congenital disabilities who, due to these factors, may have been socially challenged since birth (Henderson & Bryan, 2004; McCarthy, 1988). Thus, despite possessing the technical skills needed to perform competitive employment, some individuals with physical impairments may lack or be viewed as lacking the social skills and interpersonal savvy necessary for full inclusion in workplace communities.

McKittrick (1980) found that nondisabled colleagues tended to consider each other as friends rather than coworkers; however, they were much more likely to view people with physical disabilities as coworkers rather than as friends. A study conducted by Johnson et al. (2004) revealed that people with multiple sclerosis (MS) did not use needed assistive devices (e.g., canes) in the workplace due to concerns about coworkers' perceptions. Coble-Temple, Mona, and Bleecker (2003) interviewed employed people with physical disabilities who required personal assistant services on the job. Even participants employed in human service settings, in positions that involved helping other persons with disabilities, reported significant challenges in obtaining needed workplace accommodations. Additionally, they tended to minimize their needs in order to be viewed more favorably by their nondisabled colleagues. Clearly, the lives of employed people with physical disabilities are affected by the level of acceptance and inclusion they perceive from members of their workplace communities.

One vehicle for enhancing workplace acceptance is shared interests, such as common leisure pursuits. Indeed, shared leisure interests can lead to friendships that extend beyond the workplace. Additionally, leisure participation can be helpful in coping with disability and other life stressors. Therefore, consideration of the work-life needs of persons with disabilities requires an understanding of their leisure experiences both on and off the job.

### **Workers with Disabilities**

Despite the unique concerns of workers with physical disabilities, there is a paucity of research about these individuals. Yet, the need to better understand their experiences is growing for several reasons. First, as America's workforce ages and people want or need to continue working for personal or financial reasons, the number of workers with disabilities will increase.

This is because the longer an individual lives, the more opportunities he or she has to experience disability through aging, illness, or injury. Today, it is not uncommon for individuals to live for two or more decades beyond traditional retirement age. Many older adults will need to maintain employment for financial reasons, unable to rely on government programs such as Social Security. Another factor that is likely to increase the number of workers with physical impairments is that the first generation of young people to have grown up with the rights afforded by the ADA is now entering the labor market. As a group, these individuals have had greater educational and social opportunities than previous generations of persons with disabilities. They are likely to enter the workforce expecting, and more prepared for, full inclusion, as compared to previous generations. My research provides insight into these important issues at a significant time in the collective work history of persons with disabilities.

### **The Roles of Leisure in Coping with Disability**

Among those with physical disabilities, leisure has been found to play substantial roles in coping through the provision of social support and sense of belonging (Hutchinson, Loy, Kleiber, & Dattilo, 2003) and by enabling participants to maintain good physical and mental health (Plante, Le Captain, & McLain, 2000). Further, leisure helps with disability coping by providing a means through which individuals with physical disabilities can establish, or re-establish, identity and self-acceptance (Parry, 2007). While the benefit of a sense of identity may be particularly important to those who are unemployed, the potential benefits of social support and maintenance of health are critical for employed people who are juggling the demands of work, life, and disability. Because employment can be taxing, both physically and emotionally, the

social support and health benefits available through leisure may help workers with disabilities better manage these demands.

Researchers have demonstrated that participation in leisure and recreation has multiple benefits for people with and without disabilities. According to Coleman and Iso-Ahola (1993), the social nature of leisure is one reason it has such an impact on coping with the stressors of life. The authors speculated that leisure participation often provides people with companionship that leads them to perceive the availability of social support when more severe life events occur. Iso-Ahola and Park (1996) confirmed the importance of social support through leisure participation and that "...it is the activity and the things done with friends/companions that buffer the adverse effects of stress on mental and physical health" (p. 169). Iwasaki and Mannell (2000) determined that the perception of social support significantly contributes to one's ability to cope because it reflects a belief about the availability of support. Coleman and Iso-Ahola concluded that perceived social support resulting from leisure participation operates in times of crisis, and leisure companionship seems to lessen the stressors of daily life and helps maintain emotional well-being. This occurs whether one is dealing with few stressors or is dealing with long-term stress. Indeed, Iwasaki (2003) asserted, leisure is a beneficial resource for coping with stress "irrespective of the level of stress experienced" (p. 202).

However, for people with physical disabilities, leisure can also be a source of stress. Hutchinson et al. (2003) investigated the leisure of people with spinal cord injuries. They noted, "...leisure only served as a coping resource when it was personally relevant and when its benefits outweighed the physical and emotional 'costs'" (p. 155). Physical inaccessibility, lack

of acceptance by nondisabled recreationists and staff, and the reminder of lost abilities and/or lifelong limitations can all make leisure less pleasurable for individuals with physical impairments. Thus, leisure may be a less accessible and a less effective way for people with physical disabilities to create a sense of balance. Consequently, the presence of disability impacts work and non-work domains, such as family, friends, and self-care, and can make it more challenging for these workers to maintain balance among multiple life spheres in ways that are comfortable and satisfying.

### **Work/family Border Theory**

Clark's (2000) work/family border theory served as the theoretical framework for this study. Clark proposed that the connection between the two spheres "is not emotional, but human" (p. 748). Consequently, this theory emphasizes that how one navigates between the various domains of life is largely dependent on the roles and relationships he or she has in each sphere. One's sense of belonging within each domain and the how he or she is viewed by others in each life sphere influences the degree of support received in a given domain. Several key concepts from border theory were useful in developing interview questions and interpreting data. One critical concept is that of *border crossing*; this refers to moving between the domains of work and family. Although Clark's focus was on these two domains, I approached the study from the perspective that work-life balance encompasses additional domains, including friends/leisure and disability/self-care. People with disabilities may have very different roles and needs at home versus other domains. Even the ways in which people with disabilities get around in their own homes can be very different from the ways in which they feel they need to navigate spaces dominated by nondisabled people. For example, Hansen and Philo's (2007) study of

women with physical disabilities demonstrated that “when passing through ‘other people’s spaces,’” the women noted challenges in “how they cope with their embodied impairments in the often unforgiving socio-material environments of employment, education and community.” Specifically, they “talked of feeling pressured to pass as normal, to perform in a manner as closely corresponding as possible to an able-bodied way of doing things...” (p. 495).

Another border theory concept relevant in this study is that of *central participation*. This refers to how invested an individual is in his or her workplace community. Strong investment is evidenced by internalization of the values of the community, demonstrated competence in their work responsibilities, and connectedness with other central participants within the work setting. According to Clark (2000), members of workplace communities who are viewed as central participants experience advantages not available to more peripheral members. For example, central members generally have more freedom and options, making it easier for them to achieve a sense of work-life balance. When an individual is viewed as less central to the workplace community, it may be harder to get needed support. For example, an individual who uses a wheelchair may make decisions about work-time activities based on the possible need to go home early because of shoulder pain from pushing the wheelchair. In order to have some flexibility for leaving the office early, this worker may tend to work through lunch, minimizing social opportunities with colleagues, so as not to get too far behind in his work. While this strategy may help manage disability-related concerns, it may negatively affect how the individual is perceived within his or her workplace community. Consequently, he or she may find it harder to get the support needed to maintain a sense of balance between work and other life domains.

In addition to work and family concerns, persons with disabilities must manage and work around their impairments. This reality makes their work-life experiences different from nondisabled colleagues, in some respects. These differences are not likely to be readily understood by the nondisabled members of their workplace communities. This lack of what Clark (2000) referred to as *other-domain awareness* may make it more difficult for workers with disabilities to attain status as central participants and get the support needed to successfully move between the borders of the work and non-work domains of life. Often persons with disabilities work with supervisors who may have little understanding of their unique stressors and concerns. Furthermore, workers with disabilities may be reluctant to educate gatekeepers and colleagues about their disability-related issues for fear that they will be seen as less competent.

### **Purpose of the Study**

This study examined the lived experiences of employed people with physical disabilities working in integrated settings. I inquired about their engagement in the social/leisure-oriented aspects of workplace communities because work is a conduit through which social relationships may be formed, and such relationships can influence the experience of balance between work and other aspects of one's life. However, my interest and intent with this study were broader; thus, my questions were designed to get a sense of the significance of leisure and social inclusion in participants' lives. My goal was to gain insight into the leisure needs and work-life balance (WLB) of the study participants. Specifically, I sought to understand how each participant defined social inclusion and work-life balance and what factors contributed to their perceptions of inclusion and balance. Through this project, I hoped to illuminate not only the potential challenges faced in work and leisure settings, but the unique concerns of employed people with

physical disabilities and the impact of these concerns and experiences in the creation of a sense of balance. I utilized the methodological approaches of social constructionism and symbolic interactionism to guide this study.

As a person with disability myself, and having worked for many years in the field of vocational rehabilitation, I brought to this project my own thoughts about how employed persons with physical disabilities might define and seek to achieve work-life balance. However, I believe that whatever commonalities there may be, disability is a highly individual experience. Therefore, I engaged with my participants from a standpoint perspective. In other words, I realized that some shared history would likely reveal itself in their responses, but that each individual would have his or her own story to tell, and each would have a different view of the concept of work-life balance.

An application of this research is to provide a basis for rethinking perceptions of disability by highlighting the diversity and various capabilities among individuals with disabilities. Moreover, it creates a basis for discussion among employers, coworkers, employed people with disabilities, and vocational rehabilitation professionals. Such discussions would acknowledge the additional concerns of workers with disabilities and consider ways in which society, employment specialists, employers, and workers with and without disabilities can all contribute to the creation of more welcoming and inclusive work communities. Finally, this research provides information that may enable leisure providers to include and better meet the needs of recreationists with physical disabilities.

### **Research Questions**

The questions I sought to address with this study included:

- What is the significance of leisure and work in the lives of the participants?
- How does the presence of disability influence the leisure and work lives of the participants?
- What beliefs, strategies, and relationships contribute to the Quality of Life (QOL) and work-life balance of participants?

### **Delimitations of Study**

For this study, I chose to focus on adults, age 18 and older, with observable physical disabilities, who were employed in integrated settings. Given that individuals with physical disabilities have higher rates of employment than those with cognitive impairments, I was more likely to find study participants among those with physical challenges. Further, I sought participants whose impairments would be obvious to those with whom they interact because I was curious about the role of relationships in managing their lives and wondered how an obvious impairment might influence these interactions. My reasons for choosing to study the work-life balance of this segment of society were both practical and personal.

Below I offer my story. I do this with some discomfort as I do not wish to overshadow the stories of my participants. However, reflecting on my own experiences as someone frequently referred to as a “successful” person, I realized that despite all I have accomplished in the world of work, my social experiences have in some respects been quite different from those of my nondisabled peers. My story highlights some of the unique concerns experienced by employed persons with physical disabilities, concerns which may impact social inclusion and the achievement of a sense of work-life balance. By sharing my story, I hope to give the reader a better understanding of how I approached the data provided by the participants in this study. As

Creswell (2007) asserted, when interpreting data, “the researchers’ interpretations cannot be separated from their own background, history, context and prior understanding” (p. 39).

### **My Story**

Having been born with cerebral palsy (CP), I have never known life without physical challenge. Of my mother’s six children, I am the fifth and the only one born with a disability. Neither of my parents knew what to expect when after 13 months of my not being able to walk, crawl, or scoot across the floor, they learned the reason for my developmental delays. My father later shared that his first thought was that I might be able to use a skateboard to get around; he had once seen a man with no legs lying on his belly and rolling through the streets of New York City.

My educational experiences consisted of a short stint in a preschool program for children with CP and “related conditions” (i.e., mental retardation). I was *the* one or one of a few students with physical disabilities throughout my public school education. I had my second orthopedic surgery when I was six years old. Afterwards, I attended special education classes for a brief time to “catch up” with my schoolwork, even though I am of average intelligence and did not require the kinds of assistance provided. I missed my peers and my teacher. I was the first physically disabled child to attend the school; everyone was just doing the best they could. In junior high school, I was restricted to certain parts of the school building, including a small room behind the nurse’s office, which served as my own private study hall, with no faculty and no other students. Additionally, I received one-to-one instruction in English and Home Economics, during this time. The first year, I was only allowed in the newer, more accessible parts of the building; my second year all of my classes were in the older parts of the building, as if they had

magically become accessible. Decisions regarding where I was allowed were decided for me, not with me, by people who did not have physical limitations. I dealt with it, stairs and all- at least I could be with my nondisabled peers most of the day.

My college years were equally limiting due to a campus accessible transportation system that assumed people with disabilities only ventured out of their dorms Monday through Friday, and were never out past 9 o'clock in the evening. University administration reminded us on a regular basis that we, students with disabilities, were "less than" persons without disabilities, we should be grateful for what we were given, and we needed to learn to plan ahead. I have always been a planner concerning the bigger goals of my life; however, I don't know of many undergrads who plan ahead, and certainly not when it comes to social opportunities. After all, being spontaneous is part of the fun!

I earned a BS in rehabilitation counseling. It was not my first choice. Like so many people with disabilities, I wanted to "give back." I wanted to be an orthopedic surgeon but standing for extended periods was not an option. I considered studying physical therapy. However, my physical therapist insisted I would need to be able to demonstrate positions for patients; my response: "Couldn't a physical therapy assistant do that?" However, the late 1970's was not a time when most people, even those in the helping professions, were thinking creatively about how to help people with disabilities achieve their goals. I chose to focus on vocational rehabilitation because I love working. My paid and volunteer experiences offered opportunities for me to contribute and to demonstrate what I *could do*, and I wanted to help other people with disabilities experience these possibilities.

My first job was at a vocational rehabilitation center where the only accessible bathrooms were those in the clients' work area. We promoted the employment of people with disabilities with local businesses, yet the staff bathrooms indicated that we had a history of not practicing what we preached. I went on to get a MS in human resource management with an interest in working with people with disabilities who were competitively employed in integrated settings.

I have been blessed with wonderful friendships and awesome opportunities in both my personal life and my career. In so many respects, my physical condition has been as much of an asset as a limitation. Still, as a Black female with a visible disability, I would be lying if I said it has been easy. For so long I denied how hard it was (and is), so much so that in a recent conversation one of my brothers reminded me, "Wanda, you know I have never seen you as disabled; you are a pioneer!" and one of my sisters said, "School and everything always seemed so easy for you!" The inclination to forget my disability was even evident in my dealing with colleagues in rehabilitation. For example, one coworker told me, in front of several new staff members, that she had a hard time remembering that I have a disability. She explained by exclaiming, "...well, because you know you are so competent and creative!" I reminded her that it is possible to be both a person with a disability and a capable person; the two situations are not mutually exclusive.

These colleagues and family members have little awareness or memory of the ways in which disability has impacted my social opportunities and the personal challenges involved in trying to fit in. They do not comprehend that no matter how much I accomplish, I will still be different, sometimes in ways that prevent nondisabled people from seeing me as a whole person.

Just as frustrating, some see me as an exception rather than an example of *one way* of experiencing life with a disability.

Throughout most of my childhood, the professionals who worked with me insisted that I be independent and not ask for help with physical tasks (e.g., picking up my crutches, opening doors, etc.). I was to find a way to compensate and do for myself. Yet when I continued these habits, especially in the workplace, they met with mixed reviews. Some colleagues, usually those in support positions, admonished me for doing everything for myself. However, some in middle and upper management made me feel as if I had done something wrong whenever I pointed out the things that would enable me to fulfill my responsibilities without it being so physically taxing; for example, scheduling mandatory meetings in locations with adequate parking near the entrance. Further, the need to conserve my energy and their respect led me frequently to decline offers to socialize with my nondisabled coworkers. When they invited me to go to lunch, I considered how much time and energy it would take to get in and out of the car, to sit and get back up again, and sometimes, it just was not worth it. In the early years of my career, inaccessibility was the norm and it was not unusual for social gatherings to be planned at places I could not easily navigate; sometimes strangers, men who had had too much to drink, would insist on carrying me up the stairs. On top of that, my father passed on a strong Protestant work ethic, and my triple minority status further exacerbated my feeling that I needed to not only work hard, but also had to prove myself among my mostly white, able-bodied, and often male colleagues. These pressures, while admittedly at least partially self-imposed, have led me to choose work over play, especially from nine to five. For all of these reasons, I rarely played at

work. When I did participate in water cooler conversations or other social activities, I was often keenly aware of how different my experiences were from my nondisabled colleagues.

I like to play in my free time, and this too, has been a challenge. During my early childhood most of my recreation was with my siblings and with disabled friends. However, when I started elementary school, I did make some nondisabled friends. In college, several of my friends were people with disabilities of various kinds, and some were people without disabilities. After starting my career, I did not want to spend my non-work hours with my consumers or potential consumers (it is tough to have down time while playing with your Monday morning appointment!). Although I maintained friendships with some people with disabilities, it was important for my sense of balance to be less involved with activities that centered on disability during my free time. I started seeking out community-based fitness and recreation programs and was often the sole participant with a visible physical impairment. When the only sit-down aerobics classes I found were held at local senior centers in the mornings, I joined a local gym and asked to use a folding chair during the regular aerobics class. At that time, the idea that someone who needed a seated exercise class would be under age 55 and employed full-time was apparently inconceivable. My leisure pursuits of travel, reading, volunteering, swimming, horseback riding, jazzercise, writing, handcycling, and rock wall climbing have been a wonderful way for me to have fun, relax, improve my physical functioning, meet new people, and challenge myself, by choice! Still, even leisure is work. Everything takes more time and energy.

As I became more aware of the significance of leisure in my own life, I began to ask my colleagues with disabilities what they did for fun. They repeatedly shared that outside of work

and family obligations they had little energy for play. In some cases, even if they did want to participate, lack of transportation or physical assistance to change into “play clothes” kept them home.

For years, I have been frustrated and saddened by tales of consumers who reported that their social lives did not improve, as they had hoped, once they entered into employment. After all, isn't the workplace a source of relationships that add to our lives, both in and outside of the office? Yet even my colleagues with disabilities, those who like me had gotten their jobs (as far as we know) on the same basis as our nondisabled coworkers, told of being overlooked when officemates got together socially. These disabled colleagues were very well-respected and genuinely liked, and we were all working in a setting that presumably accepted and valued people with disabilities. The fact that they struggled to be included emphasized the magnitude of the problem. We understood that one of our responsibilities in our workplace community was to help our nondisabled colleagues feel comfortable with our differences. Interestingly, this usually required that we demonstrate considerable professional competence while being willing to tolerate their pointing out our limitations and accepting their assistance when they determined we needed it!

It is not just my own story, but also those of my colleagues and our consumers, that inspired this study. Nevertheless, my personal and professional experiences undoubtedly shaped the study and my interpretation of the participants' perspectives. It is my sincere hope that this study will highlight the diversity of experiences among persons with disabilities and provide insight into how social inclusion and leisure participation impact perceptions and maintenance of a sense of balance between the work and non-work domains of one's life.

## **Conclusion**

In this chapter, I introduced my study and explained the significance of and purpose for this research. I indicated my theoretical framework and the research questions I sought to address with my project. I also explained the delimitations of this project. Lastly, I shared my own story as a person who lives and works with a physical disability.

## **CHAPTER 2**

### **LITERATURE REVIEW**

In order to provide a foundation for understanding the significance of physical disability on social inclusion in workspaces and how this dynamic affects the work-life balance (WLB) of employed people with physical disabilities, it is necessary to consider a number of concepts from a variety of disciplines. It is not possible to provide an exhaustive review of any one of these topics. Therefore, my goal is a focused review of several topics as they relate to this research project. This review is based within the fields of leisure studies and disability studies. Additionally, concepts from the fields of psychology, rehabilitation, and human resource management are integrated to create an understanding of what it means to be an employed person with a physical disability.

The first part of this chapter details Clark's (2000) work/family border theory, which served as the primary theoretical framework for this study. Unlike earlier theories that focused on feelings or "emotional linkages" as the primary connection between work and family systems, Clark proposed that the connection between the two spheres "is not emotional, but human" (p. 748). Border theory considers the degree to which individuals are seen as integral members of their workplace communities as a critical indicator of the options and support they are likely to have in their efforts to maintain balance between the work and non-work spheres. In this section, I also describe Bird's (2003) concept of work-life balance, which includes four life domains: work, family, friends, and self. Further, I discuss how these ideas are relevant to the lives of employed people with physical disabilities.

The next section of this chapter is a literature review of research related to disability, social inclusion, employment, leisure and work-life balance. The first part of the review examines understandings of disability from an individual and societal perspective. Additionally, literature related to how these socially constructed definitions have contributed to employment discrimination and the social isolation of persons with physical disabilities is analyzed. In the second part of the review, I outline literature related to coping with disability. Particular emphasis is given to the roles of leisure in disability coping. Literature regarding the negotiation of leisure constraints is also examined in this section. The third section of the review examines literature pertaining to significant historical and political factors that have affected employment of persons with disabilities. Key disability-related employment legislation is described. This section includes a discussion of the status of employment among persons with physical disabilities. This leads into a fourth section that examines work-life balance literature. A summary of how researchers have conceptualized the work-leisure relationship is included in this section.

The fifth section of this review analyzes literature related to workplace social inclusion. Common myths about the employability of persons with disabilities and factors that contribute to inclusive work environments are addressed. Literature related to work settings as sites for leisure and friendship is also examined in this section.

### **Theoretical Framework**

In general, the day-to-day experiences of persons with disabilities tend to be more stressful than for those without disabilities (Henderson & Bryan, 2004). Additionally, people with disabilities experience unique job stressors (Gignac, Sutton, & Bradley, 2007). Thus, it is

useful to consider the social inclusion of such workers by their nondisabled colleagues within a framework that acknowledges these additional concerns. Workplaces are microcosms of larger society, and there are attitudinal and physical barriers that can hinder the full inclusion and acceptance of employees with disabilities. Further, information about responses to such individuals in the arena of work, which is still central in American society, can provide important insights. For one, it can provide understanding about how individuals with disabilities may be treated in leisure settings, since leisure participation may not be viewed as essential- especially for those who are not expected to work or who are presumed to be unemployable. Secondly, it may provide insight into the particular work stressors persons with physical disabilities experience and the kinds of leisure pursuits that may help them deal with these stressors. Additionally, awareness of the degree to which persons with disabilities are included in workplace communities, and the factors that facilitate or constrain such inclusion, provides insight into the work-life balance needs of these workers.

Work/family border theory is the result of Clark's (2000) efforts to more fully and accurately explain, "how people manage and negotiate the work and family spheres and the borders between them in order to attain balance" (p. 750). She defines balance as "satisfaction and good functioning at work and at home, with a minimum of role conflict" (p. 751). The theory describes domain negotiation as a dynamic process influenced by the similarities and differences between the work and non-work domains of an individual's life. Additionally, the presence and power or prestige of the individual and those with whom he or she must interact when moving between borders is another important component of this process.

In border theory, work and home represent two distinct spheres; in fact, Clark (2000) likened them to two countries, each with its own culture. She emphasized borders or “lines of demarcation between domains ...the point at which domain-relevant behavior begins or ends” (p. 756), and included several kinds of borders, addressing a gap she observed in earlier theories. Physical borders such as the walls of one’s workspace, temporal borders such as one’s work schedule, and the psychological borders that dictate when one’s thoughts, behaviors, and emotions are suitable in one domain and not the other, are all taken into account in border theory. Clark advised that movement between the domains often requires individuals to alter their goals and interpersonal styles to meet the demands of each of these settings. The notion of *border-crossing* is how Clark described movement between the two domains.

As in border crossing in a literal sense, an individual’s experience of transitioning from work to other domains is affected by the nature of the border. Clark (2000) described the nature of borders in terms of permeability, flexibility, and blending. According to Clark, the more permeable the border, the more easily positive or negative aspects from other domains can enter. This concept takes into account such things as the potential of “spillover” of emotions from one sphere to another. Flexibility refers to the degree to which a border will shrink or expand based on the demands of one domain or another. An example of flexibility is the freedom to work from any location, such as when one is telecommuting, which can make it more difficult to physically and psychologically separate work from non-work domains. Clark pointed out that the more flexible the border, the more freedom an individual has to move between borders, when needed. Further, ideas, insights, and emotions flow more easily between domains when the border is flexible. Clark advised that blending occurs when there is considerable permeability

and flexibility around a border. When this happens, a *borderland* is created that cannot be exclusively referred to as either the work or family domain, within which the individual fulfills both work and family roles, such as in a family-run business.

Clark (2000) noted that borders could be strong or weak. She posited that when one's work and home domains are similar, weak barriers make it easier to attain work/family balance. However, when the domains are different, stronger borders facilitate the achievement of balance. When one border is strong and the other is weak, the individual will find it easier to achieve balance if he or she is most committed to the stronger border. For those with significant physical impairments some level of flexibility may be essential to their maintaining employment. Further, as noted by Lirio, Lee, Williams, Haugen, and Kossek (2008), supervisors play a critical role in determining whether employees actually take advantage of options designed to support work-family balance. It would seem that workers who are most comfortable with their colleagues and feel a sense of belonging would be more inclined to request and utilize these programs.

Not all workers have the same capability and resources to negotiate the borders. Some workers are more centrally involved or connected within their workplace communities, whereas others have a more peripheral association. Clark (2000) described border theory as one that "encompasses the human interaction," and this is most evident in her explanation of the concept of central participation. Central participation is a critical element in border negotiations. Clark asserted that "border-crossers can be described on the degree to which they are peripheral or central participants in either domain" (p. 759). Within border theory, central participants of a particular domain are those persons who have internalized the values of that domain,

demonstrated competence in their responsibilities within that setting, have a connection with other central participants, and have personally identified with the responsibilities of the given domain. These attributes give central participants advantages that are not available to border-crossers, whose participation is viewed as peripheral. These advantages help them to attain a sense of balance more easily. Because of their competence, connections, and commitment, central participants have influence. Clark advised that this influence provides the “power to negotiate and make changes to the domain and its borders” (p. 759). This means that central participants typically have more autonomy and options, which makes it easier for them to achieve a sense of balance between the work and home spheres.

Central participants internalize the values of the domain and possess a sense of identification with domain responsibilities. According to border theory, this results in individuals’ identity being strongly tied to their domain membership. Their strong personal identification makes them more motivated to manage the borders and domains of their lives. As workers who share the values of the domain, central participants are more able to negotiate their needs with individuals who serve as border-keepers, such as supervisors, and other domain members such as coworkers. These other central participants are committed to the border-crosser as a “total person” (Clark, 2000, p. 763), and are supportive of the other domain obligations he or she may have because they respect, value and have more in common with the central participant.

Desrochers and Sargent (2004) noted that a limitation of Clark’s (2000) border theory is that it focuses solely on the two domains of work and family. Although Clark focuses on family and work, she often refers to one domain as work and the other as home which is broader than

family, in my view. Also, in defining the nature of borders her language suggests that other domains might exist in one's life. For example, she stated that, "permeability is the degree to which other domains may enter" (p. 754). Her reference to domains, in plural, encourages me in terms of how I view the concepts of border crossing and central participation being relevant to people with disabilities, how they might develop support networks at work, and how these relationships might extend into their personal lives.

### **Applying Border Theory to the WLB of Persons with Disabilities**

Belkin's 2005 work (as cited in Riley, 2006) on the employment challenges of people with disabilities, illustrates the dilemma of border crossing:

Few of us ever bring our true selves to work. We bring adapted and arranged versions, edited to fit the job. Our dress tends to reflect the rules of the workplace, written or not. We don't talk of our families nearly as often as we think about them. Our hobbies, our problems and our health are subjects generally left at home. We are someone else at the office.... (Riley, 2006, p. 155)

The expectation that workers leave some of themselves at home when crossing the border into work affects persons with and without impairments. However, the very nature of physical disability makes this more challenging. Simply navigating the work environment requires that these workers maintain some degree of awareness of the presence of impairment. For this reason, I believe employed people with disabilities are constantly negotiating not two, but a minimum of three domains. They manage work, life, and disability (or self-care). For those who have children or other family obligations, I would submit that this represents a fourth domain. Further, those who employ personal assistants, who could be friends or family members, fill an

additional role and spend time on the blended border on which they fulfill the dual role of employer and care recipient. Most significantly, whatever the other spheres within which the individual has to move, he or she enters and operates as a person with a disability.

While I would emphasize that disability is not the only and in many cases is not the primary identity of the individual, it is an aspect of the person's life that has implications for the opportunities he or she may have to develop support systems in workplace communities. This affects the degree to which he or she will be viewed as a central participant or as a more peripheral member of the community. The belief systems that have resulted in the stigmatization of persons with disabilities (such as the perception that by virtue of disability they are less competent) are counter to the beliefs held about central participants.

Vash and Crewe (2004) stated that "...a crucial part of job satisfaction is working with and around compatible people. More than this, work provides an avenue for many people to form friendships" (p. 127). However, it may be difficult for workers with physical disabilities to find individuals with whom they feel truly compatible. The educational, employment and social experiences of persons with disabilities are often quite different from those of nondisabled persons.

Workers with disabilities typically enter the workforce later and retire earlier than do their nondisabled peers (Mitchell, Adkins, & Kemp, 2006). They, like other marginalized groups, tend to be in lower-level, less autonomous jobs, and are provided fewer supports and opportunities for advancement (Cokley, Dreher, & Stockdale, 2004; Stone & Colella, 1996). These realities give persons with disabilities less time and opportunity to develop the reputation of competency required for central membership in the organization. This limits the influence

they have in negotiating the borders between the domains of their lives. The very presence of disability puts these workers at a disadvantage.

Participants in Randolph's (2005) study of employed women with physical disabilities reported that they were reluctant to request workplace accommodations because of attitudinal barriers and the likelihood that coworkers would view them as less capable. One woman described how difficult it was to change from using a manual wheelchair to a motorized chair, despite the fact that the latter would help her more easily perform her job. She stated, "...I knew the minute I went into a power chair, people would say, 'Oh, what's wrong with Betty now?'" (p. 373). The human service workers with physical disabilities interviewed by Coble-Temple, Mona, and Bleecker (2003) expressed similar fears. Ironically, in terms of social supports, nondisabled persons generally report more positive feelings towards workers with disabilities who are competent and willing to ask for help (Miller & Werner, 2007; Stone & Colella, 1996). This dilemma, I believe, represents another kind of balancing act that workers with disabilities face. Goffman (1963) referred to this dynamic as impression management. He advised that "...during mixed contacts, the stigmatized individual is likely to feel that he is 'on,' having to be self-conscious and calculating about the impression he is making, to a degree and in areas of conduct which he assumes others are not" (p. 14). Moreover, Goffman noted that the stigmatized person is inclined to feel that the "usual scheme of interpretation for everyday events has been undermined" (p. 14). Consequently, he or she feels that "minor accomplishments" may be viewed as "remarkable and noteworthy" given the circumstances (p. 14). It appears that when relating to persons without disabilities, those with disabilities cannot be too disabled nor can they act as if they are nondisabled; rather, they must be something or someone in between.

The socialization experiences of people with disabilities also affect their ability to form networks and effectively engage in border crossing. This is particularly true for those who have congenital conditions or who become disabled early in life, as the social development of these individuals may be different from their nondisabled peers (Henderson & Bryan, 2004; McCarthy, 1988; Vash & Crewe, 2004). Thus, while most individuals with disabilities share many of the same values of larger society, some may find it hard to identify strongly with nondisabled persons, especially in social situations. By the same token, I suspect it is at least as difficult for nondisabled persons to identify with individuals with disabilities. Thus, interactions within integrated work settings may be difficult for both those with and without impairments.

By definition, it is presumed that members of marginalized groups do not share the same values as those in the dominant culture (Roenblum & Travis, 2006); and I believe that the social discomfort demonstrated by some persons with disabilities may add to this perception. Additionally, if workers with disabilities engage in the self-care strategy of pacing themselves at work or strive to prove their value to the company by exceeding performance expectations, these behaviors may be viewed negatively by their colleagues. Finally, because people with disabilities often work in settings where everyone else is nondisabled, they encounter border keepers who may have little awareness of the workers' self-care domain, making it harder for workers to meet their needs in this area.

Clark (2000) defined balance in terms of degree of role conflict. This certainly can be an issue for persons with disabilities who may be expected to take on the sick role (Kaplan, 2003), be angelic (Clapton & Fitzgerald, 1997), or overcomers (Linton, 1998), depending on the domain they are in and with whom they are interacting. These multiple personalities of sorts are dictated

largely by what border the individual is negotiating and whom they interact with in that domain. Given their perceived and real dissimilarities from the central membership, in both work and leisure settings, people with disabilities are likely to find it more difficult to achieve balance. They may feel pressured to continually prove their value as workers and therefore less likely to ask for needed support. Additionally, when support is requested, they may not receive it due to an inability of gatekeepers and colleagues to grasp the many, often subtle, ways that physical impairment affects one's work and life.

Tighe (2001) reported that for the participants in her study, "disability became paradoxical" in that on one hand, they were viewed as "defective members of society," (p. 518) yet, when they attempted to engage in typical activities of daily life, such as grocery shopping, they encountered barriers that highlighted their differences from the general population. Certainly if these routine activities challenge the way that people with disabilities view themselves and highlight the limiting ways in which society views them, being part of a integrated work setting or participating in integrated leisure is likely to be equally challenging. Consequently, for persons with disabilities, the achievement of a sense of balance between work and non-work domains may be more difficult than it is for their nondisabled colleagues.

## **Understanding Disability**

### **What is Disability?**

There is no universal definition of disability. However, definitions used by such programs as the Social Security Administration (SSA) and the World Health Organization (WHO) are among those most often referenced when describing physical disability. Since its inception, the SSA has defined disability as "the inability to do any substantial gainful work"

(Social Security Advisory Board, [SSAB], 2003, p. 12). Stubbins (1988) noted that “[m]edical advances have transformed the central meaning of disability from physical survival to the search for meaning when one is socially isolated, unemployed or underemployed, and lacking essential environmental accommodations” (p. 24). Additionally, the nature of work has also changed. It is considerably less physical today than in the past, and with current technology, many individuals with significant limitations can perform jobs once beyond their physical capabilities. Nevertheless, the definition used by the SSA remains the same as when the program was established (SSAB).

WHO defines disability as “any functional limitation or restriction in the ability to carry out activity resulting from an illness, injury, or birth defect” (Vash & Crewe, 2004, p. 26). The organization now endorses the International Classification of Functioning (ICF). ICF is a “biopsychosocial model...an integration of the medical and social” (WHO, 2002, p. 9). In this model, some aspects of disability are considered to be largely internal to the person, and others are viewed as almost entirely external or socially constructed (WHO). For example, physically inaccessible workplaces can disable an otherwise qualified worker from gaining employment in that space because the physical design of the site impedes access by a jobseeker who uses a wheelchair.

Meyerson (1948) pointed out that it is not possible to understand physical disability if it is viewed only from a physical standpoint. Referring to physical disability as “simply a variation in physique upon which, ordinarily, we place a highly negative value” (p. 4), he noted that the impact of physical difference depends largely on the social environment the individual is in and the way the disabled person views his or her situation. Meyerson noted that even in settings

where disability may be more common (such as in his example of a man in a coal mining town versus a woman in Hollywood) “... physical disabilities...consistently carry negative values” (p. 4).

Definitions of disability as negative, limiting, and indicative of inability are still common. However, in recent years disability advocates have challenged disabled individuals to “reclaim the definition of disability and take control over the naming of [their] own experience” (Triano, 2003b, Para. 4). Triano (2003a, Para. 1) noted that disability is “highly prescribed and carefully defined in civil rights laws,” while other human differences that are subject to legal protection (race and gender) are not. Further, she argued that common definitions that view disability as a limitation, weakness, or barrier to be overcome deemphasize the social oppression and discrimination experienced by individuals with disabilities. Founder of the Disability Pride Parade, Triano (2006) professed that Disability Pride is “...a direct challenge of systematic ableism and stigmatizing definitions of disability...a militant act of self-definition, a purposive valuing of that which is socially devalued...” (Para. 1).

### **Social Construction of Disability: Influence on Identity and Inclusion**

Social construction (Berger & Luckmann, 1966) is a significant theoretical concept in examining how people with disabilities cope. According to Schwandt (2001), the constructionist seeks to explain how human beings interpret or create some states, practices, conditions, experiences, ideas and beliefs, within specific linguistic, social, or historical contexts. Over time, these concepts or interpretations come to be thought of as the way things are. Rosenblum and Travis (2006) noted that “cultural concepts such as dependency and independence—which bear heavily on judgments about what constitutes disability—are most often imposed on disabled

people by those not so identified” (p. 24). Still, socially constructed perceptions are so commonly accepted that the individuals who identify with marginalized groups, such as women, racial minorities, and persons with disabilities, often internalize societal views and help to perpetuate them.

Campbell (2008) examined the issue of internalized ableism; she noted that many people with disabilities “still adopt culturally valued roles to blend into society” (p. 152). She aptly described the challenge of living with a disability in a society that considers physically able bodies the desired norm, stating, “...the disabled subject is caught ‘between a rock and a hard place’; in order to attain the benefit of a ‘disabled identity’ one must constantly participate in processes of disability disavowal, aspiring towards normativity, a state of near ablebodiedness, or at the very least to effect a state of ‘passing’” (p. 156). These efforts undertaken by individuals with disabilities in order to protect themselves from stigma and enhance the possibility of acceptance from the nondisabled majority can make it more difficult for people with disabilities to accept themselves.

Regarding the “otherness” of marginalization, Clapton and Fitzgerald (1996) stated, “...it is difficult to know where our constructions end and the reality begins (for the constructions shape the reality)...” (p. 1). They noted that in comparison to some other cultures where disability is “accepted as being normal,” “the script we [in Western culture] have written for people with disability is a narrow one” (p. 1). The authors described three models of disability: the religious model, the medical model, and the rights-based model. Other scholars have identified additional models or referred to these three models by different terms. However,

broadly defined, the models described by Clayton and Fitzgerald encompass the primary ways in which people with disabilities have historically been viewed by society.

The religious model (also referred to as the moral model), is the oldest model of disability and the least prevalent today (Kaplan, 2003). This model represents two different views of disability that were common prior to the 19<sup>th</sup> century. One aspect of this model views disablement as a consequence of sin. Disability was “seen as the result of evil spirits, the devil, witchcraft or God’s displeasure.” Alternately, people with disabilities “were also signified as reflecting the ‘suffering Christ’, and were often perceived to be of angelic or beyond-human status to be a blessing to others” (Clapton & Fitzgerald, 1996, p. 2). These conflicting beliefs led religious communities to respond to people with disabilities in a variety of ways. These included promoting and seeking cures through exorcisms, purging and rituals, as well as providing care, hospitality, and “acts of mercy” towards “needy strangers” (Clapton & Fitzgerald, p. 2). Although not as prevalent today as it once was, the moral model still influences how some people view disability. Kaplan (2003) noted that many cultures (and individuals) still associate disability with sin, shame, and feelings of guilt, “even if such feelings are not overtly based in religious doctrine” (p. 1). In this model, disability is seen as the consequence of the sins of the individual or his or her parents and is associated with shame on the entire family. These beliefs contributed to family members with disabilities being hidden away, kept out of school, and excluded from participation in society. This way of viewing disability is particularly troublesome to people with disabilities because, “even in less extreme circumstances, this model has resulted in general social ostracism and self-hatred” (Kaplan, p. 1).

Historically, the most prevalent way of viewing disability is within the medical model. This model came about in the 19<sup>th</sup> century with the development of modern medicine (Kaplan, 2006). During this time, medical and scientific knowledge greatly increased, and “the doctor and scientist replaced the priest as custodian of societal values and curing processes” (Clapton & Fitzgerald, 1996, p. 2). This model assumes individuals with disabilities are sick and in need of being healed by nondisabled professionals who presumably know the needs of persons with disabilities better than the individuals themselves. In this model, people with disabilities are “in the sick role... [As such] they are excused from the normal obligations of society: going to school, getting a job, taking on family responsibilities, etc.” (Kaplan, 2003, p. 1). During this era, the futures of persons with disabilities were defined by their medical prognosis. At this time, institutions were established with a role as “agents of custody for social control and institutional segregation for those now described as subnormal, [and] institutions became the instruments of social death” (Clapton & Fitzgerald, 1996, p. 2). Within this model, the problems associated with disability are thought to reside within the individual. According to Longmore (2003), the medical model “defines disability as limitations in social and vocational functioning,” and makes disability the “exclusive and inevitable consequence of physiological impairments” (p. 1). In the medical model, society has no responsibility to include people with disabilities, “since they live in an outsider role waiting to be cured” (Kaplan, 2006, p. 1).

Goffman (1963) defined stigma as “the situation of the individual who is disqualified from full social acceptance” (Preface). He explained the term as “an attribute that is deeply discrediting,” and he emphasized that “...when its discrediting effect is very extensive” it may

also be called “a failing, a shortcoming, a handicap” (p. 3). In a very real way, societal beliefs have led to a social construction of disability and the stigmatization of persons with disabilities.

Throughout history, individuals with disabilities have, to varying degrees, been subjected to what Rosenblum and Travis (2006) referred to as the “stereotypes about people in stigmatized master statuses” (p. 30). These include believing that persons with disabilities do not possess the same values as the dominant culture, viewing people with disabilities as problems and as having problems, seeing individuals with disabilities as lacking self-control and sound judgment, viewing them to be less intelligent than nondisabled people, and considering persons with disabilities to be both childlike and monstrous. Within these stigmatizing belief systems, people with disabilities have been viewed as unable to work and regarded as less than full citizens of their communities.

In recent years, some members of the disability community have begun to see disability through different, more empowering frameworks such as the rights-based model of disability. Clapton and Fitzgerald (1996) noted, “The emphasis has shifted from dependence to independence as people with disability have sought political voice, and become politically active against social forces of disablism” (p. 3). Longmore (2003) referred to this set of beliefs about disability as the minority group model, and Kaplan (2003) used the term disability model when describing this viewpoint. Unlike the medical model, the rights-based model does not consider disability to be within an individual. Rather, it focuses on the way in which society impacts community membership, participation in, and access to societal activities such as employment, education, and recreation (Clapton & Fitzgerald, 1996, p. 4). In the rights-based model, disability is considered a normal part of life. Anyone can become disabled at any time, and

limitations are a natural part of growing older. Rather than viewing a person's physical condition as the problem, this model recognizes societal discrimination as most debilitating (Kaplan, 2003). Oliver (1990) proposed a social model of disability based on the disability movement in the UK, which moves the issue of disability even further from one of individual tragedy or responsibility than the social model in the U. S.; it considers disability a social creation.

Referring to the language used by the Union of Physically Impaired Against Segregation, Oliver (1990) explained the social construction of disability, stating, "Disability is a disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (p. 11). While definitions such as that used by WHO acknowledge that there are social aspects to disability, these definitions do not consider disability as arising from social causes. Abberley (1987) noted that, taken to the extreme, this viewpoint erases the presence of any bodily impairment, and he cautioned against a focus on the disability experience as solely socially constructed. He argued that this leads to the "rejection of the authenticity of impaired life forms" as revealed in everyday life by comments such as 'but I don't think of you as disabled', which though intended as a compliment denies a "key aspect of a disabled person's identity" (p. 9).

Clapton and Fitzgerald (1996) emphasized that the shift towards viewing disability as a social construction has been beneficial to the disabled community, but there is considerable work yet to be done to significantly improve the lives of persons with disabilities. They wrote, "While rights-based discourse, at a strategic level, has brought some additional entitlements to people

with disability, it has not significantly altered the way in which disability is constructed...despite legislative changes, some people's lives have not necessarily changed" (p. 5). This is due in large part to the fact that while a rights-based perception of disability has developed within the disability community, society by and large, has not fully grasped or accepted this view; social policies still primarily view disability as a problem belonging to or within the individual (Johnson, 2003; Linton, 1998; Oliver, 1986).

Reeve (2002) noted that some scholars have criticized the social model for its focus on "public experiences of oppression such as social barriers at the expense of the more personal experiences of oppression which operate at the emotional level" (p. 495). She asserted, "these psycho-emotional dimensions of disability ... affect what disabled people can *be*, rather than what they can *do*" (p. 495). According to Reeve, these dimensions include such experiences as being hurt by others' reactions or being made to feel worthless. She asserts that these experiences are rooted in the negative attitudes and prejudices society holds toward those with disabilities.

History has indicated a high tolerance for the disposal of persons thought to be imperfect by the dominant culture (Pfeiffer, 1994). The Eugenics Movement, supported by some of the most educated and influential citizens of the late 1800's and 1900's, is evidence of this (Henderson & Bryan, 2004; Pfeiffer, 1994). Unlike the hatred that led to killing members of racial and ethnic groups presumed to be inferior, the sterilization and killing of people with disabilities has been and continues to be considered not only justifiable, but also merciful. The belief that the killing of people with disabilities is an act of mercy is at the center of debates around assisted suicide, a practice supported by nondisabled persons who cannot imagine living

with a significant disability. Some persons with disabilities also support euthanasia. This may have less to do with their disability and more with society's response to their disablement. In his book, *No Pity*, author Joseph Shapiro (1993) describes the 1989 case of 34-year-old Larry McAfee, who had quadriplegia as the result of a motorcycle accident. This case demonstrates how disabling policies and beliefs can lead people with disabilities to prefer death to living with significant impairment.

McAfee, after being moved to various nursing facilities over a nearly five-year period, decided he would rather die. A judge praised McAfee as "sensible and brave" and approved the request for assisted suicide given McAfee's claim that he was physically unable to kill himself. Ultimately, McAfee decided to continue living. He changed his mind about dying after being introduced to technology that would enable him to consider a return to work utilizing his existing engineering skills and moving into community-based housing that provided personal assistant services. Initially, it was not his disability that led McAfee to insist on dying, but rather the frustration of trying to work through the bureaucracy of the healthcare system to get the money and supports he needed to create a life for himself as a man with a disability. Yet when he sought help from the courts, he was not evaluated and offered counseling as would have likely been the case had a nondisabled man made the same request. No effort was made to look at how funding policies could be revised to provide him with other, more appropriate and hopeful housing options. Given the nature of McAfee's physical limitations, the judge not only agreed with but also commended him on his choosing death over life with a significant physical disability.

In her work on disability identity, Darling (2003) used McAfee's story to illustrate her point that "identities are not static and are likely to change over time" (p. 889). McAfee initially represented what Darling calls resignation mode; he was not in the majority of nondisabled people nor was he connected with the disability community. Once he attained the resources he needed to improve his quality of life, he became involved in efforts to assist others with disabilities to do the same. As a result, McAfee's identity shifted to what Darling terms crusadanship. Darling asserted that "crusadanship typically becomes transformed into normalization after one or more turning points (such as finding a job in an integrated setting), during which new opportunities become available" (p. 890). She noted that "the normalization mode ... may or may not include acceptance of societal stigma" (p. 886). For example, Watson's (2002) exploration of the self-identity of people with physical disabilities indicated that "all that these informants [were] trying to do [was] to challenge the idea of normality and refuse to be categorized on the basis of bodily difference." (p. 525). Watson's assessment that "it's not that these informants are rejecting the social model of disability in favour of the medical model, they are merely downplaying the significance of their impairments as they seek to access a mainstream identity," (p. 525) suggests that some persons with disabilities, while not ashamed of their impairments, minimize their impact on their lives. Clearly, societal perceptions and social opportunities contribute to how people experience disability and how they view themselves and their situations.

In an examination of the everyday lives of people with disabilities, Lutz and Bowers (2005) found that "most participants in the study did not perceive disability as solely a limitation in functional status that results from the disabling condition or from the barriers of the social or

political environments” (p. 1042). Like the individuals in Lutz and Bowers’ study, most people with physical disabilities acknowledge they have impairments. Still, the limitations imposed by their bodies are only one aspect of what makes their situations challenging. Often, it is the physical and attitudinal barriers they regularly encounter that are most disabling. The notion of ableism is tied to the social construction of disability in that it, like other –isms, is the result of prejudicial behaviors against those with disabilities and a belief that such persons are inferior. Further, as members of larger society, people with disabilities may be unconscious contributors to the social construction of disability and may internalize the view that they are inferior to nondisabled people. These realities create stressors not unlike those experienced by other marginalized groups and affect the way they view themselves and how they are viewed by others in work and leisure spaces.

### **Social Construction and the Employment of People with Disabilities**

The strong Protestant Work Ethic in the United States has contributed to the social construction of what it means to be a “good employee.” Members of marginalized groups that the dominant culture views as not valuing work or not being productive, such as some racial minorities and persons with disabilities, are likely targets of employment discrimination. Further, those who do find employment may not be readily accepted by their coworkers. This may be particularly true for people with disabilities, who may be shunned by both the dominant culture and members of other stigmatized groups.

Baynton (2001) noted, “Not only has it been considered justifiable to treat disabled people unequally, but the *concept* of disability has been used to justify discrimination against other groups by attributing disability to them” (p. 33). When disability was used to justify

discrimination against women and other minorities, these groups asserted that they were not disabled and “therefore not proper subjects for discrimination” (p. 34). Thus, disability has been used to signify and justify inferiority of marginalized groups, according to Baynton. The historical view of disability as legitimate cause for disparate treatment may make full acceptance difficult for workers with disabilities, even among colleagues who are themselves members of oppressed groups.

Increasingly, the socially constructed good employee and promotable worker is defined as having desirable technical or hard skills as well as a sufficient mastery of what are commonly referred to as soft skills; these include interpersonal or relational skills (Beeson, 2009). However, for some individuals with disabilities, particularly those who are born with disabilities or who acquire disability prior to adulthood, the development of both of these skill sets may be hindered as a consequence of their disabilities and/or due to society’s response to their conditions (McCarthy, 1988). These factors also influence the development of personal and professional friendships. Thus, people with physical disabilities must cope not only with their physical impairments, but also with the interpersonal and intrapersonal stressors that result from how they and others perceive their disablement.

### **Coping With Disability**

The experience of physical disability is stressful. One stressor is the presence of physical discomfort such as pain due to arthritis, tightness of muscles due to cerebral palsy, or spasms related to spinal cord injury. Performing activities of daily living (ADLs) such as bathing, dressing, and eating, may require the assistance of another person. Whether these activities are done with or without assistance, they are likely to take the individual with a disability more time

and energy to complete than they would a nondisabled person. As difficult as this can be, the perceptions of others towards one's disability and the way in which the individual views him or herself can be most significant in coping with disability.

Vash and Crewe (2004) noted that in the beginning of the rehabilitation movement, there was an emphasis on the importance of accepting one's disability. Sometimes this referred to the absence of denial; other times, "it simply meant acknowledging one's loss without feeling rotten about it" (p. xvii). Further, while acceptance of disability was considered to be good, people with disabilities "were never supposed to *like* their disabilities." According to Vash and Crewe, liking one's disability was considered forbidden because of the perceived secondary gains. Goffman (1963) described the concept of *secondary gain* as the ability to use one's stigmatized characteristic "as an excuse for ill success that has come his way for other reasons" (p. 10). Vash and Crewe asserted that the implicit fear in this way of thinking is that if people actually found pleasure in being disabled, they would have no reason to strive towards the societal expectation of normalcy.

Today, there is a move toward not simply accepting disability but embracing it as one would other parts of his or her identity. For example, Linton (1998) noted that the term *disabled people* became more common within disability rights and disability studies circles in the early 1990's, and "rather than maintaining disability as a secondary characteristic, *disabled* became a marker of the identity that the individual and group wish to highlight and call attention to" (p. 13). Still, this attitude may be viewed by some as a kind of denial or supercripdom. That is to say, an individual may be so focused on emphasizing how similar he or she is to individuals without disabilities, that a disability identity is completely dismissed. In a variety of ways,

people with disabilities are given a message that it is best not to focus too much, or too little, on their limitations.

Henderson and Bryan (2004) noted, “persons with disabilities as a group experience stressful situations more often and more intensively than persons without disabilities” (p. 280). While it is important to avoid overgeneralization, they explained that individuals with disabilities are more prone to stress due to the overt barriers they face in such areas as education, social interaction, physical accessibility, dating and marriage, and gainful employment. These experiences, in addition to more covert forms of injustice, result in greater frustration. The authors made a critical observation in their statement that people with disabilities are more likely to react to this stress in ways that others might view as inappropriate because “social conditioning and the more limited responses available to the individual with a disability compound stressful situations...many of the appropriate ways of responding...are not available to people with disabilities, or, at best, are difficult for them to act out” (p. 279-280). For example, difficulty expressing frustration may be due to an actual speech impediment. However, even if one’s speech is not impaired, expressing negative feelings may be impeded by concern about how others might interpret this behavior. Societal perceptions about the emotionality of persons with disabilities often leads nondisabled people to take less seriously the concerns expressed by those with disabilities. Thus, the socially acceptable way of addressing conflict through dialog is less effective for some individuals with disabilities. In other words, while all people use coping mechanisms such as depression, denial, repression, and displacement, people with disabilities have fewer specific outlets for their stress. Furthermore, they typically have access to fewer socially acceptable options, such as recreational outlets, to help them cope. The

lack of such outlets and the concern for acceptance add to the level of distress experienced by persons with physical disabilities.

Johnson et al. (2004), and Henderson and Bedini (1995) demonstrated that one way people with physical disabilities cope is to avoid additional stress. They strive to maintain a sense of dignity and psychological well-being by denying themselves other resources that are equally important to a healthy life. For example, Johnson et al. found that employees with MS were reluctant to use assistive devices or request workplace accommodations because of possible discrimination and a concern that coworkers would view them as more significantly impaired. Likewise, women interviewed by Henderson and Bedini expressed concern that their bodies would be viewed negatively by nondisabled recreationists in community-based settings; therefore, the women engaged in community-based leisure less often than they would have liked. In an effort to minimize stress, workers in the Johnson et al. study denied themselves the use of assistive devices that could help them to conserve physical energy and maintain sound musculo-skeletal functioning. In Henderson and Bedini's study, the participants' concern about how they believed they were viewed by nondisabled recreationists lessened their level of leisure participation. These responses indicate that persons with physical disabilities feel a particular need to carefully manage personal resources (such as the reputation of a capable worker and self-esteem). These kinds of concerns could significantly affect one's interactions in work and leisure settings and affect how he or she views the concept of work-life balance. A participant in Johnson et al.'s study alluded to the challenges faced by employed persons with physical disabilities stating, "Oh, it costs me having a life outside of work sometimes, because I am pretty much exhausted, but I actually like working" (p. 203).

While societal definitions of disability make it more difficult to cope with physical impairment, many people with physical disabilities manage their disabilities and the response of others towards them quite well. In a review of several studies that examined the attitudes of people with physical disability toward their situations, Weinberg (1988) concluded, “It may be most appropriate to see disability as a difficulty that imposes limits and problems in much the same way that other facets of life impose difficulties...not unlike those who are nondisabled [people with disabilities], have the full range of ways of seeing their situation and adapting to it” (p. 153). This is an important point because larger society often views disability as synonymous with intense feelings of lack or unhappiness. Just as there is no one way to be nondisabled, there is no one way to experience disability. Some people have more difficulty coping than others. At the same time, it is significant to note that persons with disabilities are not immune from “other facets of life,” such as divorce, or grieving the loss of a loved one (Weinberg, 1988, p. 153). They may be responsible for the care of children or parents, and they are not immune from experiencing further disablement or illness.

Employed people with physical disabilities who manage their situations in positive, socially acceptable ways often do so with considerable effort. They must deal with many of the same concerns their coworkers have as well as with the physical and emotional stress that can accompany disablement. One socially appropriate way to cope with stress is through involvement in leisure activities. Engagement in leisure pursuits helps people, with and without disabilities, to cope with stress (Parry, 2007; Trenberth, Dewe, & Walkey, 1999).

### **The Roles of Leisure in Disability Coping**

A large body of literature within the field of leisure research considers the roles of leisure in coping with stress (Coleman & Iso-Ahola, 1993; Iwasaki & Mannell, 2000; Iwasaki & Schneider, 2003). According to Iwasaki and Schneider, the concepts of leisure, stress, and coping are intertwined with other research in the field, such as the study of leisure constraints negotiation, diversity, and lifestyle. The relationships between these various elements can be found in a relatively new and growing body of literature that indicates people with disabilities also find that leisure offers both mental and physical benefits. Among those with physical disabilities, leisure plays a substantial role in coping by providing social support and a sense of belonging (Hutchinson, Loy, Kleiber, & Dattilo, 2003), by enabling participants to maintain good physical and mental health (Plante, Le Captain, & McLain, 2000), and by providing a means through which individuals with physical disabilities can establish, or re-establish, identity and self-acceptance (Parry, 2007).

#### **Social Support and Sense of Belonging**

Leisure is often social in nature. In fact, one of the many definitions of leisure is “social activity learned in social contexts and employing social resources” (Kelly, 1999, p. 136). According to Coleman and Iso-Ahola (1993), the social nature of leisure appears to be one reason it has such an impact on coping with the stressors of life. The authors speculated that participation in leisure acts as a resource for coping because it can provide people with companionship, which leads them to perceive the availability of social support when more severe life events occur in the future. Iso-Ahola and Park (1996) confirmed the importance of social support through leisure participation: “...it is the activity and the things done with

friends/companions that buffer the adverse effects of stress on mental and physical health” (p. 169). The perception of social support significantly contributes to one’s ability to cope because it reflects a belief about the availability of support (Iwasaki & Mannell, 2000). Coleman and Iso-Ahola concluded that perceived social support resulting from leisure participation operates in times of crisis. Further, they determined that leisure companionship seems to lessen the stressors of daily life and helps maintain emotional well-being whether one is dealing with few stressors or the amount of stress is compounded over time. Indeed, Iwasaki (2003) asserted, leisure is a beneficial resource for coping with stress “irrespective of the level of stress experienced” (p. 202). In a recent study, Glover and Parry (2008) examined the role of social support through leisure in coping with the trauma of infertility. This study indicated how beneficial leisure companions can be in helping individuals cope with intensely personal concerns. It also highlighted the difficulty participants had in sharing their situations with and feeling supported by people who had not been through the same challenges. The concerns of the couples in Glover and Parry’s study are not unlike those of individuals with disabilities who are living and working in communities dominated by nondisabled people.

The social aspects of leisure may be particularly important to those who have acquired disabilities. Research related to the experience of disability (Kleiber, Hutchinson, & Williams, 2002) indicates that changes in and loss of social relationships is a significant concern for people with acquired disabilities. In a study conducted by Lee and McCormick (2002) social leisure was found to contribute to the quality of life of people who have experienced spinal cord injury (SCI). This was true regardless of the degree of injury, with quadriplegics and paraplegics finding such leisure to be equally beneficial to overall life satisfaction. Hutchinson et al. (2003)

in their work with the same population noted that study participants frequently spoke of leisure shared with family and friends as providing a sense of belonging and acceptance. Some commented that leisure provided a context for them to connect with other people based on shared experiences, not shared illness or injury.

In Parry's (2007) study of breast cancer survivors, most of the dragon boat racing participants reported that they found value recreating with others who also had breast cancer. Their fellow survivors understood their situation in a way that friends who did not have cancer could not. While one woman stated that, initially, the "idea of getting together with a bunch of other survivors did not appeal to me" (p. 61), she ultimately found the experience to be very positive. In this study, social support was viewed as significant in helping the individuals to cope with their illness and deal with the possibility of relapse. As one participant stated, "...I joined...not for physical activity, but rather for the emotional support" (p. 59).

Iwasaki, MacKay, Mactavish, Ristock, and Bartlett (2006) conducted research regarding how various marginalized groups (aboriginal people with diabetes, people with permanent mobility impairments due to physical disability, and people who identified themselves as gay or lesbian) utilized leisure to cope with stress. They found that for participants with mobility-impairments, engaging in social leisure with others who have disabilities was an important coping strategy. The individuals described utilizing their strengths and resilience through social leisure to fight against stress, including stress due to ableism. The importance of social leisure and sense of belonging was noted among all participants; however, for those with physical disabilities, a sense of connectedness and empowerment through leisure experiences with peers was found to be especially significant.

These studies suggest that whether social leisure occurs with people who are nondisabled or with those in situations similar to one's own, the opportunity to spend time sharing experiences with others aids in the ability to cope with stress. Time with family or nondisabled friends helps individuals with disabilities to feel a sense of acceptance and belonging. Alternately, time with others in similar situations can contribute to a sense of solidarity and empowerment. For example, Latimer, Ginis, and Hicks (2005) incorporated social support into their study of the roles of exercise in helping persons with SCI cope. They noted that the traumatic onset of disability results in numerous changes, including changes in relationships and job status. Participants had a positive association between levels of stress and depression at the start of the study. After six months, the exercise group that engaged in regular aerobic and strength training together no longer had this association. The authors concluded that physical activity, with similar others, provided psychological benefits to participants.

### **Maintenance of Physical and Mental Health**

Leisure also helps individuals to maintain physical and mental health and handle stressors related to disability and other life factors. In several studies (Iwasaki et al., 2006; Kleiber, Brock, Lee, Dattilo, & Caldwell, 1995; Parry, 2007), participants with disabilities indicated that they experienced a sense of empowerment and control over their bodies because of their leisure activities. They also expressed positive feelings about how leisure allowed them to focus on what they can do rather than on their limitations. Further, they found that they enjoyed the feeling of doing something they believed was good for their bodies.

Muraki, Tsunawake, Hiramatsu, and Yamasaki, (2000) determined that regular participation in sport was associated with better psychological status for men with SCI. The

level of injury and type of sport were not significant, but rather the frequency of participation was most important. Those who played sports three or more times per week showed the greatest decline in depression and anxiety and a notable increase in vigor. Taub, Blinde, and Greer (1999) also studied men with disabilities who regularly participated in sport and other physically active leisure. The men reported that participation in these activities helped them manage stigma, develop a sense of physical competence, and create more muscular physiques. Similar results have been found in studies with physically active women with disabilities (Guthrie & Castelnuovo, 2001).

For some individuals with disabilities, non-physical leisure may be equally important in combating stress. For example, participants in a study conducted by Iwasaki et al. (2006) noted significant benefits from both active and passive leisure in helping them cope. One individual spoke of how reading allows her to “forget about pain”; another shared that she enjoys doing crossword puzzles because it is a “good activity for my mind” (p. 93). Other participants viewed passive leisure as a way to create a sense of balance due to the physical and emotional energy expended each day. Participants in Hutchinson et al.’s (2003) study reported that low intensity leisure such as television viewing or playing with a pet was also beneficial in dealing with daily stress. Since the symptoms of some disabilities, such as MS, may be exacerbated by stress, these relaxing leisure outlets may be as important in maintaining physical health as more physical forms of leisure.

### **Establish or Re-Establish Identity and Self-Acceptance**

Another way in which leisure helps individuals with disabilities cope is through providing opportunities to do things that they enjoyed prior to injury or illness. In the case of

those who have always been disabled, it offers the chance to engage in activities for pleasure and to gain a sense of what they can do physically. Leisure can also provide a means for the development of a new identity and increased self-acceptance. For example, cancer survivors in Parry's (2007) study acknowledged the importance of leisure in assisting with identity formation following diagnosis. They spoke of the realization that having gone through the experience they were not the same people they were prior to their illness. As one woman stated, "Dragon boat racing...became part of my new identity. ...they made me feel normal and helped me to realize I could cope..." (p. 60).

The effects of leisure on identity were evident in a study conducted by Reynolds and Prior (2006) in which all of the participants were involved in art-making related leisure. This was consistent with their pre-cancer interests and activities. Some participants reported that they believed their illness helped them to more fully release their creativity. The participants found that these endeavors enabled them to build social networks, have an identity other than "the person with cancer," and maintain a sense of competence despite their condition.

Hutchinson et al. (2003) found similar results in their study of persons with SCI. Two aspects of leisure were identified as particularly important in helping them cope. First, leisure provided concrete benefits including a sense of connectedness or continuity with their past, a means by which they could demonstrate competence and independence within an activity, and a vehicle through which they could express valued self-attributes. The second way in which leisure assisted in coping was in the meanings that individuals ascribed to their experiences; participation in the activity was less significant than what it symbolized in terms of the person's beliefs, values, and sense of self and personal history.

## **Leisure as a Source of Stress**

Coleman and Iso-Ahola (1993) pointed out that most research on leisure and coping has focused on the impact of stress on health and how leisure moderates this impact; however, little attention has been given to how poor health affects stress levels and its potential implications in terms of leisure. For example, poor health can lead to job loss and inhibit an individual's perception of leisure options. Taking this concept a bit further, I would suggest that leisure may be a source of stress for some individuals with physical disabilities.

It may seem contradictory to think of leisure as a source of stress, given its undeniable benefits. However, Schneider and Hammitt (1995) proposed that "conflict in recreation settings may actually cause stress...and ...recreation conflict is experienced and coped with like other forms of discrete stress" (Iwasaki & Schneider, 2003, p. 110). A careful review of research on leisure and disability coping suggests that for people with physical disabilities leisure can be stressful. The potential benefits of leisure require that these individuals negotiate impairment-related constraints (i.e., site accessibility, lack of transportation or the need for physical assistance in order to participate). In addition, they may experience the universal constraints of time and money to a greater degree than nondisabled recreationists because as a group, persons with disabilities have considerably less in the way of financial resources and typically require more time in order to engage in leisure activities.

In an investigation of barriers to and facilitators of active leisure by persons with disabilities, Rimmer, Riley, Wang, Rauworth, and Jurkowski (2004) determined that lack of transportation and prohibitive membership costs deterred study participants from accessing community-based fitness/recreation settings. Notably, "the most frequently cited reason for the

reluctance of persons with disabilities to use fitness and recreation facilities was the perception that these facilities are unfriendly environments” (p. 423). The participants with disabilities reported negative attitudes and behaviors on the part of nondisabled recreationists as well as staff. Managers who took part in the study confirmed these perceptions.

Kleiber et al.’s (2002) study of persons coping with SCI demonstrated that the social aspects of leisure could be a source of discomfort. Participants reported difficulty in having to depend on others, concerns about finding care providers, and conscious efforts to avoid overburdening family members and other caregivers. The change in their relationships with others was a source of stress for these individuals. Additionally, participants reported that even when they returned to familiar leisure, they did not enjoy it as much due to the inability to participate as fully as they did prior to their disability.

Guthrie (1999) examined physical activity among women with physical disabilities. Many of the women reported managing disability symptoms through sport and other physically active leisure, and felt empowered by this. However, some, particularly those with acquired disabilities, did not play sports they once enjoyed because such activity was a painful reminder of what they had lost due to illness or injury. For people with physical disabilities, “...leisure only served as a coping resource when it was personally relevant and when its benefits outweighed the physical and emotional ‘costs’” (Hutchinson et al., 2003, p. 155).

According to Russell (2005), “Foremost, leisure makes us feel free” by offering freedom from routine obligations and freedom to “expand beyond the limits of the present to experience wonderfully fulfilling possibilities” (p. 40). The literature indicates that for individuals with physical disabilities this kind of freedom is more difficult to achieve. Given the additional,

disability-related considerations, it is not surprising that Zoerink (1988) found that young adults with congenital orthopedic impairments reported being less spontaneous in their leisure and liking leisure less than their nondisabled peers. Other studies (e.g., Aitchison, 2003) have demonstrated that people with physical disabilities tend to engage in leisure less often and tend to recreate primarily with family members, rather than friends, suggesting the possibility of less social support (or at the very least, smaller social networks) than may be experienced through the leisure participation of nondisabled persons.

Finally, the experience of disability and need to manage symptoms may change how individuals with disabilities view leisure. Although physical activity was identified as a meaningful source of freedom, choice, and control over one's life, only about a fifth of the participants in a study conducted by Henderson and Bedini (1995) described physical activity as purely leisure at least some of the time. Those who viewed such activity as necessary for rehabilitation or daily functioning thought of physical activity as therapy rather than leisure. While it would seem that these activities would likely help individuals to better cope with stress, it may be that the participant's perception of the meaning of the activity determines the degree to which it is helpful. For example, if the activity is viewed as a need or requirement for functioning, the participant is less likely to view it as freely chosen, and this may result in the activity having a lesser affect on the individual's ability to cope. Indeed, Iwasaki (2003) pointed out that "the development of enduring beliefs about the roles of leisure as ways of coping (i.e. leisure coping beliefs) seems essential to the actual and effective use of leisure as a means to manage stress..." (p. 183). Additionally, Iwasaki, MacKay, and Mactavish's (2005) investigation of leisure coping among male and female managers demonstrated that the

perception of having freely chosen to engage in an activity may moderate the stress experienced as a consequence of participation. Thus, those who feel they have to participate may perceive less benefit from participation than those who freely choose to do so. This may explain why researchers (Guthrie & Castelnuovo, 2001) have found that individuals who view physically active leisure strictly as a means of managing disability symptoms do not consider it helpful in maintaining self-esteem and accepting disability.

### **Negotiating Constraints to Leisure Participation**

The potential for leisure to be both a coping resource and a source of stress is linked to the negotiation of constraints. Iwasaki and Schneider (2003) noted, “constraints are considered elements of stress, whereas constraints negotiations appear to share commonalities with ways of coping with stress” (p. 108). In other words, constraints can cause stress, and the strategies used to deal with constraints are similar to those used in dealing with other stressors people encounter in their daily lives. Research on constraints negotiation confirms that all people, with and without disabilities, face constraints to leisure participation.

According to Jackson and Scott (1999), early constraints research was based on three assumptions. First was the assumption that the ability to participate in a desired activity was the only element of people’s leisure affected by constraints. Another assumption was that constraints are insurmountable obstacles to participation. The third assumption was that if people participate in an activity it is presumed that they have no constraints regarding participation. Mannell and Kleiber (1997) noted that more recent research demonstrated that the issue of constraints is not simply a matter of interest/disinterest; rather, many factors can keep an

individual who is genuinely interested in leisure from engaging in it or from doing so as frequently as he or she would like.

Crawford, Jackson, and Godbey (1991) proposed a hierarchical model of leisure constraints. They identified three types of constraints: intrapersonal, interpersonal, and structural. Intrapersonal constraints are internal to the individual and relate to attitudes and psychological states. Interpersonal constraints include factors that result from interaction with others; examples include the attitudes of family members and the lack of leisure companions. Structural constraints include such things as physical inaccessibility of leisure sites or cost-prohibitive membership fees. Crawford et al. posited that these constraints are encountered in a linear and sequential manner; individuals first determine interest in an activity and then, as long as they do not encounter interpersonal constraints such as a lack of recreation companions, they will move towards participation. If a structural constraint is encountered, such as insufficient funds to engage in the activity, they will not participate. However, Mannell and Kleiber (1997) emphasized that “in reality, the different types of constraints often act simultaneously and they likely influence each other in a reciprocal manner” (p. 334). In a revision of their earlier model, Jackson, Crawford, and Godbey (1993) accounted for the roles of motivation in overcoming obstacles to leisure participation. They concluded that “Participation is dependent not on the absence of constraints (although this may be true for some people) but on negotiation through them. Such negotiation may modify rather than foreclose participation” (p. 4).

Building on the work of Crawford et al. (1991), Henderson and Bialeschki (1993) developed an expanded model to reflect the leisure constraints experienced by women. Their model incorporated the concepts of antecedent and intervening constraints. The authors noted

that these two terms were broader than the terms used by Crawford, et al. Henderson and Bialeschki defined antecedent constraints as “conscious and unconscious psychological states and/or sociological conditions that influenced one’s preference or interest in leisure/recreation” (p. 237). Thus, they found that both interpersonal factors and social conditions influenced whether one would even consider participating in a particular kind of leisure. In their model, intervening constraints are defined as interpersonal and structural constraints “which immediately had an impact on decisions made regarding a leisure experience or a recreation activity” (p. 237). Henderson and Bialeschki determined that these different types of constraints were not mutually exclusive; rather, they overlapped, influencing the women’s preferences of, negotiation of, and participation in leisure activities. For example, some of the respondents expressed the belief that women may enjoy leisure traditionally engaged in by men, such as hunting or camping; however, they noted that they would not take part in this kind of leisure due to gender expectations and concern for personal safety given a lack of leisure companions. Additionally, Henderson and Bialeschki found that “an interactive link between preferences and participation was evident in the negotiation process” (p. 236). In other words, the more interested the individual is in the activity, the more likely she is to negotiate the constraints and participate. The authors noted that study participants demonstrated three levels of interest in terms of leisure preferences; these included: no interest, distal or mild interest without significant commitment to begin the activity, and proximate interest with some kind of commitment to participate in the future. The results of their study indicated that, “although not overwhelming from the data, preferences also seemed to influence or justify constraints” (p. 241).

In at least some instances, the presence of constraints may lead to increased negotiation efforts and offset the potential decline in participation. The constraint-effect-mitigation model (Hubbard & Mannell, 2001) hypothesizes that encountering constraints triggers increased efforts to negotiate. This model suggests that such efforts may at least reduce, if not completely counteract, the effects of constraints. The presence of leisure constraints “may set in motion opposing forces, forces that both inhibit and facilitate participation” (p. 149). In this model, motivation has a direct, positive, influence on participation. It also serves as an indirect, positive influence by positively influencing negotiation.

Most research regarding constraints negotiation has focused on nondisabled persons. However, the constraint-effect-mitigation model has been used in studies of nondisabled persons as well as in studies of persons with physical impairments. The model was found to effectively describe how corporate employees negotiated constraints to leisure (Hubbard & Mannell, 2001). Additionally, Loucks-Atkinson and Mannell (2007) found the model to be consistent with how women with fibromyalgia negotiated constraints. This study was an investigation of how the active leisure participation of persons with fibromyalgia is affected by constraints, motivation, and beliefs about participants’ ability to negotiate despite limitations. Encountering constraints led participants to increase negotiation efforts and engage in participation; thus, the negotiation efforts triggered by the presence of constraints eliminated the negative effect of constraints on participation. Further, the belief that one is able to negotiate effectively had a positive influence on motivation and increased negotiation efforts and participation. However, the results suggested that effective negotiation did not significantly reduce the participants’ perception of constraints. This suggests that individuals with disabilities are aware of the presence of

constraints and view them as significant. However, like persons without disabilities, persons with disabilities will put forth the effort to negotiate these constraints when motivated to do so.

Although not typically considered part of the constraints negotiation framework, the theory of substitutability (Hendee & Burdge, 1974) may provide insight into the leisure choices and experiences of persons with disabilities. This theory suggests ways that people address the presence of constraints to participation in leisure they have already decided to engage in. Substitutability describes how recreationists can meet their leisure needs if their preferred activity is not available. Hendee and Burdge defined recreation substitutability as “an interchangeability of activities in satisfying participants’ motives, needs and preferences” (p. 157). Iso-Ahola (1986) proposed a theory of substitutability in which he considered the conditions under which recreationists might resist substitution in their leisure endeavors. Iso-Ahola’s theory “views substitutability as a psychological process...” (p. 367). Like Hendee and Burdge, Iso-Ahola focused on the need to find an alternate activity when the originally intended leisure is no longer available. Brunson and Shelby (1993) modified Hendee and Burdge’s original definition and conceptualized the notion of substitutability as interchange of activities to achieve equivalent outcomes by varying the timing of the experience, the means of gaining access, the leisure setting, and/or the activity. However, Iso-Ahola had cautioned that the theory may not apply to what he referred to as “engagement or resource substitution,” which refers to “a replacement of one time or one site by another time or site without a change in the activity...” (p. 369). He posited that one’s willingness to substitute activities was based primarily on two factors. The first is the individual’s perception and analysis of what caused the need for substitution and why he or she, in particular, needs to make a substitution. The second factor is

the individual's perception and analysis of the psychological qualities of the initially intended leisure and the availability of alternatives that will provide similar outcomes. Iso-Ahola contended that the more freedom the individual feels regarding the need for substitution and the availability of alternatives, the more likely he or she is to be willing to substitute activities.

The concept of substitutability may be particularly useful in considering the leisure choices of persons with disabilities. This is because physical limitations and attitudes towards disability can present constraints to intended leisure, requiring individuals with disabilities to decide if they will pursue other options. As a marginalized group, people with disabilities face some of the constraints and employ negotiation strategies similar to other non-dominant groups. For example, like the inter-racial couples interviewed by Hibbler and Shinew (2002), people with disabilities often find it necessary to call or visit leisure sites first, to determine whether they will be welcome, and many may choose to engage primarily in home-based leisure, to avoid the stares and comments they might encounter in public leisure spaces. Additionally, individuals with disabilities may resist substituting one activity for another if they view their impairment or structural barriers to be unfair.

### **Disability and Constraints Negotiation**

People with disabilities generally face more challenges than those without disabilities in regards to leisure participation (Burns & Graefe, 2007). Given societal perceptions of disability and the reality of impairment-related constraints, individuals with disabilities encounter unique constraints in addition to those common among the general population. Even when the constraint is also faced by nondisabled people, addressing the issue may be more problematic for those with disabilities. For example, many people with physical disabilities take considerably

longer to complete routine daily tasks. Given this, they may have much less discretionary time than their nondisabled peers. Likewise, if an individual with a disability needs transportation to a leisure site, willing neighbors may be unable to help if wheelchair-accessible transportation is required.

The ways in which some persons with disabilities have been socialized may also influence leisure participation. Frequently, children with disabilities are overprotected by parents (Henderson & Bryan, 2004). Thus, they may not explore their environments and learn to take risks like nondisabled children. Children with disabilities may have fewer opportunities to socialize with peers, with or without disabilities (Zoerink, 1988). As a result, in their adulthood, these persons may have less knowledge of leisure resources and may be more reluctant to try some forms of leisure. Given their early experiences, they may harbor perceptions of inability or concerns about safety, or, as Mannell and Kleiber (1997) pointed out, learned helplessness may preclude participation.

There are other ways in which the attitudes and perceptions of a person with a disability may create stress and constrain leisure. For example, in Guthrie's (1999) examination of physical activity among women with physical disabilities, some participants with acquired disabilities did not play sports they once enjoyed because such activity was a painful reminder of what they had lost due to illness or injury. Persons coping with SCI find it difficult to depend on others and avoided asking caregivers for assistance with leisure pursuits (Kleiber et al., 2002). Individuals may believe they are not deserving of leisure, especially if they are unemployed, not unlike women whose leisure is constrained by an *ethic of care* (Shaw, 1994). Further, as stated earlier, participants in Kleiber et al.'s study commented that even when they returned to familiar

leisure, they did not enjoy it as much due to the inability to participate as fully as they did prior to their disability. Essentially, they reported that they now work harder at leisure and get less pleasure from it. This is similar to what studies of women's leisure have shown: those who are responsible for planning leisure events tend to view them as requiring more work (Iwasaki & Mactavish, 2005). For people with physical disabilities, leisure is almost always more work; this reality may diminish the benefits of participation (Hutchinson et al., 2003).

The attitudes of others also affect the leisure participation of individuals with disabilities. In an investigation of barriers to and facilitators of active leisure by individuals with disabilities, Rimmer et al. (2004) found "the most frequently cited reason for the reluctance of persons with disabilities to use fitness and recreation facilities was the perception that these facilities are unfriendly environments" (p. 423). Individuals with disabilities and program managers who took part in the study reported negative attitudes and behaviors on the part of nondisabled recreationists and staff as a significant barrier to participation. Mannell and Kleiber (1997) noted that these kinds of structural constraints can eventually be internalized, resulting in people with disabilities "beginning to believe it is they who are 'limited' and not the environment" (p. 333).

While constraints do not always result in nonparticipation, they can influence the leisure experience for persons with disabilities. For example, when people with disabilities are granted free admittance into leisure spaces because of disability or when they are denied access to certain equipment or aspects of leisure programming (such as rides at an amusement park), this differential treatment serves to emphasize how they are different from rather than similar to other recreationists (Dattilo, 2002). Even the anticipation of interpersonal or structural constraints may decrease interest in participation and create an intrapersonal constraint (Jackson et al., 1992). In

other words, the thought that others may not be accepting or that there may be architectural barriers may lead individuals with disabilities to avoid some leisure sites (Rimmer et al., 2004). Similarly, recreation professionals have confirmed that their programming is often not inclusive of the needs and interests of other marginalized groups such as racial and ethnic minorities (Allison & Hibbler, 2004); this suggests that discomfort in professional leisure settings may be compounded for persons with disabilities who are also members of racial or ethnic minority groups.

Overall, research in the area of leisure coping confirms the mental and physical health benefits of engaging in leisure pursuits. It also indicates that leisure outlets offer opportunities to develop social support and that people with disabilities experience more challenges when engaging in leisure. They may participate in leisure less often and have less positive attitudes about leisure than nondisabled persons (Zoerink, 1988). Research about coping and constraints negotiation provides insight into the difficulty employees with disabilities may have in being included in the social/leisure-oriented happenings in workplace communities. Further, given their impairment-related constraints and perceptions of leisure sites as unwelcoming, employed people with disabilities may have a particularly difficult time finding outlets that help them to maintain a sense of work-life balance during non-work time.

### **Employment and Disability**

In a study of the origin of negative attitudes towards persons with disabilities, Katz, Hass, and Bailey (1988) determined that the sentiments of many nondisabled people towards those with disabilities tend to be ambivalent. Additionally, positive and negative attitudes toward persons with disabilities tend to be “rooted to some extent in two general value orientations,

individualism of the Protestant ethic and humanitarianism...” (p. 57). This ambivalence is reflected in how people with disabilities have been viewed in terms of employment over the years. As noted by Abberley (1987), the effects of disability “are only ever apparent in a real social and historical context” (p. 12). Certainly, the employment experiences of persons with disabilities have been shaped by the political and social climate of the country at various points in time.

Prior to the Protestant Reformation, leisure was “the only life fit for a human being” (Sylvester, 1999, p. 26). However, as a result of the Protestant Reformation, work took on a religious significance and became a central focus. It was commonly believed that all people who were able to work should do so. As of the 20<sup>th</sup> century, work was not done for religious reward but rather as a means of acquiring improved social and economic resources (Sylvester).

Despite the emphasis on employment and productivity, people with disabilities, thought by society to be frail, weak, and unable, have been largely excluded. Notably, attempts were made to put disabled people to work during the rehabilitation movement, which Byrom (2001) referred to as “a bridge spanning the gap between nineteenth-century supernatural and post-1920 medical explanations of disability” (p. 133). The reformers involved in this movement viewed what they referred to as “crippledom” as a “serious social and economic problem” (p. 133). Some people involved in the movement were medical rehabilitationists who emphasized the need for disability correction or cure. Others focused on the need to change societal attitudes about persons with disabilities. A common belief within these two factions of rehabilitationists was that “employment provided the best solution to the problem of disability...the greatest problem facing the cripple was rejection from the workplace” (p. 135).

During the early 1900's, organizations such as the Institute for the Crippled and Disabled, a program of the Red Cross, provided employment services for persons with physical disabilities. The participants were trained to enter mainstream employment. However, the Institute's establishment of a sheltered workshop in 1927, originally intended as a transition from being homebound to entering the labor market, "served as a symbol of the cripple's inferior status in the job market" (Byrom, 2001, p. 145). By 1920, orthopedic surgeons were highly regarded professionals, and the medical model became the prominent explanation of disability (Kaplan, 2006). Social explanations, such as lack of employment, were all but forgotten for the next 50 years, according to Byrom. Although the number of sheltered workshops has decreased since the deinstitutionalization of the 1970's and 80's, they can still be found in several states.

Typically, when people with disabilities were given opportunities for employment it was in order to meet the needs of a community or larger society. For example, during the colonial period, a person with a disability might earn his or her keep through indentured servitude, and if he or she had no means of income, public assistance was available only after relinquishing all belongings (Henderson & Bryan, 2004). Federal vocational rehabilitation programs were established during World War I, initially to put newly disabled veterans to work meeting the needs generated by the War. Similarly, according to Linton (1998), record numbers of women and people with disabilities were employed during World War II because so many nondisabled males were serving in the military; however, when the war ended, both groups returned to their previous low levels of employment and limited work opportunities.

As it relates to people with disabilities in the workplace, one significant issue is America's changing views about independence throughout history. Linton (1998) pointed out

that “America’s glorification of independence has not served disabled people well” (p. 48). She noted that as individual worth began to be defined by financial and social independence, those with disabilities and others not in the dominant culture were seriously disadvantaged and viewed even more negatively. Despite the establishment of vocational rehabilitation programs and other legislation designed to provide greater opportunity for individuals with disabilities, the general perception of disability and the resultant lack of provisions such as physical accessibility and reliable transportation have left the vast majority of persons with disabilities out of the workforce. The most notable efforts to improve the situation began just a few decades ago with the passage of some key legislation.

### **Key Disability-related Employment Legislation**

Vash and Crewe (2004) noted that the problems experienced by all groups that are now protected by civil rights legislation were “historically viewed as natural outcomes of the characteristics and limitations of those people” and such personal limitations were “even more readily ‘apparent’ to the public” regarding persons with disabilities (p. 171). Consequently, early legislation focused on benefit programs not employment; “laws protecting disabled people’s rights to equal opportunity for employment are among the statutory latecomers” (p. 171). In fact, until the Rehabilitation Act of 1973, employers could legally discriminate against qualified job applicants with disabilities based solely on the fact that they were disabled (Jenkins, Patterson, & Szymanski, 1998).

Henderson and Bryan (2004) asserted that the enactment of Section 504 of the Rehabilitation Act signaled Congress’ realization that the inferior social and economic status of persons with disabilities was exclusively or even primarily due to disability. Rather, “...it was a

manifestation of societal barriers and prejudices” (p. 124) Section 504 offers limited civil rights by protecting qualified individuals with disabilities from exclusion from participation in any program or activity which receives federal funding. Despite its potential for bettering the lives of disabled people by improving physical accessibility, transportation resources, and employment opportunities, this legislation was not officially enacted until 1977. Final approval of the Act came only after a more than month-long demonstration by individuals involved in the disability rights movement. This effort marked the first time people with various disabilities came together and advocated for themselves. Prior to this event, most advocacy efforts were made by parents and professionals on behalf of persons with disabilities. Additionally, up until this time, the various disability-specific organizations each represented their own individual interests, as opposed to working together for the good of the disability community at large (Henderson & Bryan; Shapiro, 1993; Vash & Crewe, 2004).

While the Rehabilitation Act is significant in the employment history of people with disabilities, it was the Americans with Disabilities Act (ADA), signed into law in 1990, that provided the first true promise of civil rights for people with disabilities. Like civil rights legislation for women and racial minorities before it, the ADA has not resulted in as much improvement in the lives of people with disabilities as hoped. According to Krepcio and Cooper (2008), over the last 30 years, “the rates of employment for people with disabilities in the United States have not improved and remain unacceptably low” (p. 3). Despite the passage of the ADA, “many people with disabilities continue to endure economic deprivation and social marginalization” (Longmore, 2003, p. 19).

### **Current Status of Employment among People with Disabilities**

According to the 2008 Disability Status Report produced by Cornell University in conjunction with the American Association of People with Disabilities, the employment rate of people with disabilities is 39.9% compared to a rate of 77.8% among nondisabled persons; these rates have remained virtually unchanged for three decades (Erickson, Lee, & von Schrader, 2010). Further, despite more than 30 years of concerted effort on the part of the disability community to improve these rates, “only in the past 20 years has there been a more formal expectation that people with disabilities should, can, and want to work,” and attitudes about the competence of persons with disabilities to be productive workers continue to create barriers to their employment (Krepcio & Cooper, 2008, p. 3). Although approximately 70% of working-aged people with disabilities report that they would like to be employed, health concerns and the inability to find work that will accommodate the disability are the primary barriers to employment. Of those polled, the majority of individuals who indicated that they wanted to work but could not were persons who required personal assistance due to physical or mental disability (Harris Interactive, 2004).

These statistics reflect the disability community as a whole, including persons with mental, physical and/or learning and sensory impairments. With approximately three million wheelchair users and more than 10 million people who require assistance with activities of daily living (U.S. Census Bureau, 2002), people with physical impairments make up a significant portion of the more than 50 million persons with disabilities in the United States. A 2006 survey conducted at the University of Illinois indicated that for people with significant physical disabilities, the rates of employment may be much higher than the Harris Poll indicates (Collins, Hedrick, & Stumbo, 2007). The Collins et al. study examined the employment outcomes of University alumnae with severe physical disabilities. The success of the more than 70% of the

employed participants was attributed to the *Illinois Model*, which provides considerable personal assistance and self-advocacy training to these former students. While this is promising, most people with disabilities do not have the same opportunities to develop these critical life skills. The program is an example of what has typically been supported by public policy regarding employment of persons with disabilities. Specifically, the emphasis has been on better informing and preparing people with disabilities for work. Only recently has interest grown in looking at the understanding the needs and issues of the employer (Krepcio & Cooper, 2008).

Still, the onus is on persons with disabilities to prepare and change. For example, according to a survey of employers conducted by Dixon, Kruse, and Van Horn (2003), only 40% of employers offered training of any kind to their employees regarding working with or providing accommodations for individuals with disabilities. This figure includes smaller companies of 5-24 employees, which constitute the vast majority of employers in the U.S. Of these smaller companies, less than 35% offered any type of training related to employing and working with persons with disabilities.

What is it like for individuals who are in workplaces where they are likely to be the only person with a disability? What, if any, effect does disability have on their social lives, both on and off the job? How does the job of managing disability impact the non-work domains of their lives? Balancing work, other responsibilities, and leisure is a challenge for most employed people. The presence of physical disability adds to the demands these workers juggle as they, like their nondisabled coworkers, seek to live balanced and fulfilling lives.

### **Work-life Balance (WLB)**

The dilemma of maintaining work-life balance (WLB) is most often examined in terms of juggling work and family responsibilities (MacInnes, 2005). Although some work-life research has focused on both parents (Hill, Martinson, & Ferris, 2004), the majority has emphasized the challenges faced by mothers (Hill, 2005). Medved (2004) studied how couples balance family responsibilities in terms of daily routines and found that mothers were expected not only to do their share of childcare but also to be responsible for such tasks as regular meal preparation. Additionally, the bulk of household responsibilities, including childcare, continued to be performed by mothers (Guendouzi, 2006). This research offers information that could provide insight into how people with disabilities manage WLB because regardless of their parental status, these individuals always have their disability to care for, manage, or consider when making decisions regarding work and leisure time. These decisions often require managing limited resources of time, energy, and money, which are common concerns of working parents, especially mothers.

Some working mothers choose part-time employment in an effort to better manage work-life demands. In a study of the impact of financial concerns on WLB, Warren (2004) examined how part-time employment affected work/family balance of working mothers. Job satisfaction was reportedly similar among participants who worked part-time and full-time. Part-timers were satisfied with their work hours, but less satisfied with their social lives, and mothers whose work involved part-time manual jobs had considerably fewer financial resources.

For single mothers who are the sole provider and caregiver, resource concerns can be even greater. In a qualitative, longitudinal study, Spencer-Dawe (1999) examined the strain

experienced by single, working mothers. She found that the women feared not only financial loss, but also were concerned with the loss of work time and workplace credibility when family was the priority. This strain made it harder for them to communicate their needs to supervisors, which resulted in their being called in to cover during staff shortages and the expectation that they would take work home. As a result, the time that they expected to have with family was spent working.

Research on persons in professions that serve people with disabilities and studies about the needs of family caregivers has also provided insight into issues of work-life balance. For example, Layne, Hohenshil, and Singh (2004) investigated the intentions of rehabilitation counselors who were considering leaving the field, and Skirrow and Hatton (2007) conducted a meta-analysis of studies that examined burn-out among direct care workers. The human service employees in both of these studies routinely provided assistance to persons with disabilities. Parents are often critical helpers in the lives of individuals with disabilities, too. The physical and emotional stress experienced by employed parents of children with disabilities has also been studied (Kagan, Lewis, Heaton, & Cranshaw, 1999; Olsson & Hwang, 2006). While attention has been given to the coping strategies used by parents of and professionals who serve persons with disabilities, the ways in which employed people with physical disabilities negotiate the physical and emotional demands of the workplace have gone largely unexamined.

In their investigation of the importance of friendship in the work lives of middle managers, Parris, Vickers, and Wilkes (2008) noted that speaking of balance with the implication that equal weight is given to work and non-work activities “may be something of a misnomer” (p. 406). They stated a preference for the term “work personal life integration” (from Lewis et

al., 2003) because this term recognizes “how different areas of life necessarily interact with, and impact on each other” (p. 406) and “implies recognition of the whole person...” (p. 407). Parris et al. contended that friendships are a good example of the connectedness between different life domains. They emphasized that through the provision of emotional and practical support (such as assistance with childcare) friends can be a resource in achieving and continuing work personal life integration.

Bird (2006) proposed a more comprehensive definition of work-life balance, which, like work personal life integration, extends beyond work and family obligations. Bird’s definition considered relationships with friends and with one’s self, in terms of self-care. His definition of WLB emphasized feelings of achievement and joy rather than time. In his perception of balance, the individual experiences a sense of joy and achievement on a regular basis in the areas of work, family, friendships, and self-care. This way of viewing the work-life concept seems to depict a fuller life than one that focuses solely on time spent with work and family obligations. Further, the consideration of friendships and self-care indicates the value of leisure in creating and maintaining balance.

### **Work-Leisure Relationship**

Zuzanek and Mannell (1983) noted that several different approaches have been used to study the relationship between work and leisure. One approach has been to utilize a statistical and time-budget perspective that “examines the changing allocations of time between work and leisure” based on government statistics and time-diary studies (p. 327). The work-leisure relationship has also been investigated from a socio-economic perspective that assumes “...the relationship between work and leisure always involves a conscious or implicit trade-off between

forgone earnings (income) and the desire for more free time” (p. 328). A third approach noted by the authors is examination of the work-leisure relationship from a socio-organizational and planning perspective, which includes the study of such things as workers’ attitudes towards flextime and the impact of shift work on leisure participation. Another approach has involved studying the work-leisure relationship from a social and socio-historical context that focuses on “changing value orientations, rather than the changing allocations of time” and includes studies such as those designed to attempt to measure changes in the work ethic of different social groups (p. 328).

A fifth approach noted by Zuzanek and Mannell (1983) is the consideration of “the effects of work on leisure cross-sectionally within the framework of socio-occupational status.” (p. 329). Studies utilizing this approach do not focus on the effects of one’s particular occupation on leisure involvement, “but rather on the leisure style attributes connected with belonging to the blue collar social stratum” (p. 329). The authors pointed out that this cross-sectional approach differs from the ways that the work-leisure relationship has been examined, as most investigations have been done from the perspective of social change, and therefore, have been longitudinal in nature.

Another approach described by Zuzanek and Mannell (1983) is the examination of the direct effects of work, its structure, and organizational characteristics on the experience of leisure. This is the approach used in studies investigating what effect the nature of work has on nature of leisure behavior and how one experiences leisure. Lastly, socio-psychological studies represent another way in which the work-leisure relationship has been investigated. In this approach, “... the focus is on the effects of work-related attitudes on leisure participation and

leisure-related attitudes and perceptions rather than on the effects of the structural characteristics of the work situation on leisure behavior” (p. 329). Research regarding the possibility of spillover, compensation, or neutrality between work and leisure has been conducted within these latter two frameworks. These studies have sought to determine if attitudes and interests from one’s work extend into the leisure domain, resulting in leisure choices that are similar to or different from one’s work, or whether work appears to have no influence on what one does in his or her leisure time.

Zuzanek and Mannell (1983) pointed out some changes in how that research regarding the work-leisure relationship has been approached in recent years. Specifically, they noted that researchers have acknowledged the “possibility of multidimensional and/or reciprocal work-leisure relationships” (p. 339). Additionally, there has been “an attempt to use the work-leisure relationship as an independent variable, or an active personality characteristic, to explain how activities and satisfaction with life are structured by individual differences in personal orientations to work and leisure rather than solely by the constraints of the work situation” (p. 339). These ways of approaching the study of the work-leisure dynamic highlight the significance of both work and leisure as important to overall quality of life. Further, these perspectives consider the possibility of leisure influencing the work domain as well as work influencing the leisure domain.

Although leisure is often defined as “time left over from work,” researchers have begun to recognize that different people (i.e., women, unemployed persons, and retirees) may define and experience leisure differently (Haworth & Lewis, 2005, p. 69). Additionally, scholars such as Samdahl (1992) have noted that informal social interaction is a common form of leisure

context. Many of these social interactions take place in work settings where most people spend a considerable amount of time each week.

It has been argued that there may be significant overlap between what individuals gain from work and leisure. For example, Kelly and Kelly (1994) noted that “rather than an either/or scheme, individuals may view life more in terms of shifting ‘balance’ of the elements” (p. 259). Further, they cautioned that the experience of the full dimensions of all domains of life are not guaranteed and that “differential opportunities and invidious social definitions make factors such as gender, race, and class indices of limited life conditions in modern social systems” (p. 258 ). People with disabilities can be added to this list.

Persons with physical impairments who have made their way into the mainstream workforce need leisure just as do their nondisabled peers. However, the social bonding that is central to job satisfaction (Grey & Sturdy, 2007) and that can lead to friendships that continue outside of work (Klein & D’Aunno, 1986) may be less available to workers with disabilities. This may be due to physical inaccessibility within workspaces, attitudinal barriers on the part of coworkers, poor self-perception on the part of the person with the disability, or the real or perceived pressure to continually have to prove one’s value as an employee. As indicated by a participant in Randolph’s (2005) study of working women with physical disabilities, “You have to prove to the organization that you are capable and have the skills, but I think a disabled person has to work harder...They have to prove that their disability is not in any way, shape or form affecting their ability” (p. 373). All of these factors can influence how individuals with disabilities are viewed in the workplace, the level to which they are included or choose to

participate in the social/leisure aspects of work, and whether or not they are seen as more than colleagues by their nondisabled coworkers.

### **Workplace Social Inclusion**

“The workplace is one of the major sources of stress in the lives of Americans” (Sagrestano, 2004, p. 124). Members of marginalized groups such as racial minorities and people with disabilities experience unique work-related stressors (Gant et al. 1993; Gignac, Sutton, & Bradley, 2007). Social support has been found to be an effective buffer against stress, especially when the interaction is not directly linked to the completion of work tasks but is social and freely chosen (Coleman & Iso-Ahola, 1993), such as during the leisure-oriented happenings that occur in workplace communities. Sagrestano noted that work-related stress not only causes physical health problems, but also affects the health habits of workers who, due to stress, may smoke, drink, use drugs, fail to get adequate nutrition, or have difficulty sleeping. She noted that these potential health consequences can directly affect job performance and workplace relationships.

Within the workplace, the terms inclusion and diversity are often used interchangeably. However, as Bormann and Woods (1999) aptly noted, they are not the same. Diversity refers to the “spectrum of human similarities and differences” within an organization. Inclusion, on the other hand, “describes the way an organization configures opportunity, interaction, communication, information and decision-making to utilize the potential of diversity” (p. 4). Thus, the authors pointed out, it is possible for an organization to be diverse yet not inclusive.

Mor Barak (2000) asserted that research on diversity management suggests the “need to focus on the notion of inclusion vs. exclusion” (p. 48). He further explained that inclusion refers

to the degree to which individuals feel part of the organization in terms of formal processes (such as access to decision makers) and “informal processes such as ‘water cooler’ and lunch meetings where informal information and decisions take place” (p. 52). In other words, an inclusive workplace is one in which all employees are included not only in the formal systems of information sharing but also take part in the information exchange through the less formal happenings at work.

In order for there to be inclusion, there must first be diversity: people of various backgrounds and ability levels must be brought into the work setting. Historically, there has been resistance to the presence of persons with disabilities and other marginalized groups in many organizations. Thomas, Mack, and Montagiani (2004) identified several major arguments against workplace diversity, all of which relate to the belief that the costs of diversity initiatives exceed the benefits of such programs. The first argument is that diversity impairs organizational effectiveness; this includes the “belief that diversity, especially due to race, will create negative interpersonal dynamics among workers and thus threaten their productivity, or that workers of color themselves lack the ability to contribute meaningfully to workplace productivity” (p. 32). Further, in companies that consider employees of color to have “niche knowledge” that may allow them to reach out to new customer markets, there is the possibility of “alienation, exploitation, and possibly ‘ghettoization’ that may promote higher turnover” (p. 33). While the authors studied the ways in which these practices affected racial and ethnic minorities, it is clear that these same potential consequences are relevant when considering the workplace inclusion of employees with disabilities (Riley, 2006).

Another anti-diversity argument that centers on people with disabilities is that workers with disabilities increase employer costs. This argument is based on a number of common assumptions, such as the belief that people with disabilities are more prone to workplace accidents and absenteeism and so will increase the company's healthcare costs, or will require costly workplace modifications (Henderson & Bryan, 2004; Thomas et al., 2004). Henderson and Bryan noted additional myths about workers with disabilities. One is the assumption that people with disabilities cannot meet expected productivity levels, resulting in coworkers needing to do more work. Further, they noted that it is a myth that people with disabilities will not be accepted by coworkers and that disability-related accommodations such as accessible parking will be resented by persons without disabilities. Interestingly, the authors provided no evidence to refute this last point. Rather, they surmised that it is the lack of exposure to people with disabilities that results in nondisabled persons assuming that individuals with disabilities will not be accepted. However, existing literature (e.g., Dattilo, 2002) indicates that while potentially beneficial, exposure alone does not guarantee acceptance, much less inclusion.

Finally, an anti-diversity argument that relates to persons with disabilities and to people of color is that "diversity is just the politically correct term for affirmative action" (Thomas et al., 2004, p. 43). This argument is based on the common misperception that affirmative action mandates the hiring of unqualified members of underrepresented groups based solely on their minority group status. This argument against inclusion highlights the likelihood that persons with disabilities who are also members of racial minority groups may face particular challenges in the workplace. When practices to promote equality are viewed as unfair, it is difficult to bring about the kind of change needed to create truly healthy and inclusive work environments. Such

actions may serve to diversify the workforce, but they cannot make coworkers befriend one another.

Participants in Parris et al.'s (2008) study of the value of friendship in manager's efforts towards work-life balance stressed that these relationships were significant in both their work and personal lives. They expressed sadness and anger that the quantity and quality of time spent with friends decreased as their workloads increased. Some respondents reported that it was difficult to make friends at work due to their management positions. Therefore, they relied on friends outside of work to act as sounding boards and for companionship during leisure time. The authors suggested that one way in which organizations might assist middle managers is through developing informal support networks within workplace communities.

### **Leisure and Friendship in the Workplace**

Erickson and Lee (2008) described employment as a "key factor in the social integration...of working-age people with disabilities" (p. 1), and Ward and Baker (2005) asserted that, "For people with one or more disabilities, the opportunity to work is often an important element for their development and maintenance of social relationships" (p. 144). However, given that workplaces are microcosms of society and, thus, contain the same attitudes and other barriers, workers with physical disabilities may not be fully included in the more social or leisure-oriented happenings within workspaces. This potentially affects not only job satisfaction, but also life satisfaction, as friendship is "one of the commonest kinds of organizational experience" (Grey & Sturdy, 2007, p. 157).

Randel and Ranft (2008) defined workplace social inclusion as "the extent to which employees have informal social ties with coworkers and feel as if they belong and are socially

included by others in the workplace” (p. 213). They pointed out that this concept differs from social capital in that social capital represents “a resource available as a result of social ties and workplace social inclusion represents an individual’s perceptions of his or her belongingness because of social ties in the workplace” (p. 213). Further, the authors noted that social inclusion provides a worker a level of comfort in using the social resources he or she has available, whereas an individual who is not socially included might resist or be uncomfortable requesting help from others to gain needed resources at work. Stodolska, Marcinkowski, and Yi-Kook (2007) demonstrated that leisure time associations with mainstream coworkers can also be economically beneficial. In their study of enclosed leisure among Korean immigrants, the authors found that those who socialized with non-Koreans in their leisure time and those who engaged in leisure with mainstream coworkers, earned higher incomes than those who did not.

In developing a model of factors affecting the treatment of individuals with disabilities in the workplace, Stone and Colella (1996) posited that the expectations and affective states of nondisabled coworkers are important determinants of how workers with disabilities are treated. They noted that the issue of treatment in the workplace is not limited to such things as job assignments and pay increases, but also includes the social dimensions of work. For example, workers with disabilities may have less opportunity to provide or receive mentoring, may be less likely to be included in information sharing, and may be excluded from social activities.

### **More than Colleagues**

Task-specific interactions on the job are considered to be work, but informal social interactions tend to be viewed as leisure (Samdahl, 1992). By framing leisure in the context of

non-task-oriented social engagement, it becomes apparent that leisure occurs in workplaces. This happens when individuals choose to interact with one another as friends.

Workplace friendships are unique relationships. First, they are voluntary because coworkers are free to choose whom they befriend. Although, as noted by Grey and Sturdy (2007), “there is a social patterning in friendship, so that it is not a *pure* expression of individual choice but is rather conditioned through patterns of class, culture, locality, and so on, and in organizations by shared experiences and interests” (p. 158). Secondly, they “have a ‘personalistic focus’ in which individuals come to know and treat each other as whole persons, rather than simply workplace role occupants” (Sias, Heath, Perry, Silva & Fix, 2004, p. 322).

Klein and D’Aunno (1986) identified “the friendship network” as one of the most significant referents for the psychological sense of community within work settings. They noted that members of such social networks need not actually work together on shared tasks, such as in work teams. However, they are friends who socialize inside and outside of the workplace. Acceptance into these friendship circles may be more difficult for workers with physical disabilities, given real and perceived differences from their colleagues. While people with physical disabilities may have much in common with their coworkers in terms of preparation for and performance of job tasks, their social opportunities might be quite different. Further, the day-to-day concerns of these workers are often compounded by needs related to self-care in addition to other non-work obligations.

In one of few studies that have considered how people with disabilities are perceived in terms of meeting interpersonal expectations at work, McKittrick (1980) examined the social aspects of work adjustment for people with obvious physical impairments. She found that

nondisabled persons were much more likely to view their colleagues with disabilities as coworkers than as friends. This was despite their having the same job functions and training. The results of the study suggest that workers with physical disabilities have the technical or hard skills for the job, but may be perceived to lack the soft skills needed for coworker engagement beyond that involved in completing tasks. Workers with disabilities were viewed more favorably in situations that were task-oriented and less favorably in situations in which roles were less clear and the interactions more ambiguous.

Devine (2004) pointed out that “findings from [McKittrick’s] study suggest that leisure situations reflect the larger social structure as it relates to disability in that disability appears to have a more negative meaning in less structured (i.e., leisure) contexts...” (p. 142). Devine advised that social acceptance precedes inclusion and is the foundation for the development of friendships. Further, she asserted, “the role leisure contexts play in determining social acceptance [of individuals with disabilities] remains unknown” (p. 142).

In a more recent study of social perception of people with physical disability, Castaneto and Willemsen (2006) demonstrated that nondisabled “participants believed that others view people with disabilities less positively than they themselves do” (p. 1217). The authors posited that participants who rated themselves as more accepting of persons with disabilities than their peers may have “projected their own ableistic biases towards the disabled in the perceived others ratings” (p. 1229). In other words, the participants’ tendencies to believe their peers would be less accepting of the subject with a disability may reflect their own ableistic views about persons with disabilities. The authors noted that this kind of prejudice is found in statements about people with disabilities having an unfair advantage or hiding behind one’s disability. The beliefs

reflected in these types of comments are the kinds of beliefs that could dissuade social engagement among workers with disabilities and their nondisabled colleagues on and off the job.

Research has shown that “discretionary forms of social contact (i.e., leisure-related social contacts) buffered stress, whereas obligatory contacts at work and school did not” (Coleman & Iso-Ahola, 1993, p. 117). Thus, when coworkers relate to one another as friends, the relationship is more apt to serve as a buffer to stress than a typical workplace relationship. The social, leisure-oriented activities in work settings are a vehicle for establishing these friendships. While workplace leisure is rarely examined, its presence has been noted in studies of organizational life. For example, Grey and Sturdy (2007) referred to Roberts’ 1991 work in which he noted that the “unsurveilled spaces of organizations” are where the relationships and social bonds of workplaces are formed. According to Roberts, social exchanges take place in corridors and restrooms, before and after meetings, and during lunch breaks and employee outings.

D’Abate (2005) investigated these non-work encounters in an effort to understand how leisure and non-work activities done in the workplace, at times other than breaks or lunch, contribute to efforts towards WLB. Some of the leisure-oriented activities participants reported included office betting pools and social conversations with coworkers. Social conversations--about sports, family, dating, television, and other topics--were reported by 67% of those interviewed. These water cooler conversations are an important part of life in workspaces and help to develop a kind of community in these settings. Further, these activities can lead to coworkers choosing to spend time together outside of the workplace and sharing leisure experiences.

## Summary

The literature on work-life balance as it relates to persons with physical disabilities is sparse. However, these workers have unique disability-related concerns in addition to the usual demands of work and family. There is also a paucity of research on the social/leisure-oriented happenings within workplace communities. Nevertheless, both scholars (Clark, 2000; Parris et al., 2008) and practitioners (Bird, 2006) have suggested that interpersonal relationships are essential to achieving a sense of balance between the multiple domains of one's life, including self-care and friendships. Finding time for friends and leisure outside of work can be a challenge. However, coworkers are a potential source of leisure companionship and support on and off the job. Additionally, individuals who feel welcome and who are viewed as central members in their workplaces may find it easier to achieve and maintain a sense of balance between the work and non-work spheres. Further investigation of how leisure and friendships within workplace communities contribute to the work-life balance of persons with and without disabilities is warranted. It is particularly important to study the work lives of individuals with disabilities, as they encounter additional obstacles due to the attitudinal and architectural barriers they face in their everyday lives.

## CHAPTER 3

### METHODS

My goal in this project was to gain insight into the work-life balance (WLB) of persons with physical disabilities. I approached the topic from a relational perspective in that the theoretical framework of work/family border theory and the broad definition of WLB used in this study both emphasize relationships (with one's job, self, and others). Further, both the theory and definition consider how these relationships influence one's sense of balance. Consequently, my research questions also emphasized relationships, as well as the impact of disability on these relationships and work-life experiences. I used workplace leisure as one context for exploring these issues because of the potential for coworkers to become leisure companions and because leisure on and off the job may aid in coping with disability and achievement of WLB.

Although there are certainly commonalities among persons with disabilities, I view the experience of disability as unique to each individual. I also believe that the ways in which disability is experienced are largely determined by societal factors. Therefore, my approach to this study was guided by the theoretical concepts of social constructionism and symbolic interactionism. These methodological perspectives will be detailed further in this chapter. Additionally, I will demonstrate the relevance of these approaches to this study and the usefulness of qualitative methods in addressing the primary research questions. Further, I will discuss the research questions and elaborate on my role as the researcher.

Standpoint perspective also influenced my work. Although it is not my intent to make a strong political statement about the power inequities between those with disabilities and the able-

bodied majority, as a person with a physical disability I recognize that the reality of the lived experience is a legitimate source of knowledge for questioning societal beliefs about disability. I do hope to increase awareness about what it means, or *can* mean, to be an employed person with a physical disability, through this research project.

### **Research Questions**

I sought to address the following questions through this study:

- What is the significance of leisure and work in the lives of the participants?
- How does the presence of disability influence the leisure and work lives of the participants?
- What beliefs, strategies, and relationships contribute to the QOL and work-life balance of participants?

Table 1 reflects the specific interview questions used to explore these issues.

### **Methodological Approaches**

#### **Qualitative Inquiry**

Taylor and Bogdan (1998) stated, “the phrase *qualitative methodology* refers in the broadest sense to research that produces descriptive data- people’s own written or spoken words and observable behaviors” (p. 7). Creswell (2007) asserted that the issues that qualitative researchers study are “emotion laden, close to people and practical” (p. 43). These authors noted several characteristics of qualitative inquiry which indicate its value in the examination of the lived experiences of members of marginalized groups, such as individuals with physical disabilities.

Table 1

*Research Questions and Interview Questions*

Research Questions	Interview Questions
What is the significance of work and leisure in the lives of the participants?	<p>How important is work in your life? Why?</p> <p>Tell me about the nature of your work</p> <p>If you were to prioritize the major domains of your life (e.g., work, self-care, family, etc.) what would these be in order of importance?</p> <p>What comes to mind when you think of the concept of “leisure”?</p>
How does the presence of disability influence the leisure and work lives of the participants?	<p>How important is leisure to you? Why?</p> <p>Tell me about your leisure/social life growing up. Is it different now-how? Why do you think this is?</p> <p>Describe your typical day (morning routine through bedtime)</p> <p>In what ways, if any, does self-care influence your work and leisure decisions?</p> <p>Do you think environmental factors, others’ attitudes, and/or your physical condition influence your work and leisure experiences? If so, how?</p> <p>What kinds of things do you find challenging in your everyday life? How do you deal with these concerns?</p> <p>How does the presence of Personal Assistance influence your work and leisure experiences?</p>
What beliefs, strategies, and relationships contribute to the QOL and work-life balance of participants?	<p>Describe the social climate of your workplace community</p> <p>Do you feel connected to or included in your workplace community? Why/Why Not?</p> <p>Can you recall a time when you had fun at work? What were you doing, with whom, whose idea was it?</p> <p>Describe your ideal workplace</p> <p>Tell me about your leisure/social life growing up. Is it different now-how? Why do you think this is?</p> <p>Do you engage in leisure with coworkers outside of the office? How often, who initiates, what kinds of things do you do together?</p> <p>How do you learn about coworkers’ personal lives/leisure interests?</p> <p>Do you share your personal life/leisure interests with your coworkers? How?</p> <p>If you had some downtime at work, how would you spend it? With whom?</p> <p>Are there things you do to maintain a sense of balance between work and the rest of your life? – Describe</p> <p>Are there people in your life who help you maintain a sense of “balance”? Who are they and how do they help?</p>

Taylor and Bogdan (1998) explained that the qualitative researcher focuses on “understanding people from their own frames of reference and experiencing reality as they experience it” (p. 7). Additionally, in qualitative inquiry the researcher considers participants’ pasts as well as their current situations. Further, qualitative researchers are concerned about the thoughts and behaviors of participants’ everyday lives. While all of these characteristics indicate the appropriateness of qualitative approaches to the study of issues related to persons with physical impairments, perhaps the characteristic that is most significant is that qualitative research views “all perspectives as worthy of study” (p. 9). Taylor and Bogdan asserted that one of the primary objectives of qualitative inquiry is to study things from a variety of perspectives and to consider them all equally valuable. They advised that “In qualitative studies, those whom society ignores—the poor and the deviant—often receive a forum for their views” (p. 9).

Creswell (2007) pointed out that the definition of qualitative inquiry has changed over time. In explaining how qualitative work is typically described, he mentioned many of the same characteristics as Taylor and Bogdan (1998). For example, Creswell noted the importance of understanding participants’ perspectives, examining their experiences within a social and historical context, and focusing on everyday life. Further, he emphasized that the final report of qualitative research “includes the voices of participants, the reflexivity of the researcher, and a complex description and interpretation of the problem, and it extends the literature or signals a call for action” (p. 37). Creswell advised that by developing a large and complex picture of the issue, the researcher avoids the likelihood of being bound by “tight cause-and-effect relationships among factors” (p. 39). It is incumbent upon the researcher to point out the complex interaction between the many factors in any situation. I believe the issues highlighted

in this project demonstrate the complexity and diversity of experience among persons with disabilities.

Other significant features of qualitative inquiry noted by Taylor and Bogdan (1998) and Creswell (2007) are that the researcher is the primary instrument for data collection and interpretation, the researcher often relies on multiple sources of data, and data is analyzed through an inductive process that results in the identification of themes. When interpreting data, “the researchers’ interpretations cannot be separated from their own background, history, context and prior understanding” (Creswell, 2007, p. 39). In other words, there is no way that I could have presented the results of this study in the way I did were it not for the fact that I am a person with a congenital disability, who is also female and Black. These factors and others I may be less aware of influenced my interactions with participants and my understanding of the insights they shared. Despite my “insider/outsider” status (Collins, 1986) as a person with a disability examining the lives of others with disabilities, I could not assume that participants would readily share their stories with me. Gallagher (2004) cautioned that “Being an insider...does not mute or erase other social locations which serve to deny access, create misunderstanding, or bias interviews” with individuals with the same background; furthermore, “perceiving or defining oneself as an outsider does not allow one to claim that one’s research is value-free” (p. 205). Henderson (1998) too cautioned that researchers who are members of the groups they study may be biased. However, she noted, “good arguments exist on both sides” as it relates to group membership and that “the question is whether the individual researcher, particularly if she or he is doing interpretive research, can be a valid and reliable interpreter of the research” (p. 161).

Concerning researcher objectivity, Taylor and Bogdan (1998) asserted that “what is more important than neutrality is awareness of one’s own perspective and honesty about where one stands when the research findings are reported” (p. 28). My interpretation is but one of many possible interpretations of the data. It is however, the most thoughtful one I can offer given who I am and what the participants in this study chose to share.

Another key aspect of qualitative investigation is that the inductive nature of qualitative research requires a willingness to adjust approaches during the course of the project. As the researcher studies the phenomena within its context, the design of the study emerges. Beginning with the specifics or particulars of the situation of interest, the researcher then moves toward a more general description of the context of the study. Throughout this process, the researcher’s questions are revised based on her experiences in the field (Burr, 1995; Creswell, 2007).

While conducting this study, I frequently referred to my primary research questions and recorded my thoughts about the research process, my feelings, and the themes that seemed to emerge from the data. I continued to read about the various approaches that might prove useful in interpreting what participants shared with me. Ultimately, I chose to use Smith’s (1996, 2003) Interpretative Phenomenological Analysis (IPA). This approach, which incorporates the principles of phenomenology and those of symbolic interactionism, enabled me to present the participants’ experiences in a way that takes into account their whole personhood (Smith & Osborn, 2003). Further, this particular phenomenological approach required me to be very transparent about how I, as the researcher, influenced the data collection and interpretation process.

## Phenomenology

According to Bloor and Wood (2006), phenomenology is rooted in the fields of psychology and philosophy. Taylor and Bogdan (1998) noted that “the phenomenologist views human behavior, what people say and do, as a product of how people define their world” (p. 10). Creswell (2007) explained that hermeneutical phenomenology involves “interpreting the ‘texts of life (hermeneutics) and lived experiences (phenomenology)’” (p. 235). Thus, phenomenological methods are used to “describe and interpret the meanings of experiences of human life” (Bloor & Wood, p. 128). As with other qualitative methods, the emphasis is on representing the specific experiences of each individual. However, Bloor and Wood asserted that, “...phenomenology is perhaps more useful when the researcher is able to generalize beyond the individual and articulate transferrable meanings of what makes an experience what it is” (p. 129). For my study, I sought to understand the experiences of each of the men and women I interviewed. I anticipated that there may be commonalities among them. Using IPA to analyze the data allowed me to capture similarities while still being mindful of the individual differences among participants. Schwandt (2001) noted that “there are several ...positions on the desirability, possibility, and process of generalization within the broad field of qualitative inquiry” (p. 107). Further, he advised that Lincoln and Guba “maintain that generalization is unrealizable, but...that extrapolation or *transferability* of findings from one case to another is possible” (p. 107), if the researcher provides enough detail about the situation or case “so that readers can engage in reasonable but modest speculation about whether findings are applicable to other cases with similar circumstances” (p. . 107). While my goal is not to make generalizations with the data, it may be that some of the concerns, challenges and strategies indicated by participants’

responses could provide insight into the lives of other employed people with and without disabilities.

### **Interpretative Phenomenological Analysis**

Smith and Osborn (2003) explained that IPA is phenomenological in that it entails detailed examination of participants' personal and social worlds, attempts to explore personal experience, and is concerned with the individual's perception or account of the experience. The aim of Interpretative Phenomenological Analysis is "to explore the participant's view of the world and to adopt as far as possible an 'insider's perspective' of the phenomenon under study" (Smith, 1996, p. 264). Additionally, the process of conducting research is seen as a "dynamic process" in which access into the participant's world is "both dependant on and complicated by the researcher's own conceptions which are required in order to make sense of that other personal world through a process of interpretative activity" (p. 246). Thus, IPA is very transparent about the role of the researcher in "trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2003, p. 51).

Smith and Eatough (2007) emphasized the dual role of the researcher in the interpretation process noting that "in one sense the researcher is like the participant, drawing on mental faculties they share"; however, the researcher is also different from the participant, "always engaging in a second-order sense making of someone else's experience" (p. 36). The authors asserted that to get a sense of individuals' experiences and their beliefs about those experiences, both an empathic hermeneutics and a questioning hermeneutics are used to interpret the data. Therefore, while the IPA is interested in understanding the perspectives of participants, "a detailed IPA analysis can also involve asking critical questions of the texts from participants" (p.

51). Smith and Osborn (2003) suggested that such questions might include the following: What is the person trying to achieve with that response? Do they seem to be sharing something they did not intend to share? Do I have a sense of something going on here of which the participants themselves may be less aware? The authors asserted that by using both an empathic and questioning approach to the data “is likely to lead to a richer analysis and to a greater justice to the totality of the person, ‘warts and all’” (p. 52).

It was the desire to represent the whole personhood of the participants, as well as their self-assessments such as “I may be in denial,” “I’m not sure if I felt I had to prove I could do it,” and “I think I tend to forget bad things,” that led to my decision to use IPA. According to Smith and Osborn (2003) “IPA has a theoretical commitment to the person as a cognitive, linguistic, affective, and physical being and assumes a chain of connection between people’s talk and their thinking and emotional state.” Further, Smith and Eatough (2007) stated that the themes that emerge using IPA “focus on participants’ meaning-making and interpretation, a concern for identity and a sense of self and an attention to bodily feeling within lived experience” (p. 38). By engaging in a reflective and subjective process, the researcher “...makes ... inferences cautiously, and with an awareness of the contextual and cultural ground against which the data are generated” (Reid, Flowers, & Larkin, 2005, p. 20). The way in which the researcher considers contexts in attempting to understand the data speaks to the influence of symbolic interactionism in IPA.

### **Symbolic Interactionism**

Symbolic interactionism is a perspective developed by Blumer (1969) whose work was influenced by theorists such as George Herbert Mead. This worldview focuses on meanings,

social interactions, and interpretations. There are three basic tenets of social interactionism. First, individuals are believed to act toward objects, other people, and themselves based on the meanings they attach to them in their social context. The second principle is that these meanings are “formed, sustained, weakened, and transformed” during interaction with others and with one’s self (p. 21). In other words, meanings are “social products” people create through their interactions with themselves and other people. The third basic premise of this perspective is that individuals attach meanings to situations, other people, objects, and themselves through a process of interpretation. Blumer advised that symbolic interaction involves not only interpretation of another’s words and actions, but also conveys to the other party how he or she is expected to act.

One reason I find symbolic interactionism a useful perspective for this study is that society has prescribed a negative meaning to disability. Even meanings that are seemingly positive, such as individuals with disabilities are angelic (Clapton & Fitzgerald, 1996) or overcomers (Linton, 1998), can put negative pressure on persons with disabilities. These viewpoints influence the ways in which individuals with disabilities perceive themselves and their circumstances. This is consistent with Blumer’s (1969) assertion that “the meaning of a thing grows out of ways in which other persons act toward the person with regard to the thing” (p. 4). Further, the concepts of “role” and “self” within the symbolic interactionist perspective are fitting for this study. Referring to the earlier work of Mead, Blumer (1969) advised that symbolic interactionism recognizes humans as equipped for social interaction and that is only possible “by virtue of possessing a ‘self’” (p. 12). This, he asserted, allows individuals to place themselves in the position of others and to view and respond to themselves from this perspective.

The development of the “self” occurs through a process “role-taking,” in pretend and real life experiences. One kind of role-taking can be seen when children play; for example, when playing “mother” children act based on their experiences of being mothered. In real life encounters with parents, siblings, playmates, and others, children put themselves in these other roles although it may not be evident to those with whom they are interacting (Blumer, 2004). Blumer explained that “...the child comes to take the role of the other in the sense of grasping what the other person expects, demands, requests, or intends to do toward it” (p. 59). This same dynamic is present when interacting with supervisors and peers in workplace communities.

The symbolic interactionist perspective on self and roles led Reitzes and Mutran (2002) to use this viewpoint in their investigation of how employed, middle-aged men and women “organize their self-concepts and infuse personal significance into their roles” (p. 647). Participants in this study simultaneously occupied the roles of worker, parent, and spouse. The authors were interested in “role-making” or the importance an individual attributes to a role and how this impacts satisfaction and self-esteem. They noted that “...commitment ties a person to [a] role and role-related others;” however, importance is linked to the psychological significance the individual associates with a given role and how strongly he or she identifies with the norms and values consistent with that role. Further, this study demonstrated that viewing one’s worker role as important positively impacted self-esteem; however, “centrality of the worker role” (i.e., placing it above all other roles), negatively affected self-esteem (p. 649).

Role identification is a critical aspect of achieving work-life balance. According to Clark (2000), the more closely one identifies with his or her role as a member of the workplace community and others agree with this perception, the more support the worker will receive in his

or her attempts to maintain balance between the work and home domains. Additionally, Clark advised that it is advantageous when the borders between work and non-work are flexible, allowing individuals to move between spaces and roles with less stress. The issue of role identification may be somewhat more problematic for persons with disabilities.

One factor that may complicate the issue of role identification for persons with disabilities is that disability often has very different meanings within the various domains of life. For example, an individual with significant physical limitations may be seen as quite competent at work where he or she has the necessary assistive technology to complete job tasks. Further, depending on the specific nature of his or her work, disability status may be viewed as an asset, such as when in the role of counseling others with disabilities. However, at home, the individual may be seen in more of a sick role (Kaplan, 2003) in which others tend to his or her personal needs such as providing toileting assistance. In social and leisure pursuits, such as when out to lunch with coworkers and the waitress asks them what he or she would like to order, the individual with a disability might vacillate between these two ways of being while making sense out of the interaction. The presence of disability can make interacting with nondisabled persons more difficult. Additionally, it can make it harder to achieve a sense of balance between one's work, family, friendships, and self-care. These are the four quadrants of work-life balance proposed by Bird (2006). His model is consistent with how I view the concept of balance in that the focus is on attempting to experience joy and achievement in each quadrant on a regular basis. Disability influences every domain of a person's life, and the self-care it requires may not be readily apparent or easily understood by nondisabled people with whom they interact. Yet, these

self-care issues may well influence how people with and without disabilities interpret their social encounters with each other.

Factors such as age of onset and cause of disability can influence interactions between individuals with physical impairments and nondisabled persons. For example, a person with a congenital disability might be viewed more sympathetically than someone who acquired disability as a result of his decision to drive while intoxicated. However, the person with the acquired disability might be more accepted by nondisabled people because, prior to disablement, he experienced social skill development and leisure participation with fewer constraints; thus, he has more in common with his nondisabled peers.

According to Blumer (1969), people have options about how they will respond to others' perceptions. He asserted that within the symbolic interactionist perspective, social action is constructed by individuals; it is not simply a response to factors they encounter. In other words, through interaction with the self, individuals develop a line of action. These actions are based on what the individuals want or what is being asked of them. They set a goal and evaluate their options, prior to determining a course of action. The individual may act on this decision, delay action, abandon the idea, revise it, or identify another option. Still, Blumer emphasized that "the designations and interpretations through which people form and maintain their organized relations are always in degree a carry-over from their past...on this point the methodological posture of symbolic interactionism is to pay heed to the historical linkage to what is being studied" (p. 60).

This perspective is very empowering. Members of marginalized groups often do not believe that they have choices in how they respond to the forces that are seemingly against them.

Indeed, their past experiences may have created and reinforced these beliefs. Yet, realization that there are always options gives them a degree of power in situations in which they might feel powerless. Certainly, many people with disabilities are aware of options they can use in relating to nondisabled persons as impression management is frequently engaged in, perhaps even expected of, persons with disabilities (Campbell, 2008; Goffman, 1963; Linton, 1998). When individuals choose how they will represent themselves rather than simply succumbing to the expectations of others, they are likely to feel more positive about themselves and more in control of their own lives.

Symbolic interactionism is a theoretical perspective that is closely linked with social constructionism. In fact, the two are often used together in conducting research (Creswell, 2007; Schwandt, 2001). Indeed, Taylor and Bogdan (1998) asserted that within the symbolic interactionist perspective, "...it is taken for granted that all reality is socially constructed" (p. 19).

### **Social Constructionism**

The concept of social construction is significant in studying the lived experiences of persons with disabilities. This concept was detailed by Berger and Luckmann in *The Social Construction of Reality* (1966). They contended that human beings are conscious of the existence of multiple realities or meanings that may exist regarding an object, situation, or event. Yet, they emphasized, "among the multiple realities there is one that presents itself as the reality par excellence." This, they asserted, is "the reality of everyday life." (p. 21). In other words, the reality put forth by the most influential members of society is the one reality within which all

people are expected to operate on a daily basis. Historically, what has been considered real or true about disability has emphasized limitations as being inherent in the individual. Therefore, society has not, until recently, considered its role in the experience of disablement and its obligation to make provisions for the full inclusion of disabled persons in the domains of work and community life (Kaplan, 2003).

According to Schwandt (2001), the constructionist “seeks to explain how human beings interpret or create some states, practices, conditions, experiences, ideas and beliefs, within specific linguistic, social, or historical contexts” (p. 39). This way of meaning making emphasizes the role that social process and social interaction play in the construction of knowledge. Thus, phenomena such as disability only hold the meaning they do as a result of the way people make sense of such experiences, conditions and events.

Creswell (2007) advised that within the worldview of social constructionism the “meanings are varied and multiple, leading the researcher to look for the complexity of views rather than narrow the meaning into a few categories or ideas” (p. 20). Consequently, he emphasized the importance of the researcher relying on the views of the participants. He noted that their views are best gathered through open-ended questions that enable participants to describe what they say and do in their everyday lives. According to Creswell, “The researcher’s intent, then, is to make sense (or interpret) the meanings others have about the world” (p. 21). Burr (1995) proposed that all “truths” are created through interpersonal interaction. Therefore, within a social constructionist framework, the researcher co-constructs meaning with participants as they engage with one another. The researcher maintains a measure of objectivity by acknowledging the values and beliefs she brings to the project; however, her relationship with

participants is not distant. She sets her own perceptions aside, but does not abandon them, as she seeks to represent the phenomenon of interest as the participants describe it.

Weinburg (2008) asserted that the researcher's task is one of "giving voice" to groups that have historically not been heard. He stated that social constructionist studies seek to replace rigid, widely-held, unquestioned views about things with "...more fluid, particularistic, and sociohistorically embedded conceptions of them" (p. 14). Further, he contended that "the practical point, then, of doing constructionist studies has very often been to promote a better way of thinking and more important, living with respect to the world we inhabit" (p. 15).

Work done from a social constructionist framework is important because one's identity is developed through interactions with a world that may value things that are inconsistent with the individual. For example, in a society that insists on speedy service, people who move slowly may be viewed less positively. Berger and Luckmann (1966) wrote that "identity is formed by social processes. Once crystallized, it is maintained, modified, or even reshaped by social relations" (p. 173). Moreover, they proposed that "the social processes involved in both the formation and maintenance of identity are determined by the social structure" (p. 173).

Recognizing that peoples' self-perceptions are significantly influenced by what their interactions and experiences tell them they can be is particularly critical to understanding the day-to-day lives of members of marginalized groups. The beliefs people hold about their place in society and their personal potential can influence whether or not they believe they are acceptable and successful. For individuals with physical disabilities, the cause of disablement, the age of onset, and the degree of limitation as well as background factors such as gender, race, and socio-economic status all contribute to the disability experience and how it is defined.

Previous research regarding work-life balance has alluded to the social construction of such roles as a good worker and in particular, a good mother. For example, Spencer-Dawe (1999) examined the strain experienced by employed single mothers. She found that in an effort to maintain workplace credibility, the mothers found it difficult to communicate their personal needs to their supervisors. As a result, they were frequently scheduled to work additional hours, which further reduced the time they spent with their children, causing the women to feel guilty.

Social constructionism is a useful perspective to bring to the study of issues related to the work-lives of persons with disabilities, those who have historically had little voice in decisions such as public policy that significantly impacts their lives. Further, by and large, people with physical disabilities are absent from the literature on work-life balance, and studies that have examined interaction between colleagues with and without disabilities have not generally considered the perceptions of workers with disabilities. The examination of the lives of employed people with disabilities provides an opportunity to focus on a segment of the population of disabled persons whose experiences may dispel some of the long-held stereotypes regarding disability and its impact on both employment and leisure lifestyles (such as the assumption that people with disabilities are not interested in or are unable to work or engage in the same kinds of leisure as persons without disabilities).

### **Research Tools**

According to Lofland (1971), the two techniques most often used in qualitative investigations are, “intensive interviewing with interview guides and participant observation involving the assembling of field notes” (vii). For the present study, I conducted semi-structured

interviews of approximately two hours with each participant. These interviews took place during July and August of 2009 and were held at locations chosen by the participants. I met most participants in places accessible to the public such as coffee shops and libraries; others asked that I conduct the initial interview at their workplaces. Then, rather than engaging in formal observations, which may have been intrusive and altered the responses of participants, I made informal worksite visits. I pre-arranged visits with each participant at his or her worksite at least once, usually to drop off and review the initial interview transcripts. During these visits, I took note of artifacts (such as sports memorabilia) that reflected their leisure interests and features (such as brief exchanges participants engaged in with coworkers) that may have contributed to their perceptions of inclusion. These follow up meetings ranged from 30-60 minutes in length. All meetings took place between August and November 2009.

### **Qualitative Interviewing**

Seidman (2006) provided several suggestions for conducting qualitative interviews. These suggestions relate to ways of listening to the participant, checking to ensure understanding, and using open-ended questions. He proposed that the researcher should listen “on at least three levels” (p. 78). The most basic of these is for the researcher to simply listen to what is said by the participant and make sure that she has understood what has been said. The second level of listening involves noticing the ways in which what the individual is saying might be due to the use of his “public voice,” which is constrained by what he thinks the audience (the researcher) may find acceptable. The third level of listening that Seidman described is a the kind of listening that includes being aware of such things as the passing of time and what has been

covered during the session, while still attending to what is being said by the interviewee. Of course, these levels of listening do not occur in such a clear-cut manner. Rather, the researcher often is listening while thinking about and making note of questions that are generated by the participant's response. In essence, there is a fourth level of listening as preliminary analysis of data begins as soon as it is received.

Like Seidman (2006), Lofland (1971) instructed that closed-ended questions should be avoided. These types of questions represent a kind of "leading question." It is important for the researcher not to indicate a preferable answer, but rather present the question in such a way as to allow participants to respond as they wish. Sunstein and Chiseri-Strater (2007) also emphasized the value of asking open-ended questions. They noted that because there is no "right" answer to questions of this kind, the format provides a way for informants to highlight the things most important to them. This kind of interview style, while more demanding on the researcher, also allows for more authentic responses from the participant.

One of the questions I posed to participants was, "Please tell me what makes you feel 'connected' in your workplace." By using a question such as this, I hoped to gain an understanding of some of the happenings in the workplace, the people that are there, and how the participant views concepts that might relate to feelings of being connected (e.g., friendship, support, inclusion). I conducted semi-structured interviews using an interview guide specifically developed for the study (Appendix A). This prompted me to ask about issues I wished to explore. However, the guide was somewhat flexible to allow participants to share in a manner that was more natural for them. I was mindful that when the participant veered off track, he or she was sharing something that I needed to hear. To get at what participants viewed as

important, I asked questions such as, “What else would you like to say about that?” or “What questions were you expecting I would ask that I have not? How would you respond?”

### **Worksite Visitations**

Taylor and Bogdan (1998) proposed that fieldwork really begins before the researcher actually conducts observations. They stressed that the researcher must gain access to the site. I relied on the participants to help me gain access to their workspaces. I was able to visit these sites when dropping off copies of interview transcripts for member checks.

Observation or fieldwork is a key component of qualitative work (Creswell, 2007; Lofland, 1971; Taylor & Bogdan, 1998). It requires “physical and social proximity to the daily rounds of people’s lives and activities...in order to grasp what they experience as meaningful and important (Emerson, Frez, & Shaw, 1995, pp. 1-2). Emerson et al. emphasized that conducting fieldwork entails “both being with other people to see how they respond to events as they happen and experiencing for oneself these events and the circumstances that give rise to them” (p. 2). During observations, the researcher pays attention to such things as the brief actions of participants, their activities, the ways and degree to which participants take part in the setting, the various relationships, and the setting itself (Lofland, 1971). Sunstein and Chiseri-Strater (2007) noted the importance of artifacts as a source of data, as well. During my brief visit to each worksite, I took note of the social aspects of each work environment such as happenings in the break room, and I noted the presence of photos and other office decor (e.g., basketball hoops, desk accessories that depicted interest in a particular sport or team), as these provided some insight into the leisure of the participants on and/or off of the job. In some instances, these

artifacts indicated their involvement in social happenings at work; for example, one participant's work area contained various hostess items such as a punch bowl and serving trays which she kept on hand for office potlucks. My observations were recorded using the Work Environment Summary Form, designed specifically for this study (Appendix B).

In addition to taking notes on what I saw during each interview and site visit, I maintained a researcher journal in which I recorded my observations, my responses to these observations, and the various thoughts and feelings I had throughout the research process. This is consistent with the advice of several scholars (e.g., Emerson et al., 1995). By writing up my notes after each visit and regularly reviewing them, I was able to identify emerging themes and issues I wanted to explore further as well as items I needed participants to clarify.

## **Data Collection Process**

### **Identification of Participants**

I solicited potential participants via a weekly news bulletin that is e-mailed to faculty and staff at a college in the Midwestern United States. I also posted flyers in local area offices of the Department of Human Services Division of Rehabilitation Services and asked each selected participant to let others who might want to be interviewed know about the study. Neither of the latter two approaches yielded participants who met the criteria for the study.

In all instances, potential participants were provided with my e-mail address and asked to contact me if they wished to participate. I then e-mailed each person and scheduled a time for a brief telephone screening during which time I reviewed the nature of the project and assessed if he or she met the criteria. Those selected were 18 or older, employed in integrated work settings,

and had obvious physical impairments; further, they did not report nor appear to have any cognitive limitations that would prohibit them from understanding and responding to questions in an interview format. This purposive sample allowed me to address questions to people who were living the experiences I wanted to better understand- disability, social inclusion, and work-life balance.

### **Data Analysis**

After conducting an initial interview at each participant's worksite or a public place of his or her choice, I reviewed my hand-written notes and listened to the audiotape to determine themes, concerns, or questions that needed further exploration. I then scheduled follow-up interviews, at each participant's workplace or in spaces open to the public such as local coffee shops; the meeting location was chosen by the participant. The interviews were audio-recorded, and the notes were transcribed verbatim. All participants were given a copy of their initial interview transcript and an opportunity to provide clarification and additional information. In a few instances, I e-mailed participants after the follow-up interview to confirm my understanding of their comments.

Creswell (2007) advised that a phenomenological approach "is best suited for research in which it is important to understand several individuals' common experiences of a phenomenon" (p. 60). Wanting to understand both the commonalities and differences among my participants, I analyzed the data using a modified version of Smith's (1996, 2003) Interpretative Phenomenological Analysis (IPA). Smith and Dunworth (2003) noted that "IPA is idiographic" and that individual accounts have a "crucial place" in the analysis and write up. They further

explained that in IPA the researcher begins with specific cases and only slowly works up to more general categorizations or statements, maintaining the individual voices of participants throughout the process. Smith and Osborn (2003) suggested the following steps for analyzing data using IPA:

1. Look for themes in one case
2. Connect the themes
3. Create a chart of these themes for the individual case
4. Create a chart of themes found across cases that provides evidence of the individual experiences of each participant.

The authors asserted that IPA “is not a prescriptive methodology...but is there to be adapted by researchers who will have their own personal way of working” (p. 66). Further, they advised that “...qualitative analysis is inevitably a personal process, and the analysis itself is the interpretative work which the investigator does at each of the stages” (p. 66).

I began the analysis by reviewing the transcript of a single case multiple times. This allowed me to notice ways in which the participant’s personality was coming through in the data. I noted such things as interesting word usage and comments that seemed to be significant, as well as recurring and seemingly conflicting messages. Once I had a sense of the themes within the transcript, I reviewed it again with particular attention to whether or not the themes I previously noted seemed to sufficiently represent the participant’s comments; I also made note of additional themes that had not been apparent to me in earlier readings of the transcript. I then listed the themes in the order in which they emerged from the data and I noted examples under

each theme. This allowed me to see how some themes could be combined; it also helped to highlight which themes seemed most significant for the individual. I then created a table of what Smith (1996) referred to as superordinate or primary themes and subthemes, which in some instances included brief explanations of key words to prompt my memory of the meaning the participant gave to concepts such as work-life balance. I reviewed the table several times, keeping in mind my research questions. I sought to capture the participants' interpretation of her experiences, including her psychological responses to issues related to disability, social inclusion, and work-life balance. I went back to the transcript as needed and adjusted the table accordingly, eliminating, combining or clarifying themes and adding examples to the table. Once satisfied with the table for the first case, I began the process again, with the next transcript.

I used the same process to analyze the remaining transcripts creating a chart of primary and secondary themes that emerged from each. While reviewing subsequent transcripts, I noticed similarities and differences in the experiences of individual participants. As this information revealed itself, I made note of it, while still maintaining my focus on the particular transcript. Once the chart for each transcript was completed, I developed a brief profile of each participant within which I described my understanding of his or her perceptions about disability, social and leisure lifestyles, and perceptions of work-life balance. I then e-mailed the profiles to give each participant an opportunity to advise if any of the factual information was inaccurate. Few changes were made, and all of the participants indicated that my descriptions adequately reflected their experiences and opinions. Next, I went back to the notations made on each transcript and specifically attended to the ways in which they appeared to express common experiences, concerns, or viewpoints. I then reviewed those commonalities among transcripts

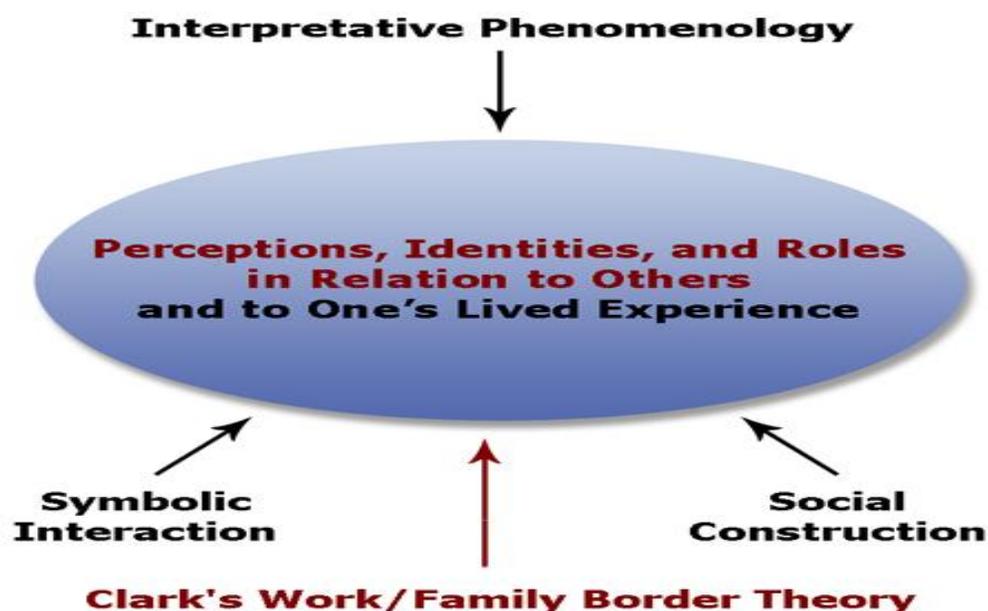
and noted any individual differences around the common primary themes; these differences were noted as subthemes. Finally, I created a chart of superordinate themes and subthemes found across the various transcripts. Quotes from individual participants were included to provide support for each of the themes. Throughout this process, I referred to notes taken during my interactions with participants and reflections noted in my journal and used these additional sources to help me interpret the data.

Taylor and Bogdan (1998) advised that the researcher and participant may not interpret data in the same way. They emphasized that the researcher's perception and the perception of the participant are equally valid. Thus, the member checks that were done were not so much for accuracy; rather, these checks were for what Schwandt (2001) referred to as confirmability and trustworthiness of the interpretation. As noted in Reid, Flowers, and Larkin's (2002) description of IPA, "successful analysis is: interpretative (and thus subjective) so the results are not given the status of facts;" rather, they are "transparent (grounded in examples from the data) and plausible (to participants, co-analysts, supervisors, and general readers)" (p. 20). Thus, my goal is to provide a reasonable interpretation of the data based on the specific information provided by participants.

### **Conclusion**

In this chapter, I summarized the goals of this study and outlined my research questions. I described the nature of qualitative inquiry and its relevance to this project. Further, I provided specific information about data collection and my method of analysis.

By approaching the study from the related theoretical frameworks of symbolic interactionism and social constructionism, I illustrated the complexity of the disability experience. By analyzing the data through a process of interpretative phenomenological analysis, I considered the experience and perspective of each participant while also attending to the commonalities among their stories and the ways in which factors such as how interpersonal relationships and individual belief systems influenced these experiences. As indicated by the diagram in Figure 1, the central concepts in the primary methodological perspectives used in this study focused on perceptions, identities and roles in relation to other people and to one's lived experience. These perspectives were well-suited for use in conjunction with Clark's (2000) work/family border theory because it too emphasizes roles, identities, and relationships. The similarities between these approaches are depicted in the visual representation.



*Figure 1.* Similarities between the theoretical and methodological perspectives

## CHAPTER 4

### THE PARTICIPANTS

The purpose of this chapter is to introduce to the reader the individuals who participated in this study. The eight participants included five women and three men. All of the participants were employed at the time of the study; however, in an effort to protect their anonymity, specific occupational information was not included in some profiles. They ranged in age from early 30's to late 50's. Five were married or in a long-term relationship. Three had children living at home. Five had congenital disabilities, including spina bifida, polio, and spinal muscular atrophy. Of those with acquired disabilities, two had spinal cord injury (SCI) and one had limitations due to multiple injuries to the lower extremities.

The reader should be mindful that there are several different types of spinal muscular atrophy and spina bifida. Further, there is a range of possible symptoms related to post-polio syndrome, a condition that affects some, but not all who have had polio in their childhood. There is also variation in the experiences of those with acquired disabilities based on the particular location of their traumatic injuries. Therefore, the diagnostic labels, alone, convey little about these individuals and offer only partial insight into what life with their particular disabilities might be like.

#### The Participants

##### Callie

Callie, a financial services professional, is in her 40's. She is paralyzed "from about the mid-thigh down" as a result of spina bifida, a congenital disability. She is unable to wear shoes due to clubbed feet. She uses a manual wheelchair for mobility. Callie has an undergraduate

degree and remains active with the sorority she pledged while in college. In addition to her full-time job, she oversees management of a farm that she owns and which her brother maintains. She is single and has no children. As her friends have married and/or become parents, she finds that they are less available to spend leisure time with her. Many of her leisure activities center around time spent with her siblings and their children. She has proactively joined social groups to increase her social opportunities and number of potential leisure companions. When it comes to getting together with family or friends, Callie often finds she is the initiator. For Callie work is a primary social outlet. Without work and the chance it provides to be with other people, Callie reports that she might find it hard to get up and out of the house each day. For her, “balance” involves having friends to lend a hand and an ear, taking time off from work to relax or attend family functions, avoiding stress, and planning ahead.

### **Craig**

Craig injured his spine in his mid-20's when he fell while walking alone in the woods. Having sustained a “T-8” injury, he is paralyzed from just below his chest, down. Married at the time, he soon divorced. Now in his late 40's, he is in a long-term relationship with a woman he met through work. Craig was working in sales at the time of his injury and determined he needed to change careers because his job involved going into private homes, many of which would be inaccessible to him as a manual wheelchair user. He returned to graduate school shortly after the accident and initially studied rehabilitation but switched majors because he “didn't want the job to relate to the wheelchair.” He is currently a school counselor and enjoys coaching track, hunting, and travel.

Craig prides himself on being “strong” and “independent” and “strives to be normal.” However, he reports that his disability is “like a cloud” that is always over him. He still feels a sense of “loss” and is most bothered by the less obvious consequences of his disability, such as back pain that can make it difficult for him to get through the workday and discourages leisure participation. He feels that no one in his personal or work life fully understands his situation and admits that he is reluctant to share some facets because he doesn’t want to “burden” them. He tends to keep his work and personal life separate, and he rarely engages in leisure with his colleagues. He notes that this is primarily because they do not share the same interests. Over the last few years, Craig has experienced numerous health concerns. Additionally, his workplace community is not as cohesive as it once was, and his job responsibilities have changed to the point that his current job is one that he “would not have applied for.” He uses leisure as a way to deal with these stressors and is in the process of developing a fully accessible retirement home with various leisure amenities. For Craig, the concept of “balance” involves making self-care a priority, adapting how he performs activities of daily living, and remembering that “it’s all about choices.”

### **Irene**

Irene is a single woman in her early 30’s. She is proud of her triple identities as an ethnic minority, and a female with a disability. She experienced a spinal cord injury in her late teens when she was a passenger in a motor vehicle accident. Having sustained a “T-11/12” injury, she reported, “I’m just paralyzed in my legs, but I can move everything else pretty normally.” Irene uses a manual wheelchair for mobility. A life-long sports enthusiast, Irene believes that getting

involved in wheelchair sports shortly after her injury greatly enhanced her life. It expanded her network of friends and gave her “more people to play with.” Sport has also helped her to maintain a fit body and better physical functioning, although she notes that she is beginning to feel the consequences of working her body so hard. Irene reports that she rarely socializes with her colleagues. During the workday, her time is spent almost exclusively with those in her immediate work unit. Much of Irene’s free time is spent engaging in competitive wheelchair sport. This serious leisure commitment has made it difficult for her to accept social invitations from coworkers.

A teacher, Irene found it easier to make friends in her last job. There, she worked more closely with other teachers and she and her coworkers shared similar leisure interests. Irene views work as something she needs in her life in order to give her a sense of structure. However, she is extremely passionate about leisure and believes in seizing the moment and enjoying all that life has to offer. To Irene, “balance” means having a plan for the day, leaving work on time, remembering that relationships matter, adapting to obstacles, asking for help when needed, and finding time for leisure--no matter what.

## **John**

John, age 40, is a married father of two. . He works in a sales-related position in the non-profit sector. He often travels for work, which has a “cumulative effect” on his family. . However, it is the desire to provide for the needs of his family that drives him to work so much. His leisure centers around time spent with family and a relatively small group of friends. He enjoys sports, especially golf, and manages to play at least once a week. Born with spina bifida,

John insists that he has not had many of the negative experiences often associated with “what a typical handicapped person” would experience. He wears Ankle Foot Orthotics (AFO’s) and a wide width shoe to accommodate his clubbed foot. Faith is important in John’s life and seems to contribute to his perception that despite his limitations he has “nothing to complain about” compared to others with spina bifida or other impairments. For John, “balance” involves being prepared for the future, fitting in leisure without sacrificing family time, and reluctantly letting go of pride and adapting to the invisible and frustrating limitations presented by aging on top of disability.

### **Ken**

Ken, who is in his late 50’s, acquired polio in infancy and considers it a “blessing” that he has only known life with limitations. From his mid-teens through early adulthood, the only indicator of Ken’s disability was that he walked with a limp. In his 40’s he was diagnosed with post-polio syndrome and began walking with forearm crutches, wearing full leg braces, and using hand controls to drive.

Ken and his wife met in college where they both worked in the school cafeteria. They have two adopted children. He holds an undergraduate degree and has had a successful career that has included both self-employment and working for others in various positions involving computer technology. He is a newcomer to his current workplace, having been there about six months at the time of our meeting. He enjoys spending time with his family. The social interaction he experiences through work is a “highlight” that he views as essential to his continuing to thrive as he ages. He has found that others’ willingness to adapt leisure activities

has allowed him to continue doing some of the things he has enjoyed since childhood, such as hunting and fishing. As he looks toward retirement in a body that is becoming more limited, Ken is concerned about how he will be able to enjoy his free time. He has begun to modify his leisure lifestyle to include less physical activities such as coin collecting. For Ken, the concept of “balance” includes adapting to change, accepting help, and maintaining a sense of gratitude.

### **Marie**

Marie, who is in her early 40’s, has spinal muscular atrophy, a form of muscular dystrophy (MD). She enjoys a career in the nonprofit sector. Marie is a lesbian in a committed, long-term relationship. She and her partner have one child. Marie walked until her early teens. She began using a manual wheelchair in junior high school and a motorized wheelchair when she started college. She reportedly has always had a “normal” social life, has maintained friendships with people from as far back as grade school and joined a sorority while in college.

Although active with the Muscular Dystrophy Association for many years, Marie reports that her disability has never defined her. She views it as a feature--much like her hair color or the color of her eyes. As she ages and her disability progresses, she is spending more time and energy on disability-related concerns. She requires some personal care assistance and considers this her greatest source of stress. For Marie, “balance” means having a routine, making time for family and community, fitting work into life, and acknowledging the need for help as she ages with disability.

**Princess**

Princess was born with spina bifida. She was tutored at home for a short time before being mainstreamed into public school. . As a child, she wore full leg braces. Today, she wears Ankle Foot Orthotics (AFO's). About 10 years ago, in her early 40's, she reluctantly began to use forearm crutches for walking distances. She still prefers to use a single cane whenever possible and often walks unaided inside her home. A life-long animal lover, Princess spends her free time helping with animal rescue and raising funds for charities that do this work. She and her husband of nearly 20 years have no children. Princess attended community college for a short time but decided not to complete her program, preferring to enter the job market instead. She has held a number of clerical support positions during the nearly 30 years that she has worked for her current employer. Her boss is a good friend. She has a number of close friends and social acquaintances. Some are long-time friends from school; others are former coworkers or people she met through them. She enjoys shopping, eating out, and traveling. At this stage in her life, she wants to begin an exercise program but is uncomfortable going to a gym alone. She reports that of her friends who work out, all are at a different level than she. She would like to have a friend whose ability level is more similar to hers so they could work out together. For Princess, the concept of "balance" involves adapting and taking better care of herself as she ages with disability.

**Rose**

Rose, a single woman in her mid-40's, acquired disability about eight years ago when she fell asleep while driving. She experienced multiple injuries to her lower extremities.

Consequently, she requires special socks and shoes and uses a cane for distance walking. She reports that her limitations have been life-changing. Following her injury, it took several years for her to return to aerobics, which she views as critical for her physical and social health. She has been unable to return to some of the leisure activities she once enjoyed.

For Rose, the most difficult aspect of disability is relying on others to do “simple things.” She has always prided herself on being an independent woman who could take off at a moment’s notice. However, now she finds she has to ask for help and often needs to plan ahead. Her friends, family, and her coworkers--who are “like family”--all play significant roles in her ability to manage work and non-work demands through their encouragement and willingness to provide accommodations without prompting from her. She has hired help to take care of her home. For Rose, the concept of “balance” includes adapting by planning, practicing patience, and praying for “peace of mind.”

### **Conclusion**

In this chapter, I have provided a summary of the participants in this study. I introduced each individual by offering a brief description of his or her life, disabling condition, employment, and leisure interests. I also indicated the ways in which each participant seemed to define the concept of work-life balance. In an effort to maintain anonymity, I used pseudonyms selected by the participants and gave them the opportunity to review and provide feedback regarding the accuracy of their profiles. I also asked that they indicate what, if any, personally identifiable information they wished for me to change. It is my hope that these profiles give the reader adequate context within which to consider the data presented in the next chapter.

## CHAPTER 5

### IDENTITIES, INTERACTIONS, AND QUALITY OF LIFE

This study examined the lives of persons with physical disabilities employed in integrated settings. My initial interview protocol included questions designed not only to inquire about interpersonal relationships at home and work but also to get some sense of each person's relationship with him or herself. One of my goals was to understand how the relationship to self and care for one's self might influence decisions (such as declining social invitations or the chance to work overtime). While conducting the first interview, I recognized the need to consider the ways in which each participant appeared to identify him or herself. This was especially important given that disability and ability are definitional opposites. Linton (1998) commented on the significance of the prefix *dis* asserting:

The prefix has various meanings, such as not, as in *dissimilar*; absence of, as in *disinterest*, opposite of, as in *disfavor*; undo, do the opposite of, as in *disarrange*; and deprive of, such as *disfranchise*. The Latin root *dis* means apart, asunder. Therefore, to use the verb *disable*, means, in part, to deprive of capability or effectiveness. This prefix creates a barrier, cleaving in two ability and its absence, it's opposite. Disability, is the 'not' condition, the repudiation of ability. (p. 30)

Similar to those in Watson's (2002) study on disability identity, my participants tended to view themselves primarily in the context of their various roles and relationships, as opposed to defining themselves based on their disabilities. Their comments demonstrated not only that each has multiple identities reflecting the various domains of his or her life, but that each one also has

multiple and changing disability-related identities. Their responses support Reeve's (2002) view of disability identity "as multi-faceted and fluid rather than a fixed concept" (p. 504).

Watson (2002) advised that people with disabilities do not share a common religion, common political views, or a common social class; rather, they differ in terms of gender, age, ethnicity, sexual orientation, and other factors. Consequently, I believe that each individual's experience with disability is unique and any attempt to understand his or her life must take into account these intersecting identities. I sought information about participants' responsibilities at home and in the workplace and examined the roles of relationships, leisure, and self-care in their efforts to maintain work-life balance as they each conceptualized this phenomenon. Ultimately, this was a study of the quality of life experienced by these eight men and women.

In this chapter, I present five themes that emerged from the data. This set of themes and subthemes is not an exhaustive list; rather, it represents key themes that most clearly address my research questions. However, I have also included themes that were not anticipated but seemed particularly significant, such as how aging with disability influences perceptions of work-life balance and quality of life. The most salient themes that emerged from the data were *Identities*, *Disability does not Define Me*, *The Same but Different*, *Work is a Way to Connect and Contribute*, *Leisure is Super-important*, and *Balancing Life is Work*.

### **Theme: Identities - My Disability does not Define Me**

Identity was a critical component in how participants viewed their lives, their work, and their relationships. They described several different types of empowering identities. Their stories demonstrated the significance of background factors such as gender and socio-economic

status. In addition, they emphasized the various roles and responsibilities they have in the work and non-work domains of their lives. In all of these ways, the participants demonstrated that they are more than persons with disabilities. They are complex individuals with full lives.

### **Subtheme: Empowering Identities**

There is no single disability identity (Darling, 2002; Gill, 1997; Warner, 2002).

Participants in this study demonstrated diversity in terms of how they identified themselves in light of disability. Most participants' comments indicated a commitment to maintaining a sense of themselves as capable and empowered people.

Craig, who sustained a spinal cord injury 20 years ago, asserted, "I live my life separately from being disabled." Further he advised, "I really strive to be just another person... I personally don't think about [my disability] that much." Yet, moments later, he confided:

It's like a cloud; there's always something right over me that reminds me of- whether it's a mobility thing or an access thing, I always think about it... Every time, *e-every time*<sup>1</sup> I get in that thing [his modified van] and I hear that motor... then I'll think sometimes, *my life is messed up*... hundreds of times a day, several times an hour.

He summarized his feelings stating, "disability has affected me in a way, there's a, you know, a sadness."

Craig's seemingly contradictory comments about the significance of disability in his life exemplify the internal challenges people with disabilities may face when seeking to create an identity of themselves in a society that has historically associated disability with weakness,

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<sup>1</sup> *Italics are used to denote the emphasis the participants' placed on particular words.*

inability, and fear. Craig and other study participants demonstrated ongoing efforts to maintain empowering self-perceptions. In some instances, this involved an apparent distancing of the self from the disability or at least from the stereotypical images of disability, images that each of them grew up with and internalized.

**Not the handicapped kid.** One empowering way that some participants represented themselves was by distinguishing themselves from the image of the “typical handicapped person” or by “not being the handicapped kid.” For example, John, who has spina bifida and referred to himself as a “patient,” seemed to view his disability as separate from his self. For him, his diagnosis is a condition for which he occasionally seeks medical advice, not something that influences daily functioning. John wears Ankle Foot Orthotics (AFO’s). These plastic braces reach to just below John’s knees and are not apparent through his slacks. They fit comfortably inside of a regular, wider width shoe; thus, John’s limitations are not obvious unless he is ambulating. He noted:

By all appearances, I guess, ya know, [it] wouldn’t come across ‘til I get up [and] somebody sees me walking...I’m just sitting at a table, [and] somebody walks in, I’m just like them- as much as anybody is like somebody else. ...It could be very easy for me...and there’s times when I’ll be like, ‘oh man, I’d really like to get a handicap sticker put on my car so I can park right outside the front door!’...but there’s something internally that says, hey, I don’t need to do that!

According to John, his parents and friends contributed to the image he projects and how he identifies in terms of disability. He recalled, “...our circle of friends...they ... always said,

‘we just never *saw* you *that* way’ and I think my parents didn’t treat me *that* way. I didn’t see myself *that* way; I didn’t want to project *that* image.”

Marie, who has spinal muscular atrophy, a form of Muscular Dystrophy, told a similar story. Although she currently uses a motorized wheelchair, she walked until her early teens. Consequently, she was reportedly more independent than many of the kids she met at a summer camp sponsored by the Muscular Dystrophy Association. Regarding her childhood she insisted, “I wasn’t babied...I wasn’t given special treatment.” She asserted, “I was so driven not to be the handicapped kid...part of that came from my parents, you know, being driven not to make me the handicapped kid.”

Marie reported that when she began school, public school administrators told her mother that Marie needed to go to the school for children with disabilities. She explained, “They were gonna decide that I needed to go to a special school because I had a disability-I wasn’t using a wheelchair, but I had a disability, so all those students went to this one place.” Her mother’s response was to enroll Marie in a private school, instead. Marie faced a similar challenge when she began college and her reaction, like her mother’s many years before, was to avoid being grouped with other students with disabilities:

I went away to this big State university and they had- the thing that got me was- they had all the disabled students all living together, which totally threw me off ‘cause I’m like, why? *Why am I not integrated into where everyone else lives?* ... for me, that was an issue that I pushed away from because I thought, that’s shoving me in a corner of non-integration and just because I’m in a wheelchair doesn’t mean I need to live, and breathe, and eat with all the other disabled students...I made an effort NOT to be part of that.

Irene sustained a spinal cord injury more than 10 years ago; she, too, is aware of disabling stereotypes. She makes a conscious effort to distance herself from these stating, “I try to carry myself pretty confident- confidently, so that people- that’s how they’re gonna see me.” Still, sometimes people make assumptions about her abilities. When this occurs, she wishes she could tell them “I’m just in a wheelchair, I’m not dead! - ya know (laughs). I can figure things out.” Grinning she added, “[I am a] pretty bright person.”

Craig summed up the challenge for many persons with disabilities, when I asked how he would describe himself if someone inquired, “Who are you?” He hesitated briefly and asked, “You mean how would I describe *myself*? ... I’d really...not like to define myself as disabled, you know? But, but that’s the first thing a person sees.”

This distancing of one’s self from disability seemed to indicate a struggle with being able to view disability and competence as possible within the same body. I addressed this with Marie, to see if my interpretation was consistent with her thoughts. Specifically, I commented that it seems that people sometimes think it is not possible to be both a person with a disability and a capable person. To this, Marie responded, “You know, if somebody else says it, then it makes sense [that sometimes the two conditions seem like opposites] but I don’t know that I would ever say it that way, but yeah (matter-a-factly).” She then proceeded to describe how her friends are “always reminding” her that she is disabled and telling her ‘if you would just admit that you have a disability, it’s the first step!’ She chuckled and repeated...- “it’s the first step! You have a disability.” Smiling, she shared her standard reply, “I’m like, shut up!”

With some caution, I raised a similar question with John. We were talking about when his doctor told him that he needed to stop playing tennis, a sport he had only recently taken up

and one of few leisure activities he and his wife enjoyed as a couple. I asked if he would ever consider using a wheelchair to play, and if he thought it was possible to be an active person and a wheelchair user, a person with a disabled parking permit and a golfer. He began to speak before I finished:

I mean, it does seem disconnected in some regards. I don't know how to, how to overcome that. But... there may be a day...ya know talking to my doctor about...my knees and things like that, he said... 'You need to really watch yourself and take care' and ... he's been encouraging me to spend more time riding golf carts on the golf course- 'cause I walk- up until this year, with my knee, I walked all the time...and that's a fairly, that's a good hike, you know?

Without directly addressing my question, John, who unlike most of the participants appeared fit and at a weight well within an appropriate range for his height, explained: "I view it as an opportunity for exercise- I used to ride my bike to work all the time but I don't do that anymore, so I feel like I...I kinda need that activity and the exercise, so...it can't hurt me to go walk a couple blocks down to the parking garage, walk up and down the stairs, and, burn a few extra calories ...so... (quieter now) I don't know."

Ken, who is in his 50's, expressed a more integrated identity that suggested acceptance of his disability as part of who he is. Ken commented that able-bodied people have asked if he would ever want to not have his disability. He asserted, "[Polio] is so much intertwined with who I am. I like who I am. So, why would I want something that I don't know?" He wants people to know that it is possible to have a disability and be happy, like he is.

**An example and an educator.** Another empowering identity expressed by participants was that of being an example and an educator. Irene, a physically fit and athletic woman in her 30's, identified with her disability by seeing herself as an example. Throughout the interview, she referred to the fact that her experience may be very different from individuals whose disabilities are more limiting. Regarding what it was like to be the only person with disability in her previous workplaces she recalled:

It was cool because I felt like I was giving them a good example of someone with a disability? Like they met me and... 'cause then they'll see like, oh, people with disabilities can do anything! You know what I mean? Whereas if they ran into somebody who had severe cerebral palsy and was in a power chair, like that's a different example, you know?

Ken after several decades of essentially "normal" functioning, now has significant physical limitations due to post-polio syndrome. He expressed a similar way of viewing himself in light of his disability. Reflecting on his involvement with the youth volunteers who assist with an adaptive hunting program he participates in he commented, "Part of what I hope to do in my lifetime is to be an example, to be out there, so they can see people with disabilities and to understand ...have a little more compassion for people with disabilities." Similarly, Rose welcomes questions about her disability and gladly takes the opportunity to educate others about the dangers of falling asleep at the wheel, which is how she sustained multiple injuries to her lower body, nearly eight years ago.

Irene, Ken, and Rose see themselves as examples of what it means to be a person with a disability and use this identity to educate others in the hopes of improving society's acceptance

of people with disabilities. Craig also finds himself in this role. For him, it is less passive in that the advocacy he engages in involves “fighting.”

**An advocate, a fighter, and a survivor.** Craig shared, “I never wanted to be much of an advocate for wheelchair disability, but you gotta fight for yourself some, you know?” He explained that after completing his graduate degree, he insisted that he be allowed to wheel across the stage to accept his diploma. The request turned out to be a “big deal.” He recalled, “I didn’t feel like fighting for it...shouldn’t have been necessary” Admittedly reluctant to take on this role he added, “I guess I’m a little reluctant to take up the charge for disability rights...but once I do, I get pretty involved in it.” He proudly explained that his efforts resulted in better wheelchair access allowing all students the experience of crossing the stage to receive their diplomas.

Marie is a reluctant advocate, too. Yet, she feels she can fulfill this role by simply living her life. In this way she exemplifies identities of both an advocate and an example. She explained:

I feel like my life is a testament to, you know, being out there and ... doing things and being an advocate, even though I don’t think of myself in that same way. I mean, *I think living life is an advocacy in itself*, generally for just the people that I meet. I mean, I would think that my coworkers would tell you ... I never thought about things like access and you know, but working with Marie, you know, my eyes are open on blah, blah, blah. I think, you know, so that having that kind of impact on people that you touch day to day, people you work with, people at the grocery store... is an advocacy in itself, but I don’t-

I'm not the one that I'm gonna run up to the Governor's mansion and have a sit-in and be arrested and dragged away. I'm- that's not me.

Like Marie, the other participants focused more on living full lives than on fighting on behalf of the disability community. Nevertheless, their descriptions of their lives indicated that life with disability includes struggles, not only in attempting to complete ordinary tasks but also in managing to live into adulthood, and seeking to be viewed as a capable person. For example, both Rose and Princess spoke of the frustration of having to wait for help from others to do "simple things" such as change a lightbulb or lift a casserole dish out of the oven. Princess, who has been disabled from birth asserted... "I HATE asking somebody to do things for me!" Both she and Rose reported that asking for help is the biggest stressor in their lives.

Irene and Marie also seek to do for themselves first, asking for help only as a last resort. Marie, the only study participant who requires personal assistant services, stated:

I can't speak for others, but I would think that most- a lot of people that have disabilities, that that asking for help thing is just an issue because - it's a sign of weakness, ya know, in some aspects that you have to ask for help for things that are simple like getting the book off the shelf or putting the backpack on the wheelchair -whatever simple task it is, that I put so much pressure on that I should be able to do myself.

Independence and the fight to maintain self-reliance is central of these women's identities.

Ken reflected on what it means to be a surviving member of a "dying breed" of persons with polio. He stated, "I'm one of the few that are still out running around...with the Polio ...there's been hundreds of thousands of people that had polio that came before me and I'm

sure...right now, because we are a dying breed, everybody that has done studies, the only people that respond to a study are the ones who have learned to adapt and survive.”

John, who is in his early 40's, shared that he, too, is one of the fortunate few with his diagnosis, spina bifida. He advised, “A lot of the pediatric kids, that I was hanging out with growing up and that were having surgeries, a lot of them just didn't survive because they had hydrocephalus issues, things like that, so I feel pretty fortunate.” Princess, born with the same condition a decade earlier expressed her survivorship status this way: “It's unusual to find someone as old as I am that has spina bifida and is still walking around and not...obviously, I don't have a lot of other health issues.”

Unlike Ken, John, Princess, and Marie who were all born with their disabling conditions, Craig sustained a traumatic injury in his 20's. Paralyzed from the mid-chest down, for him, the battle began in the moments of his injury. Alone in the woods, he fell and lay there waiting to die. Craig recalled:

When things started spinning and I got dizzy I was sure I was *I'm going die out here*. It was coming fast and I didn't think I could stop it. I just closed my eyes and waited for it to come.

Shifting his body, he continued:

Then I realized shortly afterwards that, you know, I may be alright, but I mean I *knew then*, I knew then, I said, you know my marriage may not make it and it didn't; I'm gonna make it. Somehow, some way, I'm going to make it and I think my mental toughness from sports contributed to that, I think. (pauses) And I *still* feel that way. I mean, I feel like I'm gonna make it. I feel like I'm, you know it depends on what lens you are

looking through, you know. For a lot of people I *have* made it in some ways. You know, *you overcome things and become a taxpayer and an employee* and that.

Craig expressed doubt that one could ever really “make it” with a disability as he spoke about what he referred to as “the stress of living with disability” and the strong sense of loss he still feels two decades after his injury. He still misses “*Walking, running- all those things that you know are taken away from you when you have a spinal cord injury.*” Despite a good education, a good job, a long-term relationship with a significant other, and the ability to live independently, Craig insisted, “I think people that are *happy-go-lucky and pushing wheelchairs, look, ah, I don’t believe that shit!*”

I was talking with John about aging with disability when he made a comment that seemed to summarize the challenge of maintaining an empowering identity. He proposed:

[Aging] may be even harder...for the disabled person who has fought their whole life, perhaps overcoming those types of barriers and not wanting to be perceived differently and ..., I don’t wanna be labeled this way because [of] how I look...I know I can do these things and by caving into this, you know- do people judge me differently?

The participants in this study embraced empowering identities that involved distancing their sense of self from their disabilities, seeing themselves as examples, and viewing themselves as advocates, fighters, and survivors. Although Marie, John, Ken, Princess, and Rose all indicated frustrations at times with their limitations, only Craig spoke of his situation in disempowering terms. Yet, even in his case, this was not consistent; most of his remarks were those of a man who sees himself as quite capable. He shared that he believes his heightened sense of loss is due to his pre-disability identity, which was associated with participation in

sports stating, “I think, because I was so-o athletic, I think ... where I identified and other people identified me by my body, I think, the things that I did in sports.”

### **Subtheme: Intersecting Identities**

Each participant is not only a person with a disability but also has membership in other groups based on such factors as gender and income. Commenting on her many identities Marie asserted:

My disability does *not* define me...the things that identify me are the things that...I have passion about...- my child, my partner...my church...things that I do at work, places where I’m active...what my interests are...-those are the things that define me, as a person- not that I’m a lesbian or that I use a wheelchair or- those are all features of who I am and...it’s part of how I live my life.

**Gender.** In terms of gender, differences were noted in that the men emphasized their toughness while the women demonstrated their femininity in terms of their leisure interests and attire. For example, speaking about his back pain during our mid-afternoon meeting Craig insisted, “I’m a *tough guy*. I mean, I can put up with a lot of stuff but...like this morning- my back has been hurting all day long.” Describing how he is considering getting a pushcart for his golf clubs John shared, “I don’t consider myself weak or anything, but it is, it’s not an insignificant amount of weight that you’re strapping on your back every time...” All of the men expressed interest in sports such as fishing, hunting, baseball, basketball, football, and golf.

The women, on the other hand, demonstrated their femininity in various ways. Self-described as “not a girlie-girl,” Irene told of how she and group of friends decided to get tattoos.

The males and females all got the same tattoo, except the “the girls added a flower.” Princess spoke of her love for dressing up, applying make-up and getting her hair and nails done. She also advised, “I have a cane in several places...I exchange them in the car when I need them, depending on where I’m going.” For her, the cane is as much a fashion accessory as it is a walking aid.

All of the women wore make-up and several seemed to be quite fashion conscious based on their modern attire. Irene wore stylish cargo pants and Grecian sandals, Marie was dressed in a hot-pink cotton dress and print scarf, and Princess paired a black, empire-waist, lace blouse with white, cotton capri-style pants. Callie and Princess spoke of a passion for shopping, especially for clothes. In fact, Princess held a part-time job as a sales clerk in a women’s clothing store for many years. This was in addition to her full time receptionist position. Despite the physical consequences, she enjoyed the customers and viewed her second job as a form of leisure. She explained, “My legs would be swollen, my feet just felt like they were glued to my shoes, but ...it was worth it, because I just loved it.”

While Callie and Irene expressed a strong interest in sports, all of the women spoke of interests more traditionally associated with women such as scrapbooking, volunteering, and aerobics, and getting together with friends. They all described themselves as social and expressed a need to be around people. Of the male participants, only Ken expressed this same need.

**Socio-economic status.** Socio-economic differences were also noted among participants. Craig mentioned that he and his family did not have a lot of money growing up. However, now he reports, “I’m pretty independent, I have some money, I get out and do some things.” Irene

spoke of her family being “pretty poor” and recalled summer vacations spent close to home. Although Ken makes a good salary, his family has some additional expenses related to his son’s disability and he is careful with his income. With a heavy sigh he advised, “My son’s disability kind of, there’s a cost issue that we have to make sure ... we wanna try to have as much money as we can to help him do things like go to doctors and stuff like that.”

Marie spoke more specifically about her socio-economic status. Commenting on her decision to attend an out-of-state school she explained, “it would have been the *last* thing on my list to stay at home and go to college...in my community...we lived in a very affluent community. Everybody went away to college, you know.” She referred to her financial resources again when recalling a time that she needed help opening the door to an office building she wanted to enter. With laughter in her voice, she said, I was [downtown] and I needed to get into the building and I asked a guy to open the door for me and he said (in a gruff tone) ‘I don’t have any money for you!’” Laughing aloud she added, “I was like, no, I’m not begging! For money! I just need to get IN! Trust me; I wouldn’t have a motorized chair, if I didn’t have any money! Where would I plug it in?” It is noteworthy that Marie countered the stranger’s perception of her as a poor beggar by pointing out how her disability-related equipment denotes wealth, not poverty. She also highlighted her upper middle class upbringing when describing her motivation for work, “I wasn’t so rich that I couldn’t work- ‘cause I had friends that were. ...I was middle class; that’s what the middle class did. Upper middle, but...that’s what we did.”

**Ethnicity.** The participants represented a homogeneous group in terms of their racial composition; all but one identified themselves as white. Irene referred to herself not by race but

rather by ethnicity. She often referred to herself as “a minority within a minority group,” emphasizing the fact that despite disability, she is “pretty mobile” and does not require a power wheelchair. When asked what her triple minority status means to her, she spoke of being “proud of” all three- her gender, her ethnicity, and her disability. Further, she insisted that her spinal cord injury has created “so many opportunities” that she would not want to change this or any other aspect of her identity.

Finally, another way participants identified themselves was in terms of the roles and relationships they have in their lives. They are spouses, parents, siblings, and coworkers. They are members of neighborhood associations, sororities, and religious communities.

### **Subtheme: Relational Identities**

Participants also identified themselves in terms of their relationships with other people. Their identities within their workplaces, their families and their communities helped to define how they viewed themselves.

**Coworker/employee/boss.** All of the participants were members of workplace communities. In order to get a sense of their work concerns and how connected and included they felt, I inquired about their experiences at work and their relationships with their colleagues. Their comments suggested four primary ways in which they are viewed or would like to be viewed at work- committed, competent, valued, and included.

Princess stated, “...I feel like...I have a job and regardless of what the weather is like ...I’m obligated...I need to be here.” She comes into work even in inclement weather. She knows she will need to be extra careful as she crosses the street from the parking area to her

office building because her crutch tips are likely to slide when they encounter the bricks that line the path she takes to the nearest entrance.

Craig shared that he does his best to be at work for his commitments, even when he has to go home unexpectedly. On the day of our follow-up meeting, his catheter came off during the lunch hour. He was scheduled to meet with a student that afternoon. He advised his secretary that he needed to go home and would be back as quickly as possible. After getting in his van, driving home, showering, and changing clothes, he returned to his office. He was able to see his appointment just a few minutes later than scheduled. There was tension in his voice as he told me that he was concerned that his boss, who was there when he returned, may have assumed he was not being responsible because she did not know all he had done to keep his commitment. He stated, “After it’s done I’m sweating, ya know?” He chuckled slightly and continued, “And so, I thought I’d just come back and you just try to get in the routine of just doing your job.”

Craig credits his parents and grandparents for raising him with good values including a strong work ethic. He stated, “Working hard and those kinds of things...values were instilled in me.” Several other participants also commented on their strong work ethic, which was modeled and nurtured by their parents.

In addition to being committed, Craig strives to be seen as a competent member of his workplace community. He insisted, “You can match my productivity against anybody.” In fact, the desire to be viewed as a capable employee literally gets him out of bed in the morning. He explained:

That's why I get my ass up and go a lot of times even though I don't feel like it... 'cause *I don't want to be looked at as the weaker handicapped person...* I think that's a *huge motivating factor* for me.

Admitting to his share of interpersonal challenges at work, he confided:

I've had some disagreements...over time [which], *I like* in a way because it doesn't have anything to do with my disability. They just don't like something I did ... "I guess I'm just saying that I like those ...interactions...I guess because I don't want people- I don't think they do- they don't take it easy on me.

John, too, makes a concerted effort to not appear less capable than others at work.

Responding to my question about whether his production goals were ever adjusted because it takes him physically longer to get to and from appointments he stated, "I don't want people to have to worry too much or ...I don't want people to think 'Oh (in a pitying tone), John's just looking for the sympathy vote'." Ken expressed his competence with the simple statement "That's the reason they hired me, because I did have experience."

In addition to being committed, competent members of their workplaces, the participants also indicated that they felt like valued members of their workplace communities. Explaining her employer's obligation following her injury Rose said, "They had to guarantee me a job, *but not my job.*" Her boss not only kept her job open during her many months of recovery, but he provided special parking privileges near the office without her having to request it. Yet, more than this, Rose was most touched by the fact that her boss sat up with her family at the hospital the night of her accident. She was also encouraged to receive more than 150 cards and letters from her colleagues during her recuperation and stated, "I didn't realize how many lives I had

touched 'til I was in the accident...it was kind of neat to see the fruits of what I just do automatically by being nice and socializing.”

John believes his value in his workplace community is evidenced by the roles he fills there. It was his boss' idea that John seek promotion a few years ago. He advised, “My supervisor counts on me to serve on committees...I feel like I fill some other roles that are perhaps, unique.” He feels these other contributions are viewed favorably and help him to be seen as an important contributor even if he sometimes falls short of meeting productivity goals.

Another way that participants felt connected to their workplace communities was through inclusion in the social or leisure-oriented aspects of work. For example, Callie, who lives alone, spoke of the workplace as a primary space for meeting her social needs. With a strained chuckle she confided, “that's probably the reason why I come in and do a lot more talking ...when I come in here, you know?... because when you go home, you don't have anybody to talk to.” She regularly eats and plays card games and dominos with a group of coworkers during their lunch hour. Regarding the occasional office potluck, she advised, “...I'm usually the one to--I always bring stuff.”

Rose also spoke of a socially active workplace. She and her coworkers frequently play practical jokes on one another. They bring in homemade treats to share and often have meals together. They have birthday parties and baby showers, sometimes during the workday. They listen to the radio and enter each other into contests. Sometimes Rose looks after her boss' grandchild who occasionally accompanies her to the office; she plays catch with him.

Although Princess sometimes plays cards with her boss during the lunch hour, most of her socializing with coworkers occurs after hours. For example, she invited all of her colleagues

to her last birthday party and was delighted that everyone attended. She has gone boating with one of her officemates. Princess has also hosted garage sales and gone on vacation with her boss who is among her closest friends.

Callie and Rose also indicated a spillover in social companionship from work to home life. Callie sometimes offers her extra sporting event tickets to coworkers who then join her at a game. Sometimes she and other work friends will attend the games of a team coached by another member of their workplace community. On occasion, Callie joins her coworkers for the monthly happy hour after work. Rose sometimes goes to lunch with other clerical staff from different units in her office building; occasionally they spend the weekend scrapbooking together.

Some participants' workspaces are not as collegial. Craig, John, and Marie mentioned current efforts to improve and increase the social interaction among those in their workplace communities. None of these participants expressed dissatisfaction with the degree to which they feel included; they recognized that the overall social climate of their workplaces was not ideal. As managers in their work units, they reportedly expected to be less socially engaged with their colleagues. John emphasized the need to maintain boundaries given his managerial responsibilities. Referring to his colleagues as "friends in a small 'f' sense, at least," he explained:

As I get into a managerial role...I think it's important that you take care in your employees' lives and ... appreciate what they are going through...whether it's a health issue or a family emergency or something like that. But...if you're too much of a friend, you can't be a boss, too.

Marie expressed a similar perspective. When asked if she felt connected to her workplace community she replied:

To an extent. I mean, I'm the boss, so, I certainly have that kind of boss persona –Am I included and connected with all their doing? – No, 'cause they don't want me to be, 'cause I'm the boss! Am I connected to some more than others? Yep...I try to connect with everybody, the same, so it's just a matter of you know, what's going on and whether or not they want to boss to know about it or not.

Further, she noted that there is minimal social interaction among others in the office. Coworkers rarely eat lunch together, and at the monthly potlucks staff members often fill their plates and take them back to their individual workstations. Marie and John stated a preference for spending their free time with family members and close friends, not colleagues.

Craig does not rely on his coworkers for companionship, either. He asserted that the social climate of his workplace has been negatively affected by office restructuring and staff changes. He noted, however, that it is “becoming more collegial.” He enjoys his coworkers and has found those in his peer group to be supportive. Craig expressed concern that his supervisor has little understanding of his disability-related needs and this is a source of stress for him.

A significant finding was that none of the participants felt that the presence of disability influenced their inclusion in the social aspects of the workplace, despite the fact that most had no coworkers with disabilities. Those whose workplace communities included other people with disabilities commented about this. Callie mentioned that she was “a little concerned” when, without requesting it, she was provided with a designated parking spot. She worried that another

employee who also had a disability would be “agitated” and want the same privilege. However, that colleague no longer works in Callie’s office.

Interestingly, Irene has several coworkers with disabilities; yet, she reportedly felt the least included of all of the study participants. When questioned as to whether she felt included or connected to her workplace community she thoughtfully responded:

“No, not here. I don’t think I am and I don’t know if that’s because I’m *really busy*?... I’m always busy...I’m doing my own thing and traveling .... I kinda--I wonder-- no, I don’t feel connected. And when I get the invites of ..., you know, we’re gonna celebrate someone’s so and so’s whatever, or, there’s a happy hour for so and so, but I don’t feel like I’m in, I have a group, you know, that I belong to.

Comparing this to her interactions in previous workplaces where she was the only person with a disability she reflected, “It’s like in one case, it’s like I’m anti-social and in the other one I’m like the social butterfly!” Irene suspected that this was due at least in part to her being single and having no children, factors that Callie also felt limited the degree to which she and her colleagues got together, especially outside of the office. Finally, Rose’s comments about her first job, many years prior to her becoming disabled, demonstrate the potential for work to improve one’s quality of life and for coworkers to become friends. She recalled the challenges of trying to fit in with her peers as a newcomer to the neighborhood and as someone from a less affluent home than her classmates. Her first job dramatically improved her social life. She recounted fondly, “I got my job in the bank and I was 15 and I started working!” Smiling broadly, she continued:

It was great because everyone there, we became friends and then with those people I joined a bowling league with the bank workers, ...they had like Christmas parties we went to, and ...we had, I made friends there and our friends, we all went to Great America, once, we went to Old Chicago, we went to concerts... once I got my job, I worked, you know, my social life became better.

**Friend.** For all of the participants, working offered a chance to be with other people. And for the most part, they enjoyed their colleagues. All spoke of friendships established through their current or previous employment. Some of them counted their coworkers among their closest friends. Others spoke of their strongest friendships being with people outside of their workplace communities.

The relational identity of friend was important for participants. Many reported friendships that have been maintained since their youth. For example, Craig is still in contact with friends who were teammates during his high school and college sports career.

John has small groups of friends that he sees regularly to enjoy favorite leisure activities; he goes golfing weekly with one group and attends a monthly reading group with the other. Some of his friends are former coworkers or their spouses. Reflecting on the time it takes to nurture friendship he noted, "It takes a lot energy for one to be a really good friend." Speaking fondly of his friends, Ken also commented that developing friendship "takes time." He told of how one friend installed special seating on his fishing boat so that Ken can join him on an annual fishing trip. Rose emphasized both the quantity and quality of her friendships commenting confidently, "*I have a ton of friends...ahh...a ton of friends and I just call, they're there.*"

Princess also has many friends. Several have been in her life since grade school; the others are former coworkers or people they introduced to her. They have dinner together at least twice a week and they go on shopping trips. Some of her closest friends, all nondisabled, have a good understanding of the frustrations she experiences due to limitations imposed by spina bifida and are a great support to her. She reported, “I never really felt like an outcast in my group...it was nice having my friends that accepted me for me...they would always include me...they still do.”

Irene emphasized the support she gets from her friends. Although she was able-bodied until her late teens, most of her friends have disabilities. According to Irene, they offer a kind of support that nondisabled people cannot. She explained:

...I think that's why it's important [to have friends with disabilities], 'cause you need to be able to share ...ask questions ... even like I said, sex, um, you know well what position works better for you or like what do you feel better doing .... I mean, I'm not gonna ask like my sister who has, you know, complete feeling- it's completely different. And then...clothing ...dress, like oh, what works for you? ...stuff like that.

According to Irene, her injury has “enhanced” her social life by increasing her circle of friends. Speaking more about the significance of these friends in her life she said, “... I mean, you always need that “in group” like the people that understand you. Kinda like, it can even be ethnicity, too ... like I like when I can talk about my culture with other people.”

Marie and Callie referenced their sorority memberships when reflecting on their social lives and friendships. Both were the only women with disabilities when they pledged in the late 1980's. They both expressed gratitude for the sororities not only giving them an opportunity by

selecting them for membership but for the willingness of the organizations to make the sorority houses wheelchair accessible so that they could be included. Although Marie has friendships dating back to her childhood, most of her leisure time is currently spent with friends from her church, the parents of her daughter's friends, or couples she and her partner know through the LBGT community. Callie, however, continues to be active in her sorority and helps plan events for the group. She is also an active member of her neighborhood association's social committee. Callie reports that it is much harder to meet new friends now, especially men. During her college years, she relied on the sorority as a main social network and regularly attended dances and hayrides with dates from a fraternity.

**Partners and parents.** Another relational identity in the lives of participants was that of spouse, partner, or significant other. Both Ken and John are married, and Craig is in a long-term relationship. Of the women, Princess is married and Marie is in a long-term committed relationship with a partner. All of these participants noted that they rely on their significant others for support. Marie expressed concern about the expectations on her partner stating, "...I've got somebody that I trust and know in my partner to provide the [caregiver] service even though I know I should probably do more with the caregiver to ease [my partner's] burden." Ken and John emphasized their responsibility for providing for their wives and children. Princess shared that her husband makes coffee every morning and brings her a cup, as she gets ready for the day.

Craig confided that when his girlfriend first approached him about a relationship, he declined and he still tries to "protect" her from the less pleasant aspects of his life with disability. He expressed concern about how their plans to move in together might affect their relationship.

Although it was not the only factor in his divorce, his disablement was more than his former wife could handle, and Craig thinks that his girlfriend's dealing with his issues on an everyday basis "can only hurt the relationship."

Ken and his wife of more than 35 years have two adopted children. John and his wife, married more than 15 years, have a boy and a girl. Marie and her partner of nearly 20 years have a young daughter. Each of these participants spoke about their parental roles. For example, Marie said that the household routine and social events center on her daughter. One of few parents in her workplace community, she stated, "I think being a mom influences me in all aspects of my life that ...right now...my knowledge base ...deals a lot with kids...so conversations around the office typically involves talking about my daughter or my family."

Ken spoke of his children, both in their early 20's, as if they were much younger. He confided, "Both my children have been challenging ...but they're just children." He and his wife raised several foster children prior to adopting. When it was discovered that his son had a disability, a friend bluntly suggested that they "take him back." Ken's agitation with this comment was still evident as he shared his reply, "You don't have a choice when you have biological children, you take what you get...we'll learn to deal with this."

John's commitment to family was also obvious from his frequent references to the importance of being able to provide for his wife and children. Clearly putting their needs above his own, he said, "I do have career aspirations...if they happen, great. If not, I make a very good living and am able to provide for my family, which is ultimately what it's all about."

Commenting on the priorities in his life, he shared:

My faith is first, my family is second, and...I think those are tied directly together because...my faith life tells me that ... we not only strive to get ourselves to Heaven, as part of my relationship, I wanna get my wife and my kids to Heaven as well...

**Other relational identities.** In addition to their identities as members of families and workplace communities, the participants spoke of other identities as members of religious communities and various organizations. John and his family are members of a local church, Ken attends mass each morning before work, and Marie regularly socializes with her church family. Rose is also very active in her church and a volunteer in one of its ministries. All of the participants have siblings and made reference to these relationships especially when describing their childhoods. Ken, spoke of being the son of an aging parent. Callie and Irene, who have no children of their own, spoke of their involvement as aunts in the lives of their nieces and nephews. Some participants also mentioned relationships in their larger communities commenting on neighbors who look out for each other and socialize together. They have ordinary lives.

### **Theme: The Same But Different**

The participants indicated that their lives have been very much the same, yet different from those of their nondisabled peers. They told of childhoods playing with siblings and schoolmates. They rode bikes, played sports, and sometimes went on family vacations. Yet, they also had concerns and experiences that were different from their peers. Further, as adults, they noted that aging with disability is different. Still, not all of their differences related to disability; several participants shared ways in which they felt they were different from their

coworkers due to factors such as marital status, parental status, and incompatible leisure interests.

### **Subtheme: Growing up Different**

Each of the participants with life-long disabilities reported being the only or one of few children with an obvious physical disability throughout their schooling. In some cases, they spoke of classmates who became disabled; but these kids were different, because they were once able-bodied. When Princess mentioned a schoolmate who sustained a spinal cord injury, I asked her if this affected her. She replied, “I don’t think it affected me at all because...we weren’t in the same category...it was just kinda like two different worlds.” Growing up, she had no friends with disabilities. Princess confided that she wore diapers until the 2<sup>nd</sup> grade and although she made friends, she stated that other children made fun of her.

Although John, like Princess, has spina bifida, he reported that his parents refused to have him wear diapers once he started school. Instead, he relied on medication to help control his bowel and bladder issues. Nevertheless, he was hesitant to play basketball in elementary school, not because of his physical limitations, but because he was fearful that he might wet himself while on the court.

John and Ken spoke about other children with disabilities that they met while in the hospital. However, these friendships did not continue once they returned home. Despite spending many summers at MDA camp, Marie did not socialize with other children with disabilities outside of that setting. In the other spaces (i.e., school and work places of her life) she had only able-bodied companions.

John, Ken, and Princess spoke of having had multiple surgeries. John's surgeries continued through early adolescence and took place over his summer breaks so as not to interfere with school. Ken spent a considerable amount of time in the polio wards and recalled having to attend a school for kids with disabilities when recuperating from surgery. Princess had a urostomy as a youngster and required additional surgeries when there were complications related to that. Ten years old at the time, she had already outlived many with spina bifida, and the urostomy was a new procedure for someone with her condition.

Ken insisted he did not experience social exclusion growing up. He reported that his father had a lot to do with his feeling included. His father was a firefighter, and Ken reported that this created a kind of extended family for him and provided many opportunities for socializing. Further, Ken and his brother used to help their father with odd jobs while other children were playing, so being away from his peer group was about being with and helping his family, not because of his disability. When he did play, Ken stated that his younger brother was a frequent leisure companion. In general, family members were primary leisure companions during childhood, for both those born with disabilities and those who acquired disability in adulthood. However, those who were able-bodied as children spoke of spending considerable leisure time with schoolmates who were teammates. For example, Irene shared:

We weren't really allowed to go that much; my parents were really strict. So, I didn't go out to parties or I didn't get to go on dates until I was a senior in high school. So a lot of my social activity included like sports, because that's the only thing I could do.

Several participants mentioned ways in which they differed from peers at play. Describing his favorite childhood activities, Ken stated, "I liked to play baseball, you know

football, and basketball... I was able to do pretty good; I *could not play on a competitive level with anybody who was any good, but I could play.*” Princess spoke of how her friends regularly modified activities so that she could participate stating, “I never really felt like an outcast in my group...it was nice having my friends that accepted me for me...they would always include me some way that I could be included in the activity without...standing out so much.” John recalled with a chuckle how he played the trumpet in his high school marching band, “It was always kinda funny. Always thought about the people that were up in the box at competitions watching” Grinning broadly he continued, “There’s one guy’s just kinda out of step there!”

Describing her childhood, Princess referred to other kids as “mean” and when I asked if she could recall any specific examples, she confided that she thinks that she tends to “forget bad things.” Marie mentioned mean kids, too. Speaking about the transition to using a wheelchair at age 13 she noted:

Plus! At 13, kids are just mean anyway, so at that stage of my life, kids were just mean in general. I had the experience but I had really good friends that weren’t my friends because of the wheelchair, they were my friends because of who I was.

Interestingly, John, Marie, and Irene all recalled seeing other people with disabilities at college but chose to have little or no contact with these individuals. For John and Marie it was reportedly a desire to avoid being seen as part of a cluster of people with disabilities. Irene returned to school just a couple of months after her injury and did not feel comfortable approaching the other female wheelchair user although she recalled that it “felt good” to see someone similar to herself on campus. Distancing one’s self from others with disabilities does

not necessarily change how one is viewed by other people. Marie was reminded of this a few years ago when she went to apply for a driver's license after relocating to a new state.

After successfully passing the written exam, she was ready to surrender her old license and accept the new one. However, her disability status resulted in a different scenario: They said, 'you have to take the driving test.' I'm like, what? ... But, I already have a driver's license, I don't understand. Why? So, then I was thrown into another category and then that just made me angry and so then I skipped that whole thing. I kept my [old]... license as a protest for two years. Then I had to vote in the election and it was like, I have vote, what am I gonna do? I haven't driven in three years. So then I got an ID card (sounding defeated) - that's ... the worst thing ever.

Callie talked about how environmental barriers present challenges that make her feel different and "awkward" in social situations. Speaking about going out with friends, she said, "...if we do something ...- sometimes they have to make special arrangements because I'm in a wheelchair. That sometimes makes me feel a little (softly) uncomfortable." She emphasized, "Sometimes- well it depends, you know. You feel included- that's a good feeling. And, other times, you feel awkward when they have to make other arrangements because of – and it can be with family, too." She described a recent family get-together in which their large party was seated in an inaccessible part of the restaurant, a significant barrier for this manual wheelchair user who is unable to walk due to clubbed feet. She reported, "They had to get me up a good-sized flight of stairs ... And then, you have a feeling of being *stuck*." With no way to move about on her own, she could not leave the area without assistance.

John apologized during our interviews concerned that he was “a really terrible subject” because he is independent and has not had many of the experiences of a “typical handicapped person.” Yet, when he reflected on what it was like to grow up with a disability, his words told a different story:

Growing up, I just didn't have anybody like that to talk with and kind of share any struggles whether it was ...dating or ... bathrooming issues or...surgeries or ... you're frustrated because you ... feel bad or what have you or learning struggles or anything of that sort or ... socialization issues – that was just the people, ya know, that ya hung out with. And so, I didn't, never really felt like ...anybody else would identify.

He quickly minimized these feelings stating, “kids were so much more resilient then ... I never really thought about it too much.” I wish I had thought to ask John why kids were “more resilient” in his youth. I wonder if what he was alluding to is the way disability was viewed at that time, the way he learned to view it, as something to disassociate one's self from as much as possible.

While thoughts of being different may not have been an everyday concern for him, John vividly recalled a turning point in his understanding of how physically different he appears to other people:

I had this revelation one day.... I was walking up to the library and it was the latter part of my college career. It was really bright and sunny so it was just like a mirror (referring to being able to see his shadow) and I watched myself walking the whole way up and I never noticed it before either, because I had my head down or whatever, but that particular day, I said, “Wow...that's how I look to somebody else!” And, it was at that

point I said, “OK, I gotta do something to change my life, socially”...I didn’t have a girlfriend or anything like that. But I just took a leap and I wound up dating somebody for about a year in college--it didn’t work out but...I just said, “Gee...it’s interesting how other people perceive me.

Ultimately, John reconnected with and married a long-time friend and former classmate. He stated, “She’d gotten to know me as a person ...rather than just physically how I appear to her.”

Despite an active social life in college, Callie said that her dates never resulted in anything more than friendship. Now, in her 40’s, she finds it especially difficult to meet men. Reflecting on her limited dating opportunities she shared, “I haven’t found anybody and it’s kinda hard sometimes.” Thinking back to her teenage years, she lamented, “...I think I was different, so that just didn’t happen.” In high school, Princess dated much less often than her friends did, and she was careful regarding whom she told about her urostomy. Although most of her friends married shortly after graduation, Princess met and married her husband in her 30’s.

Irene’s boyfriend of three years broke off their relationship about a year after her injury, unable to deal with her disablement. She stated, “I was in love with that guy...I was already struggling with being disabled and then I get dumped, you know?” Although she has a boyfriend now, it is a new relationship and she is cautious about what she shares with him regarding her disability. She confided, “I haven’t even told the guy that I’m dating that I use a catheter.”

Participants emphasized that throughout their lives they have been “just like everybody else.” They reportedly experienced the usual milestones at the same time as their peers. They began driving in their teens, most without any kind of modification. They graduated with

their high school classes. They moved out on their own during or shortly after completing college. Their friends were people who did not have disabilities and they just wanted to fit in, as evidenced by Princess' assertion, "I was gonna blend in no matter what!"

As they made their way into adulthood, and started their careers, their differences presented some obstacles. Despite having entered the job market after the passage of the ADA, Marie has chosen never to disclose her disability prior to a job interview; she is certain she has been denied employment because her wheelchair makes people uncomfortable. Ken recalled a manager who "assumed too much." He would not consider Ken for promotion, stating, "We were concerned that your polio would hold you back." Princess shared that when she interviewed with her employer some 30 years ago, she left her leg braces in the car. Once hired, she did not wear them to work initially. Finally, at her mother's insistence, she began to wear them in the office.

### **Subtheme: Different from Coworkers**

Participants reported ways in which they are different from their colleagues. Some of these differences are related to disability. Other differences were not related to their disabilities.

Craig commented the most about being physically different from his colleagues. He spoke fervently about how the seemingly constant presence of pain influences his work life. He stated, "Trying to fit an 8-5 or 8:30-5 job into- having a paraplegic fit into that...is...ya know, it depends on the injury and the *person* and but it's square peg round hole, you know?..."

Ken advised that his coworkers are very accommodating. There is always somebody around to open doors and help make it easier for him to navigate his workplace. Further, they

make certain he has what he needs to do a good job, without his having to exert much physical effort. He said:

They take care if I need information that would have been easier for a normal person to go out they try to bring it to me. Like taking pictures...of things that I need to know instead of me going out to sites - that makes it a whole lot easier.

John's disability makes some aspects of his job more difficult, too. He frequently travels for work and often has several appointments each day. In order to keep to his schedule, he usually rents a car and relies on taxis during his trips. So far, this double expense for transportation has not been questioned by his employer. However, more concerning for John is maintaining good self-care, especially while traveling. He is careful about his diet and uses the restroom at every opportunity. A few years ago, he became ill while away and he soiled himself during a meeting with a potential client. He explained that his spina bifida makes it harder for him to know when he needs to go to the bathroom and that certain foods may cause him to have to go more quickly than others. Fortunately, John was able to shower, change, and complete his business. However, the "episode" was an "embarrassing" and "scary" experience.

Marie recalled her own challenges with getting to the bathroom on time, while at work. Remembering what it felt like, she commented:

It was awful. It was! It was just awful. Um...there were three instances. I worked at three different places and I think there was one at each location that I worked (smile).

The first place that I worked was a Hospice, so I had lots of nurses around. Um, I always have my cell phone on my chair. It's always on my chair...and so I called from my cell phone to my [secretarial] assistant and I said I have an issue and I'm in the bathroom but

I need you to put a sign on the door that the bathroom is- out of order (slight chuckle). ... at all three places, that's what I had to do. And then, I called my partner.

It was these instances that led Marie to acknowledge her need for a caregiver during the workday, a reality she succumbed to a few years ago. Although her coworkers never mention it, she feels that having her caregiver come into the office emphasizes her differences and makes her use of the restroom, a matter that is "typically private," public.

Not all of the differences mentioned by participants were specifically related to disability. For example, Marie spoke of being one of the few parents of young children in her workplace. As single women without children, both Callie and Rose felt different from most of their colleagues. Princess and her husband were unable to have children. Regarding her childless status she said, "If I had had children then I would have been able to have a lot more things in common with my coworkers, with my friends...even with my other family members, because they all have children."

Craig does not have children of his own but spoke proudly of his serving as a role model and friend to the children of a former coworker and the able-bodied youth he coaches in his free time. Other than his disability, the most significant difference between him and his colleagues is in their leisure interests. For example, he expressed considerable disappointment that on the day after a big sporting event no one in the office is talking about it because they do share his love for sports.

Other participants indicated personality differences. Princess stated that she has a very different personality from most of her coworkers, referring to herself as "more of a go with the flow" kind of person as compared to their tendency to be more "my way or the highway" people.

Callie and Rose, both single and living alone shared that they are more talkative than their colleagues. Marie emphasized how she and her coworkers are different; she referred to herself as “an extrovert” working with “a bunch of librarians.”

Most of the participants are in their 40's. Now squarely in mid-life, they noted that aging with disability is different. They expressed considerable concern about how aging has further limited their physical capabilities. Moreover, they described how their families, coworkers, and medical professionals do not seem to understand.

### **Subtheme: Aging with Disability is Different**

The challenge of aging with disability was a prevalent theme among the participants. Addressing the impact of aging on their physical functioning was important to their sense of work-life balance. Craig was reportedly “quite healthy” until age 40. As a wheelchair user for nearly half his life, he has had a hard time maintaining a healthy weight, especially in recent years. He realizes that this creates other challenges noting: “I put on some weight and...it’s all kind of cyclic, you know?” Age and weight gain have caused increased pain, which makes it more difficult for him to engage in an active lifestyle. He lamented:

If I could get by back pain, I feel like I could do more. And I’d be more active...and *I’d want to do more*. It’s just, I think chronic back pain is *what gets me* maybe more than anything. It’s... it’s always there.

Additionally, Craig feels that his comments about pain are not taken seriously, even by his family. He confided, “I find it kind of hard to talk to people about that ...because they say

that's just part of getting older and I don't want to say '*you don't know shit.*'" His frustration was evident on his face as he leaned toward me and continued, "You *don't* know!"

In his late 50's, Ken is the oldest of my study participants. He spoke of trying to keep a positive outlook as he ages. He stated:

My physical condition is changing, it's deteriorating so, ... it's forcing me to adapt *in all ways*, ... (sighs)...because it's ... constantly changing...I mean, I don't, I'm not facing anything anybody else is not gonna face, as they get older, I'm just there a little earlier (matter-a-factly)...that's a challenge and... it's a good challenge (louder)...for me, I mean, I know that, but sometimes it's very depressing, too (more quietly), you know, because *why?*, why, why, why? And it's like *there's no answer to why*, but...so, I imagine everybody asks 'why me?'

Ken described how efforts to help maintain good functioning can have negative consequences, too. Although walking with braces and crutches is extremely tiring, he rarely uses his scooter because he is somewhat overweight and walking from the parking lot to his office and back each day is the only exercise he gets on a regular basis. He realized he needed full length leg braces more than ten years ago, but there was a "downside." He explained, "That was an adaption that I made, but...it it also caused my leg to get weaker because I could no longer use the muscles the way it is." Shifting in his seat, he continued, "you know, what is it, get hurt or you know, try to help yourself not get hurt, or...adapt."

John expressed concern about the "non-visible things that are going on" as he ages. Specifically, although only 40, he is dealing with increased issues of bowel and bladder control. Reluctant to use any mobility aids other than his AFO's, John also has knee problems, which his

doctor believes is directly related to his gait pattern. His doctor encouraged John to manage his life better so that he can prolong his enjoyment of favorite activities. Cautioning John he stated, “if it means you have to have knee replacement in 20 years instead of ten, isn’t that worth it?”

Princess, who is in her early 50’s, has already had a knee replacement. Like John, she has spina bifida and used only AFO’s until her 40’s. Recalling when she began using a cane she shared:

[My doctor] wanted me to use crutches first and I threw a fit-so, [I] started out with the cane...[I] have to remind myself that my knee will wear out if I keep [walking without assistance]. So, I have to use crutches.

Craig emphasized that for him, aging with a disability is “even more complicated.” He advised, with a slight chuckle, “I can’t feel two-thirds of my body.... And what I feel, hurts a lot of times, you know.” Craig made a comment that seemed to highlight a significant difference between aging with disability versus without, “you hear people complain about aches and pains of getting older, just anybody getting older...I mean how do I figure out what’s *that* and what’s my disability, you know?”

Marie is the only study participant with a progressive condition; she has experienced decline in her abilities throughout her life. She was advised by her parents at an early age that she would eventually be unable to walk. She stopped walking and began to use a manual wheelchair in junior high school. While this was a difficult transition, it did not compare to the challenge of moving to a motorized wheelchair five years later, as she started college. Reflecting on that time, she stated:

Even in high school people pushed me...and so, it was out of necessity [that I got a motorized chair] because of the setting. And it *was a hard one; I did not want to move to a motorized chair!* But, I had to, ya know. And even in college, my first year whenever I was in the dorm, I got out of my motorized chair and I was in my manual chair.

I was surprised; Marie struck me as fiercely independent. When I commented that it seemed she might be more independent in the power chair, she explained:

Yes. That is true. But it was more of a stigma... at 18, I was stuck on the stigma. And I would rather be in my manual chair. To me, it was more freedom. Yeah. Even though I had to rely on people to move me around.

In our next meeting she spoke more about the transition to a motorized wheelchair:

Yeah, I used a manual chair I mean right up to the very last second! I mean, it was, to me *moving to a motorized chair was such a h-uge step and statement, that it took for-ever, for me to get there. For-ever. And then it was just like ... I can't do this, I'm gonna have to go to a chair that drives* (slight chuckle). So I think ... those are the hurdles that as a ... as a person with a disability, that I struggle with are those big hurdles that define, *oh, gosh, you've moved to the next realm of disability.*

Having entered the “next realm of disability” as a teenager, Marie was still not prepared for what was to come. She confided, “I don’t think I was prepared for losing strength...not being able to do things. ...that never really comprehended ...that’s really the progression. I knew I would be using a wheelchair, but independence was always part of that. ...” For Marie, requiring assistance with toileting, one of the most private tasks in everyday life, is a big source

of stress. She asserted, “Having PA care just is a reminder of deterioration or...disability...it’s just, it’s back in your face again-- ‘cause you have to deal with it--...I feel like it’s a weight sometimes.” Aging with a progressive disability, Marie now realizes that she is likely to need more help in the future.

A final concern related to aging with disability is participants’ perceptions that their doctors do not understand. Regarding her avoidance of doctors Princess asserted, “They have been looking at me like I’m a specimen for 50 years and I’m done.” She has been the subject of three medical studies about people with spina bifida. As an older person with her condition, she reported that doctors are very interested in her. Describing her experience with medical professionals she said, “They’re like going, ‘Oh, well look at this!’ and I’m like... ‘Hello people, there’s a body underneath here-- I’m not your specimen!’”

Craig expressed his disappointment with physicians stating, “I’m astounded by how little doctors know about paraplegia and spinal cord injury.” John is also very concerned about his medical care as he ages. He noted, “...medical providers should have a certain degree of knowledge...but once you get beyond pediatric care I just, I don’t think there are people [doctors that understand], at least in the SB [spina bifida] world anyway...” He commented on the significance of good medical care on quality of life:

I think they’re treating it more just like a regular patient rather than somebody, who might have some other issues, you know-let’s figure out what’s really going on here. I understand medical science isn’t perfect. ...But, I think the...I think my quality of life is very good- I don’t know that it’s ideal....is there more that could be done?

Like John, Marie would prefer that her doctors initiate discussion about possible problems ahead of time and that they provide her with “more resources.” She finds that she is spending more time and money on disability-related concerns as she ages. When asked what her doctor has told her about aging with disability she responded “Nothing. It’s kind of an anomaly-- to live this long...”

John emphasized the increasing need for medical professionals to better understand disabling conditions previously associated with early death:

When I was born and growing up, there were not a lot of people who survived into adulthood...I’ve come to the realization that probably...people with disabilities--and as medical science improves and lives are prolonged--they don’t know how to treat adults ...with specific disabilities.

Most of the study participants are in their 40’s. They have disabling conditions that took the lives of many of the young people they met while in the hospital or at summer camp. Having survived to adulthood, they planned for and entered into the world of work like their nondisabled peers.

### **Theme: Work is a Way to Connect and Contribute**

The participants spoke positively about the importance of employment to their quality of life. They viewed work as a way for them to “connect” with other people. Employment also provided a means through which they could “contribute” to their families and society.

As employed people, they interact with colleagues on a regular basis and have the chance to use their skills to benefit others. In some instances, the nature of their work involved helping

other people. In addition, for those with families, income from work was important in providing for their partners and children.

For some participants work was critical to their social and emotional well-being. Ken commented, “[work is] my way of reaching the world, networking with people, and forcing myself to go out.” Callie also views work as a way to connect with others. Regarding the significance of work in her life she said, work is important “because ... it makes you get out... definitely forces- you know sometimes I wonder how much I would really get out if I didn’t have work.” Explaining why she would not want a reduced work schedule, such as a 4-day workweek if offered, she said, “...coming into work is my social, you know.” Marie also pointed out the value of work in terms of the chance it provides for interaction. She stated, “... I think [work is] very important; [it] offers mental stimulation ...interaction with other people...”

Ken noted the importance of work as a way to contribute. He commented that like many employed in technical fields he has focused on work and given little attention to developing his leisure lifestyle. For him, work is “what I do.” He stated, “it’s something I enjoy...I feel I’m successful with it...it makes me feel good.” Additionally, he confided that there is little he can do at home without his wife’s help commenting, “It’s fine and dandy when my wife is around, but when she’s working, then I’ve really got very little I can do.” Yet, at work, he is engaged, his years of experience are valued, and his colleagues seek his input.

Although she initially viewed working as a “way to fit in with everybody else,” Marie now enjoys work for what it gives her and what it allows her to give back. Regarding how she feels about work today she said, “I feel productive- you know. I’m doing my part.” Further, she noted the significance of work to identity and the perceived value of people in society asserting,

“I think work is...so much a part of who people are-How are you? What do you do? ...I think it’s super-important to people with disabilities to be able to feel a part of that...adult grownup-ness kind of thing...”

For Irene, work offers structure she feels she needs in her life. She commented, “...I *think That working provides that structure that I need* – just because it’s something every day. And so, that’s probably where the importance comes in. *Not necessarily like something that I value, but because it provides something that I need.*” The structure of work helps her to do the things she needs to do throughout each day. She noted that she thinks that there are “other things that would take priority [over work]-...my family and my friends...my hobbies...”

John also has a high regard for the family domain of his life. While he gets some satisfaction from the ways in which work enables him to contribute, for him, work is primarily associated with providing a good life for his wife and children, now and in the future. Reflecting on how he feels about his work he stated:

I think that’s really important--the people aspect of it [the ways in which it allows me to help people]...behind all that is kind of a sense of fulfillment...there are times when I wish that I had a job that was...touched a deeper part of my self...but...I...I do have a degree, a sense of purpose, but it’s not like it’s the highest order of purpose at least as it would be reflected in my own life, or my own values...

Princess commended, “If you don’t have a job, you don’t have a home. If you don’t have a home, it’s hard to have a family.” Other participants also viewed work as a necessity to “pay bills” and provide for their families. Yet, they emphasized the ways in which being employed

contributes to their overall well-being. One of the ways employment helps with this is by providing resources that can be used for leisure. Princess asserted, “I work so I can play!”

### **Theme: Leisure is Super-important**

Irene passionately stated, “Leisure is super-important!” She and other participants noted a number of reasons why leisure is significant in their lives. Leisure is a way to recharge, it offers the opportunity to do things not permitted or possible at work, and is a means for nurturing relationships with other people and with one’s self. Participants acknowledged that leisure participation involves considerable planning and can be physically taxing. Nevertheless, they viewed the benefits of leisure as worth the effort.

### **Subtheme: Leisure is a Way to Renew, Recharge, and Escape from Work**

For John, leisure was associated with “an opportunity to escape,” and to do things that are “not permitted by your everyday life.” The chance to sip a cup of coffee while reading the morning paper does not meet his definition or expectation of leisure. Rather, he explained:

[My definition of leisure is] definitely...much more active...I’ve always felt like I needed that, too...I don’t know psychologically, disability-related, that I always felt like I had to prove that to myself or that I needed that in order to get out and do it...but maybe.

Although he enjoys his book club and playing poker with friends, his physically active leisure best meets his need to get away from everyday obligations. Beaming he stated, “Golf is my great escape!”

Marie offered a more flexible definition of leisure. Laughing she said, “Leisure is anything but work isn’t it?” She emphasized that leisure involves “no agenda...you don’t have a

schedule.” She noted that it is not the same as other non-work times, like weeknights or vacations. She explained, “You’re always on a schedule on vacation, trying to squeeze out every moment of vacation. For me, leisure time is weekends...I don’t consider night time leisure because if you work, it’s still pretty structured.” Marie described how the essence of leisure is in the freedom to choose stating that leisure means “no plans- so to speak. Nothing that can’t be canceled (chuckle). ...You can always cancel... for whatever reason- I don’t feel like it, I’m tired.” Further, while people often joke with her that “it must be great to sit” all day, it is not as convenient as it might appear. Relying on weak muscles to keep her upright, she said, “... it takes something to sit in this position all day long--you know, from 6:30 [in the morning] to 9:30 [in the evening].” Consequently, both her body and her brain welcome the chance to relax on the weekend after having been physically and mentally “on” all week.

Ken relies on leisure to help maintain creativity and focus for his work. Regarding leisure he stated:

It’s very important because it helps me to stay focused on work.... I just find at the end of the week *if I don’t get away from it and think about something else*, that I get very *stagnant*. And, I can’t, I don’t come up with the ideas that I need to do...it’s sorta like getting very tired and not being able to function at a higher level ...that’s mental tiredness ... I think I *get mentally tired a whole lot quicker than I do physically* (sigh) and...so then, I, by switching to a different thing that has nothing, not related to that, allows me to relax...and actually come back...recharged, I guess.

**Subtheme: Leisure is the Real Me**

Some participants indicated that for them, leisure was a time and place in which they could be more authentic versions of themselves. Although they realize their mostly sedentary jobs are well-suited to their physical conditions, they have adventurous spirits and enjoy physically challenging leisure activities. These preferences reflect aspects of their identities that might not be apparent in their everyday lives.

Describing his job, Craig stated, “It’s a *desk* job. I can get to it. I can sit at my computer and keyboard and do it.” However, he has always gravitated toward physical activity and prefers being outdoors. Speaking about his leisure time he said, “I do physical, hard work for able-bodied people! - lifting, moving, swinging a hammer.” He told of how he went rafting with friends a few years ago and insisted on having his own raft because he wanted to see if he could manage it independently. The rubber raft, called a “rubber ducky,” offered no support to help him stay upright; he fell out, several times. He chuckled as he recalled the events of that day stating, “It was *one of the most daring things* and *one of the more stupid things*, I’ve probably ever done, I suspect...but, I wanted to try it, you know? Craig and his girlfriend like to travel. On a trip to Vancouver, British Columbia he met one of his long-time goals, going to the top of a glacier. He explained, “The glacier was a goal of mine; I don’t know why...being on a glacier in a wheelchair, that’s pretty good.”

Princess also reported doing things in her leisure time that are more suited to her personality than is her employment. Princess has always worked in the clerical field. When asked how she chose this line of work she said:

I wanted to do a lot of different things. But they [my parents and teachers] said I was gonna be a secretary [the only sit-down job they could think of] and that's what I was gonna be!...I just went with the flow.

She views her work as “a job, not a career,” and she has never been that interested in clerical work. She compensates for this by pursuing her passions in her leisure time. Princess enjoys the outdoors. A lover of animals and flowers, she volunteers with an animal rescue program and has taken horticulture classes for pleasure. Princess has an adventurous side, too. She enthusiastically described how she went zip-lining during a recent vacation she took with her boss. She had decided to try this new sport simply for the thrill of trying something new.

**Subtheme: Leisure is a Time to Connect with Family, Friends, and Self**

Ken emphasized the role of leisure in nurturing relationships. He stated that in addition to helping maintain his mental stamina for work, his leisure participation “also affects my children and my wife...I mean, it's how I draw people to me, too.” He enjoys “simple things” like going out to dinner or “just sitting around and talking.” For Ken, leisure is mostly about “spending time with people.”

Callie also focused on the social aspects of leisure. When asked what comes to mind when she thinks of the concept of leisure, after a brief pause she stated, “Leisure? --I would think, being with friends.” Passionate about shopping and “the art of the deal,” she believes that the only thing better than shopping is shopping with a friend. Unfortunately, with only one close friend living nearby, she often shops alone. Much of her leisure time is spent attending various family celebrations. Sometimes when she and her nieces are together they visit a spa for a bit of

pampering. Whether for family or friends she stated, “I’m one of those people that I’m probably gonna be the one there at a baby shower, a wedding, that kind of thing.”

Irene’s concept of leisure includes “hobbies, fun- things that I wanna do.” A sport-enthusiast, world traveler, and fan of outdoor concerts, she enjoys leisure most when it involves other people. Regarding the importance of leisure and relationships, Irene stated:

[It is] definitely, definitely, important. I mean, it’s ... definitely one of the priorities of my life- ‘cause I need to have fun, and I need to hang out with people that I wanna have fun with. And that I love and that I enjoy my time with. Leisure is super-important!

Some participants emphasized the significance of leisure in maintaining their physical functioning and independence. For example, Craig is planning to build a fully accessible retirement retreat. He explained, “The whole point of what I’m doing is fishing and swimming there--which gets into self-care...I’m planning to do things to get myself healthy”

Rose spoke of the importance of aerobics, one of her favorite leisure activities, in helping her regain abilities and maintain her independence. She asserted that regular exercise has helped delay additional surgery for three years longer than her doctors predicted. She shared how being active makes her feel:

It gives me a sense of myself. Being single and being independent it gives me a sense of- it gives me a really good sense of accomplishment, to say ‘Hey, I’m disabled and I’m doing these aerobics; this person who has no, anything, is sitting...is a couch potato.’

Marie also associated leisure time with independence and self-care, although in a somewhat different way than the other participants. She emphasized the need to be comfortable in her

leisure time which includes being in spaces where she can function as independently as possible.

She explained:

Leisure to me is being comfortable in a space that I'm at...in my home, I know I can go wherever I wanna go...at work I'm still...I'm still on guard- what if I have to go to the bathroom? What if it starts raining, What if I can't ...So, you know, leisure's about just kinda feeling comfortable where you are.

The participants noted that leisure participation does not come without costs. For example, John commented that because of his gait pattern he is "very prone to pulled muscles" and needs to consider this when hiking and engaging in other physically active leisure. Rose has to take pain pills well before the start of her aerobics class so they have time to "kick in"; without the medication, she cannot participate. She and Princess advised that weather conditions also affect their leisure participation. When it is humid, Rose's joints hurt and the plastic from Princess' AFO's is very uncomfortable against her skin.

Marie and Craig spoke of the stress involved in traveling with a disability as they described "accessible" hotel rooms with features that were not only inaccessible but unsafe. For example, on a recent trip Craig encountered a bed that was so high he struggled to transfer onto it from his wheelchair without falling. Marie spoke of her agitation with hotel clerks who accept her reservation and then advise that they cannot guarantee an accessible room upon check-in. She also reported that she was injured when airline personnel dropped her while providing assistance. Despite considerable planning, the only thing they can be sure of is that they are likely to face obstacles that will create stress, more than the typical traveler experiences because they deal with the usual hassles of travel, in addition to and their disability-related concerns.

Driving until they are tired is not an option. They need special accommodations, and that means planning ahead.

Irene, Marie, and Rose spoke of the need to plan ahead even when their leisure is close to home. Irene noted that some of her friends live in apartment buildings that do not have elevators; when she visits she has to be carried up the stairs. Marie commented that her leisure decisions are influenced by the need to be near an accessible bathroom or close enough to her home that she can get back quickly if the restroom at the leisure site does not meet her needs; concern about toileting sometimes means declining invitations to get together with friends. Rose explained how disability affects her leisure participation:

I have to be really careful what I do, when, and where I go. ...I have to scope out in advance, like I'll have to call and I'll say do you have chairs? Or do you have benches? or there are certain parks I can't go to because they don't have benches close enough or...so as far as my leisure activity goes, a lot of times I have to call ahead, find out what they have what they don't have, *so I can plan - I just can't be spontaneous anymore.*

Leisure is essential to the lives of the participants. It takes considerable effort-but it is worth it. Princess emphasized this commenting, "If I'm gonna be dying or hurting ... [I want to be doing] something fun!" Rose explained her belief that leisure and work are equally important: I'm a workaholic, ok (chuckles softly)...but, I couldn't do it without my aerobics, which to me is my leisure. I couldn't do it without clearing my mind like working Sudoku puzzles every night, otherwise, my mind would be racing with what I have to do tomorrow ... So it's important. I'd say it's equally as important as work because it keeps me in balance with work - if that makes any sense.

### **Theme: Balancing Life is Work**

Few participants had heard the phrase “work-life balance,” before. To get an understanding of how they conceptualized this and what strategies they used to maintain balance, I specifically asked about their priorities and their sources of stress. I also asked how they managed these priorities and stressors. Of course, their responses to questions related to employment, leisure, relationships and self-care also provided insight into their work-life habits and concerns. Considering all of these factors, I summarized how each participant defined the concept of balance and what he or she seemed to feel was required in order to maintain it. These summaries were shared with the participants to ensure that they captured the essence of their thoughts.

#### **Subtheme: Balance Means Planning Ahead and Having a Routine**

Several participants indicated that planning ahead and having a routine was critical to work-life balance. Callie described how she gets up about an hour and half before she needs to leave for work. In addition to bathing and dressing, this usually gives her time to feed her pets, do a load of laundry, and enjoy a cup of tea. In a questioning tone she stated, “I could probably, maybe, do it a little faster, but usually, I just take my time. She finds that “being late is stressful” and she would rather not start the day behind schedule. To save time and energy during the week, she prefers to cook on the weekend and stores her meals in single portion servings that she can microwave when she gets home from work. Most meals consist of pre-packaged foods prepared on top of the stove; because they are easier to prepare.

Irene and Princess also spoke of the importance of routines. In fact, both mentioned work as an important source of “structure” in their lives. Because she likes to sleep, Irene said

she has to be “fast” in taking her morning shower and grabbing something to eat as she heads out the door. Although she insisted that she does not move slower since her spinal cord injury, she tends to be late and this can be stressful. She explained:

I think my time-management stresses me out- ‘cause I’m always late. ...when you’re late for one thing that kinda pushes back your whole day- so that can be a little stressful...I’m like...oh, shoot!, I have 15 minutes to get there and I’m not even close to being done ...I’m always late.

Princess stated, “I’m very spontaneous...but I like structure.” She has a set morning routine, and having a job to go to is an important part of it. Her biggest source of stress is having to ask for help. She expressed frustration in needing to plan ahead for tasks related to managing her things at home, such as cooking for she and her husband. She described how she felt the last time she cooked, stating, “I didn’t wanna have to call him. I wanted to be able to take it out of the damn oven and put it on the thing--do it myself!” She described having to coordinate plans with him so that he would be home in time to get the food out of the oven before it is overcooked.

Princess lives a few towns away from where she works. When she needs to run errands, she said, “...I try...to do my little circuit and do everything all at once...I don’t usually make a lot of spur of the moment trips.” By planning ahead, she is able to limit tiring tasks like grocery shopping to twice a month.

Rose’s routine involves waking up “at least half an hour” early “in case” she needs to take a pain pill. If she does need medication, this extra time allows her to “lay there and let it take effect” before she gets ready for work. Her aerobics classes and church participation

provide structure for her evenings and weekends and give her something to “look forward to.”

Errands are planned around available time and energy. Rose, who navigates 15 stairs to get from her apartment to her car, reportedly has the most energy right after aerobics. She stated:

I try to do everything like right after aerobics and then I usually get home about 2 and then... I nap ‘til like 5 or 6 and then I’ll get up and do like housework or whatever. But, I do have to sit for like a 3 hour stretch of time. So I try to get all my errands done while I’m out, so I don’t have to go ... out because once I’m home, I generally try to stay home because of my stairs.

Describing his evening routine, Ken spoke about how importance of following it to the letter. He explained:

I find myself very regimented because I have to, I wanna go to bed at night; it takes me *a while to get my braces off* (he speaks this more slowly giving an indication of the additional time required)...get all set up to go and (exhales) ... sometimes that’s very, ya know, you asked me about frustrations, sometimes that’s very frustrating. I don’t, I *wish I didn’t have to go through that stuff*, but then it, like, as soon as I skip a step that’s when I fall and hurt myself. Or, do something stupid.

All but one participant spoke of “being prepared” for the possibility of having a bowel or bladder accident during their work or leisure time. They keep a change of clothes in their cars, offices, and gym bags. For longer trips, they make sure they have enough catheters and one participant said for trips of more than three hours, “I’m not ashamed to say I use those Depends Pull-ups.”

As both a parent and a person who requires personal assistance, Marie does an extraordinary amount of planning. She and her partner “split duties” in their household; they

each have specific household tasks and responsibilities related to their daughter. They have to bring her to school and pick her up on time each day and her extra-curricular activities and homework assignments are part of the evening routine. In addition to coordinating meals and other household needs, Marie manages her personal care. Regarding this she stated:

My job that I have 8 to 5 is *way* easier [than managing caregiver services], because in that job, if I fire somebody, I gotta have a back - up plan ready. And, I don't have a back-up plan ready. That's one of my main issues is that, there's so-o much planning involved.

Marie shared that the need for personal assistance impacts her work and leisure time and is a constant source of stress. She explained:

Having to rely- having to pay someone to help me in those areas is...it's still something that I just don't like. Makes me angry sometimes (quickly adds) 'cause it's just so stressful. There's too much planning involved...I just don't have the freedoms to you know - go to the bathroom whenever I want.

Speaking further about her "very scheduled" life Marie confided:

I tell people all the time, can you imagine if you had to schedule when you can go to the bathroom? I don't think they have any idea. (Pause) Believe me *I had no idea*. The big stressor recently for me and my partner, especially since her back's gone out, has been-- 'cause we go out and about--What does the restroom look like? How quickly can we get home if we need to? Because I know I can do it at home, even with her back out. But if we're out, you know, can I have my caregiver on call on weekends? What if something comes up and I need somebody so...even, it spills over into leisure, you know...Even

though my primary caregiver in leisure is my partner, there's always the 'what if.' What happens if she can't get to me or she's out running an errand and something happens?

**Subtheme: Balance Requires Mutually Supportive Relationships**

Participants spoke about how the people in their lives help them to maintain a sense of balance. Some emphasized that these helping relationships are not one-sided, but mutually supportive. For example, Ken expressed a deep concern and gratitude for his wife and children; they are his biggest helpers. He said, "... they do all the stuff that people would normally have to do themselves ... fixing meals, making the bed...cleaning-my wife and son do all that because it's all energy that I get to save and use it someplace else." In return, he shows his appreciation by little gestures such as letting his wife know if he has plans to eat lunch out with his coworkers so that she does not make the effort to prepare something for him. He frequently commented on his commitment to doing all that he can to help his wife and children be happy.

John is reluctant to share much about his personal life with his colleagues; however, he too, considers family relationships a priority. "I try to strategically mention ... at least to those who are my supervisors... about my family- just ... as a little reminder...there's a wife and there's kids out there ...I try to incorporate that in when I can." Explaining his preferred 6 AM weekend tee time, he said "...because my family is more important, I don't like to spend my whole days doing that." He enjoys his favorite pastime and is home in time for breakfast. He described his wife as his "#1 support mechanism." Further, he stated, "She understands my issues. ... (chuckles) My psychoses...She's also a good conscience, ...in terms of 'take it easy' or 'watch yourself'..." Concerning his able-bodied spouse, he quickly pointed out, "...she's had

her own share of health issues, too...so that makes it...I don't feel like I'm imposing...there's still a benefit pro quo." Both sets of grandparents also help with the children when needed.

Princess spoke of her husband and his tendency to put things out of her reach. At just 5 feet tall and with her balance compromised by her disability, his habit creates some stress for her. Although "he still doesn't get it," she said, "he is very good at helping me without making me feel like he's...going out of his way." Her friends are another source of support. Describing how they help her manage frustration she commented, "...they're very good at reading [me]...even sometimes before I even get it...I don't think they know what I'm going through but...they're really good at reading things and that helps."

When asked who helps her balance things in her life, Callie immediately thought of a close friend who lives the next town over from her. One way that she helps is by assisting Callie with household chores. Callie used to have a housekeeper, but most cleaning agencies only do standard housekeeping. She would rather have someone who can do more than mopping and dusting. She needs someone, like her friend, who will wash dishes and change bed linens. However, Callie advised that her friend is most helpful by spending time with her and "just talk[ing]." Family and friends are very important to Callie and she makes it a point to attend the special occasions in their lives. She also contributes her time to her sorority and homeowner's association.

When describing her priorities Marie asserted, "family first, work second...and I think community and friends is important." When she and her partner were looking to relocate, they agreed to consider only towns where they already had friends. Although they initially knew only one couple, they soon joined a church and their circle of friends quickly expanded. Friends

occasionally help Marie take care of things at home when her partner travels for business.

Family members including Marie's sister and her partner's mother have also pitched in during these particularly stressful times. Marie explained:

I would need live-in assistance if I didn't have my partner. I mean, you know, when she travels, it's a whole 'nother level of complicated...it's a really challenging time... And so, what we've been ...doing, is ...utilizing family or friends to come and be the overnight staying, but then upping the caregiver to ... 4 or 5 times a day. Coming in mornings to get me up and dressed and coming to my office during the day and then coming back during the evening to help get me to bed... so it's very hard to ask a friend to come and be the person that stays in your house with you and drive you around and ... then, I have that, 'cause in the winter I can't take the bus. So, if it's a January trip, I have to have a driver.

Flexibility on the part of her employer is also a help to Marie when her partner is away.

She stated:

I have more issues with my intestinal problem- when your stress level's higher, you're gonna have more issues. So...when she's gone for more than a week, I tend to schedule myself working from home a couple of days because it's ... I guess that comfort zone- I know the house, if I needed to I could get somebody to, instead of being at the office where I- so, a lot of times, anything that's an extended period of time, I'll schedule myself 'home days'... I'll still work, but I'll arrange it so that I can work from home

In order to balance her own needs with those of her family and her job, Marie has to alter her usual routine and accept more help than usual. Adaptability appeared to be common strength

among the participants. Craig talked about some homemade aids he uses to take pressure off his knuckles when he transfers to and from his wheelchair. Other participants told of finding their own ways to accomplish tasks using the abilities they have. Princess expressed it this way, “Never quit looking for an alternative way to get what you want.”

### **Subtheme: Balance Involves Adapting to Limitations and Still Enjoying Life**

Some participants reported a continual need to adjust how they do things in order to maintain a good quality of life. They have found ways to do the things most important to them, even as their level of functioning has decreased. They asserted that this has been more challenging as they have aged.

Ken shared that his primary goal is “stay out of a wheelchair!” His second goal is to “adapt” so that he does not hurt himself. He does not like using crutches; he walked without aids for many years. He acknowledged using his motorized scooter “a lot” depending on the distance he needs to cover. Although reluctant, he uses these devices because he wants to continue to be healthy and needs to be able to get around. Ken’s limitations have caused him to adjust his leisure, too. He explained:

I used to...I mean, I can’t obviously play any sports ...I really enjoyed camping. But that was just getting physically too hard for me. ...cutting back and being smart in what I do. I’m trying to do a little coin collecting, things ... that I can do at home.

Marie is a self-described extrovert who likes to have friends around. It has become more challenging for her to go to new places because of concerns about possible inaccessibility or inadequate toilet facilities. She advised, “The older I get, the more I like to have people to my

place versus going places.” Spending time with family and friends is important to her sense of balance; now, she just does more of this at home.

Regarding her home, Callie shared “it’s not technically accessible, but ...none of the steps were very high....I could get in and out, but I had little ramps put in anyway.” Next, she plans to have the kitchen remodeled so she can more easily reach the countertops and cabinets. When this is done, she thinks she may enjoy cooking more than she does now.

John and his family live in a two-storey house. He helps with housework and childcare and does the stereotypical “Dad” things, like replacing windows and installing ceiling fans. He struggled when asked if he modified how he accomplished tasks in his home. Commenting that he might not be a good candidate for this study, he explained, “...I wouldn’t say, ‘Oh I can’t do ... don’t ask me to do that because of this or that or what have you or can we get this to make things easier,’ ...” Other than his AFO’s, he uses no aids or accommodations. However, he confided, “I’m up and down the stairs, but I tend to...think strategically...I usually go downstairs in the morning and up the stairs at night, *if I can*.” Judging from the health concerns he has had over the last ten years, he realizes he may need to make adaptations in how he gets around. He stated:

It’s hard for me to envision myself deteriorating to the point where I would need [a scooter or wheelchair at work], but...intellectually, I think I understand that could be a possibility...it’s just kinda the way it’s shaping up... [I] [I]look at myself between 40 and 30 and ...if it’s just even the same level of quality of life issue in those 10 years going forward 10 years, ... it could be a lot more serious.

He does not currently use any products for incontinence, but that may be in the future, too.

Speaking about comments from people he met through a disability group list-serve he said,

“They talk about ... needing those aids and ya know, pride tends to go out the door, as you get a little bit older. Quality of life is more important than having to worry about those kinds of things.”

This comment reflects the need to accept one’s primary disability and the possibility of further limitations with age. Just like they plan their days to manage the demands of work and home, they are beginning to plan for the future, warding off the negative consequences of aging with disability for as long as possible. One way to do this is by practicing good self-care habits.

#### **Subtheme: Balance Includes Self-care, Broadly Defined**

I inquired about participants’ self-care practices. I initially allowed each to define the term in whatever way he or she wished. A few viewed self-care to be synonymous with personal care. I then offered a broader definition that encompasses any strategies they used to help them feel or function better or that enabled them to better manage their lives.

Princess described a life-long pattern of going to extremes- often physically pushing herself in an effort to keep up with nondisabled friends. When I asked her about balance she shared, “I don’t think balance is a term that one would for me- at all...I can’t, I’ve never done anything in moderation.” Although she still pushes herself sometimes, especially in her leisure, she stated, “[Now] I choose what I expend my energies on very carefully.” Her one consistent self-care habit is praying each morning. Although not involved in a church community she finds this helps her feel more balanced throughout the day.

Faith is a central part of Rose's life. Church friends help her to keep a healthy perspective on her challenges and frustrations. She stated, "...church is a very important part of my life... church really helps me maintain my sanity."

Self-care is a priority for Craig. A few years ago, he put a sofa in his office. He gets out of his wheelchair and lies on the sofa during his lunch hour. He explained that he does this several times a week, stating, "I feel like I need to."

Marie would love to be able to get out of her power wheelchair and stretch sometime. Unfortunately, this would require more time than is available. She explained, "...the time it takes to get in the bed, get out of the bed, get the chair...there's no time for it. Even in leisure, there's no time for that. Because, life is, life is upright! You know." She used to have a massage every other week, but then her masseuse moved out of state. She confided that it is her "MO" to put off figuring out how to do things, especially if they are things that should not require so much effort, like finding a new masseuse. She said, "...self-care gets pushed down because I don't wanna have to figure it all out...I find joy in doing stuff with my family - that to me is a regenerator. Sometimes I like to just watch mindless T.V."

Craig had just returned from vacation when we met for the second time. He looked refreshed and his outlook seemed more positive than before. He was able-bodied and athletic for the first half of his life and is reportedly still adjusting to the loss of things others take for granted. Regarding the issues of balance and quality of life he asserted:

I think ultimately the thing I've learned is that it is all about choices. It really is about choices...don't let the things I *can't* do interfere with the things I *can do*...I think it's just a very personal thing (quickly adds) it has nothing to do with disability. I mean, it's

just...it's up to me...if we accept that ... that's a big thing. I mean, that's huge- if you really think about that.

### **Conclusion**

Managing the demands of life and work is challenging whether or not one has a disability. However, the presence of disability magnifies the challenge. The men and women I interviewed spoke of “regimented” lives. Not only do they have household routines for addressing their children’s needs, they have to consider their own care, too. This often entails things that their nondisabled family members and peers do not have to consider. Ken’s braces are bulky and when he walks, his right pant leg often gets caught in the metal frame. Walking with his crutches, some of his challenges are apparent. However, sometimes the participants noted “non-visible” concerns, as well. Throughout the day, many of the participants are careful about what they eat or drink; poor choices about intake could require that they get to a restroom quickly. They are concerned, based on experience that they will not be able to get there in time.

Sometimes things do not go according to plan. When the unexpected happens, the participants may have fewer options to address the problem and need to rely on others more than they would like. Callie, whose car is equipped with hand controls, stated, “I hate when... anything mechanical breaks down.” She commented on the stress she experiences when she has car trouble: Because I have to find a ride...and, (almost whispers) *I hate doing that*. Because it takes away independence, for me. And then, ...and it’s hard for me to just get another vehicle ...my family has plenty of vehicles, I could probably borrow one, but, obviously, it’s not going

to be accessible- handicapped accessible so, so it makes it *very difficult*. Fortunately, Callie uses a foldable, manual wheelchair. So, she is able to get a ride to and from work with a colleague who lives nearby.

All of the participants value their independence and seek to do for themselves whenever possible. Having to rely on others for help with toileting or even for a ride to work puts them in a position of dependence. These situations emphasize their differences and remind them of their physical limitations. Yet, in order to be successful, they cannot afford to think much about it. They just go about the day.

In many cases they are unaware of the specific ways in which they juggle the demands of their lives. With a facial expression that seemed to indicate, “that’s just the way it is,” Ken explained, “*You know what you’ve gotta do and you need to do it, even though you don’t want to do it.*” For Ken and other participants, the balancing act was more or less “second nature.” It is not possible for the human mind to think a negative thought and a positive thought at the same time. For these workers to think of themselves as capable people, at work and leisure, to some degree they have to minimize thoughts of disability. Like everybody around them, they learned that disability is bad and to be nondisabled is good. Ken, the oldest of the participants, has seemingly come to a different conclusion. Still winded from navigating the long hallway leading to our meeting place, he asserted, “...having a disability, there’s nothing bad about it. It’s just...you can live life and have a good time. (pause) I consider myself blessed that I did not know what it was like to be ‘normal’.”

Choosing to see themselves in empowering ways, choosing to connect with other people, choosing to contribute through their work, choosing to make the effort needed for leisure, and

choosing to accept help when it is absolutely necessary- these are the ways in which the men and women in this study have created satisfying lives.

## CHAPTER 6

### DISCUSSION AND CONCLUSIONS

#### Rewards and Challenges

This project was very rewarding. It was a true pleasure to meet the participants. My only regret was that I did not meet some of them sooner. We have many things in common, besides being persons with disabilities; they would be fine leisure companions. Listening to their stories, I was delighted and grateful to find a depth of information that will help me contribute to the literature and to increase understanding of what it means to live and work with physical disability. While I remained excited about my research throughout the course of the project, there were also challenges.

#### Being a Researcher with a Disability

Although my disability status seemed mostly to be an asset, with participants frequently commenting, “you might be able to appreciate this,” or “I can tell you because you’re disabled,” there were also times when it was uncomfortable. For example, Craig seemed offended when I asked if his girlfriend was able-bodied. He commented that he finds it “interesting” when asked this, “as if [his being a person with a disability meant that his companion was disabled] by default.” In this brief instance, I felt that he viewed women with disabilities as some kind of booby prize, less valuable than women without disabilities. He used to be able-bodied, and as I prepared to meet with him, I realized I had concerns about how he might view me as someone with a lifelong disability.

The assumptions some participants seemed to make about me were also interesting. For example, when I first met Princess, I was using my wheelchair. Within a few minutes of our meeting, she commented that I had “obviously adjusted” to using a wheelchair, although I had shared nothing that would have confirmed or denied this.

Oliver and Barnes (1997) pointed out some of the challenges unique to researchers with disabilities, including the fact that “for some disabled workers everyday tasks take longer” (p. 812) and they may have to deal with inaccessible transportation and buildings. At times, I found the process of conducting the research physically challenging. For example, one day I decided to have lunch at a residential dining hall on campus prior to meeting one of my participants. After lunch, I noticed a patio area and I went outside to do some reading. Shortly before my appointment, I attempted to re-enter the building and found that the door was locked. I was using my wheelchair at the time and was distressed to see that the only way off the patio was to navigate the stairs on either side. Given that there was no one else on the patio to assist me, I placed myself directly in front of the door I had previously come through and pounded on it until someone heard me. Several minutes later, a woman let me back into the building. I then rushed to my car, lifted my wheelchair into the trunk, and drove to my appointment. I got out of the car and, using my crutches, made my way to what turned out to be the wrong door. I then got back in the car, found a parking spot closer to the entrance I needed, and made my way to the correct location. When I arrived, I was more fatigued and less focused than I would have liked. Additionally, my desire to maintain my own wellness activities (e.g., physical therapy, swimming, cycling) and my effort to complete all of the interviews before the winter weather set

in sometimes led me to schedule several meetings a week, which was tiring and made it difficult to keep up with my journaling and transcription.

### **Remembering That I Only Know My Own Experience**

As a person with a disability and someone who has worked with people with disabilities for many years, I had to remind myself that whatever I know about disability may or may not apply to my participants. When I found myself wanting to put on my rehabilitation counselor hat, I tried instead to focus on my participant and only offer information that might be of genuine interest. For example, when Marie, Callie, and Princess mentioned leisure interests they wished to pursue, I was able to provide information about programs through which they could try these activities. I viewed this sharing of information as a kind of reciprocity for the time participants gave to the project.

Another challenge related to what I thought I knew is that nondisabled people provided all my foundational training in rehabilitation counseling. They taught me the rehabilitation model of disability, which is based primarily on the medical model. It is a somewhat paternalistic model that emphasizes helping persons with disabilities to use whatever abilities they have to live as “normal” a life as possible. At times, I found myself judging the comments made by my participants from this rehabilitation counseling perspective; sometimes I questioned the validity of their perceptions in light of what I thought I knew, for example, about adjusting to disability. Reflecting on my own feelings as I read the transcripts, I was reminded that as a member of larger society, with no role models to counter my perceptions, I had made assumptions about people with disabilities as a group that I at times projected onto my

participants. Further, I realized that some of the seemingly contradictory statements they made about their identities did not mean they were in denial about disability; rather, only that they, like all people, feel different about themselves and their disabilities at different times or in different contexts. In other words, sometimes they seemed to view themselves as disabled, and other times not. Their self-identification as persons with disabilities seemed to be influenced by whom they were with, what they were doing, and what they had experienced on a given day.

### **Being Helped**

One of the most significant challenges in completing this project was that most of my interview experience with people with disabilities involved working with people who came to me for assistance. I was the professional--the presumed expert. I was the helper. As a researcher, I sought help in the form of study participants, and the people I interviewed agreed to provide it. In this instance, I was not the helper but rather the one being helped. Consequently, I found myself reluctant to pose questions that I would have asked with relative ease if I had been in my more familiar helper role. For example, while I suspected that some of my participants glossed over difficult social experiences from their early years, I felt a tension between my researcher role and that of being a person with a disability who wanted to respect their privacy. I reflected on this challenge in my journal. I wrote:

I feel like being a researcher and being genuinely concerned about [my] participants are sort of counter to one another. The genuinely concerned part of me says peoples' personal issues are personal and that just [because] they're disabled doesn't mean they have to share all to educate the masses. The researcher in me needs "meat" but I like the

concerned person more and hope...to get what I need and find a way to present it and share ...in a way that truly serves others. (July 19, 2009)

### **Summary of Findings**

Figure 2 offers a visual representation of the key findings of this study. The presence of all shapes and colors depicted in each domain represents the ways in which each life sphere is influenced by the others. For example, the blue circle represents work and coworker relationships. The presence of blue circles inside of the leisure domain (depicted by yellow triangles) indicates that coworkers may also become friends or leisure companions. Participants reported that work, home, and leisure were important life spheres in how they viewed the concept of work-life balance. The relationships and roles they had within each of these domains also influenced how they managed the other domains. Further, the presence of disability and the need to be mindful of good self-care practices, especially due to aging with disability, influenced their work and leisure lives.

## Work-Life Balance and Disability

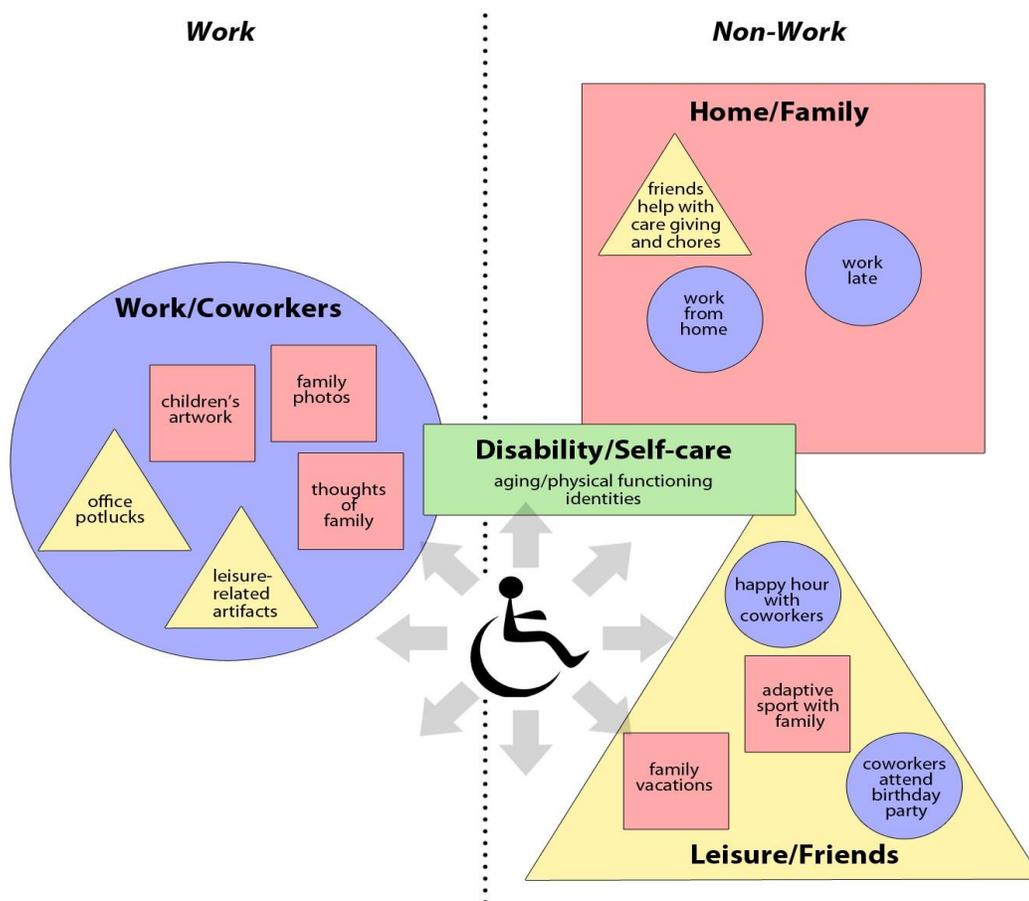


Figure 2. Visual representation of key findings.

The responses of the men and women I interviewed indicated that they view both leisure and work to be significant life domains; both contribute to their social and emotional well-being. The presence of disability influenced their work and leisure choices and their participation in these settings. In some instances, frustration with limited job options due to the need for sedentary work seemed to be compensated for by leisure that was physically challenging. Issues

such as poor balance or bowel/bladder concerns sometimes caused participants to decline invitations or modify their leisure plans.

Family and friends represented other important life spheres; they provided companionship and support, which the participants reciprocated. The married men commented on the importance of being able to provide for their families, and all of the men mentioned encouraging their partners to pursue their own passions, indicating a genuine interest in the needs of their mates. In many instances, especially for the women, work-related friendships spilled over into leisure time.

Disability/self-care represented another significant life domain, one which required more of the participants' time and attention as they began to experience decreased functioning with age. They noticed these changes about a decade sooner than they typically occur for persons without disabilities. Further, because many of them have disabling conditions which were in previous generations associated with early death, they have no role models for dealing with aging on top of disability. Few people in their lives, including medical professionals, seemed to understand their unique concerns. Further, given that they outlived many of their peers with disabilities, grew up with negative stereotypes about disability, and desired the acceptance of their family members and nondisabled peers, most of the participants reportedly had few if any friends with disabilities.

### **The Significance of Leisure and Work**

One of the questions I sought to answer with this project was, "What is the significance of work and leisure to the participants?" The participants indicated that they greatly value both

work and leisure, noting that these life domains offer vital social interaction. Further, work allowed participants to contribute to their families and to society, and leisure represented a means of good self-care through rejuvenation. Most preferred physically active forms of leisure and stated a preference for engaging in leisure with companions, even when physically tired, because they recognized the health benefits of being around others. This is consistent with Iwasaki and Mannell's (2000) work about how the perception of social support aids in coping with stress. Leisure also provided a vehicle for the expression of passions that were in some cases more consistent with participants' more authentic selves than was their employment. Having settled for "desk jobs" because of the need to sit all or most of the day, they enjoyed challenging themselves, by choice, in their leisure pursuits. These behaviors support Mannell and Kleiber's (1997) assertion that "it is in the liberating context of leisure that identity alternatives are often initially considered through the expression of personal interests" (p. 293). A few participants (male and female) mentioned that they tended to place the needs of their spouse, children, and/or church before their own needs, and this decreased the amount of time they engaged in leisure of their own. This is consistent with research such as Guendouzi's (2006) study of working mothers who reported guilt whenever they felt they put their own needs before those of their children. For individuals in my study, the presence of disability further affected their work and leisure participation.

### **Influence of Disability on Leisure and Work**

Another question addressed by this study was, "What is the influence of disability on the leisure and work lives of the participants?" The participants participated in a variety of leisure

activities such as golfing, hunting, cycling, skiing, scrapbooking, eating out, and shopping.

Many stated an interest in traveling and expressed considerable frustration about the amount of planning needed--because no matter how much planning they do, it is likely that they will encounter considerable obstacles during their trip. They spoke of supposedly accessible hotel rooms that had beds so high that they struggled to keep their balance when transferring from their wheelchairs, and one participant reported being dropped by airline personnel while being assisted off the plane.

A few participants expressed sadness over leisure interests they once enjoyed, but which are no longer physically possible. Further, leisure participation often required the use of additional mobility aids, such as scooters, which the participants reported they avoid whenever possible. Concern about access and having to have a restroom nearby also constrained their leisure. In response to some of these concerns, a few participants have started to do more home-based leisure. These changes in leisure participation are consistent with several studies about leisure and aging that indicated that as people age, they tend to decrease participation in activities outside of the home and requiring a high degree of physical exertion or high level of involvement (Mannell & Kleiber, 1997). The presence of disability resulted in my study participants changing their leisure lifestyles sooner than is typically the case for persons without disabilities. Aging also led to functional limitations secondary to disability; these issues presented problems at home and at work.

Regarding how the presence of disability influenced their work lives, some participants spoke about going into careers they did not enjoy because they needed to do sedentary work. Despite the sedentary nature of their work, the act of getting ready for work and working through

the day was reportedly quite taxing; a few mentioned that their doctors and/or other people, with and without disabilities, have suggested they stop working and apply for disability benefits. Participants with chronic pain, bowel/bladder concerns, and/or a need for personal attendant care who were willing to advise their supervisors of these needs reported feeling more supported by their employers than did those who were reluctant to articulate their needs in the workplace. Reportedly, all participants felt connected to their workplace communities. This seemed to be tied largely to their ability to meet the demands of their particular positions. Those in supervisory roles stated a preference for minimal socializing with their “direct reports.” The participants tended to minimize their disability-related needs in their interactions with colleagues, and this may have been a factor in their sense of inclusion. While none of the participants felt that the presence of disability hindered their social inclusion at work, a few of the women shared that issues such as marital and parental status negatively influenced their feelings of inclusion. These statuses may have been influenced by disability in that women with disabilities often have a more difficult time finding romantic partners than do men with disabilities (Gill, 1996).

### **Contributions of Beliefs, Strategies, and Relationships to QOL and WLB**

A final question considered by this project was, “What beliefs, strategies, and relationships contribute to the QOL and WLB of participants?” Balance in the lives of the participants seemed to be significantly influenced by relationships, planning, and routines. Belief systems that focused on gratitude rather than loss and on ability rather than limitation also influenced perceptions and achievement of a sense of balance and quality of life. For example,

Ken, John, and Irene were especially adamant about their gratitude that their situations are so much better than the lives of other people they have met with disabilities. Conversely, Craig's focus on what he has lost seemed to make it hard for him to experience genuine enjoyment of the many abilities and resources that he still has.

Relationships at home and at work played a key role in participants' management of work-life concerns. They felt they were as included in their workplaces as other people and reported that in most instances their employers valued them and were willing to accommodate their disability-related needs. In some instances, workplace social inclusion was reportedly influenced by the participants' work roles. Similar to those in studies conducted by Berman, West, and Richter (2002) and Parris et al. (2008), the participants in my study whose work roles involved supervisory responsibilities felt it best to maintain some distance from their supervisees. Their supervisory roles contributed to these individuals being viewed as valued and central to their workplace communities. Study participants whose jobs did not involve supervision and participants who did not have children expressed more freedom in how they utilized their free time. For example, they spoke of taking a day or two off to attend family events and of taking regular vacations, whereas at least one of the supervisors in this study stated that he rarely stayed away from the office, even during scheduled vacation time. For all of the participants, feeling that they were valued for the contributions they made to their workplace was a factor in their feeling included within these settings.

Relationships in their personal lives included able-bodied spouses or significant others, children, other family members, neighbors, and leisure companions. In these relationships, they are reminded to "take it easy" and they seemed somewhat more willing to accept support

because they viewed the helping relationship as reciprocal. Relationships with family members were a top priority even for participants who do not have spouses or children of their own. Bonds with family and friends were reported to be essential to participants' well-being and life satisfaction.

Surprisingly, while all had some childhood or post-injury experiences that would have enabled them to meet others with disabilities – multiple hospitalizations, time in special schools and at camps for children with disabilities -- only one of the participants had close friends who also had disabilities. Of note is the fact that Irene, the participant who reported the strongest connection to the disability community, was able-bodied until her late teens. Yet Marie, a long-time volunteer and former foster child for the MDA, described feeling “disconnected” from others with disabilities and said when she comes across another person with a disability on the street, they often nod at her “like there’s some weird social club” to which they presume she belongs.

Most who reported friendships with other people with disabilities indicated that these relationships had been established only recently. In one case, the participant reconnected with someone she knew long ago via Facebook. In another case, contact was made via a disability-specific list-serve. Two participants were hoping to make friends with disabilities through their recent involvement with adaptive sports programs. Some participants commented that, at this stage in their lives, they would really like to meet others with disabilities. They emphasized that they would like these introductions to occur “socially” but “not in a support group!” A few asked me where they could meet others with disabilities that have full lives, as they do. Studies such as those conducted by Iwasaki et al. (2006) and Goodwin and Staples (2005) demonstrated the

value that recreationists with disabilities perceive from being able to engage in leisure with others of similar circumstances. The participants in my study were seeking social connections with people who not only had similar disabilities but whose life experiences were similar to their own as well. In other words, they wanted to meet others who were employed, owned homes, and pursued leisure interests.

The majority of participants described living regimented, structured lives. Their routines were essential to their management of multiple domains. Reportedly, they were not always conscious of the ways that they balanced everything. Several spoke of the balancing act as something they naturally do. They are used to their routines now, and they make adjustments due to disability (or family needs or work demands) without a lot of thought. In this way, I suspect they are similar to their nondisabled colleagues.

In addition to managing the demands of their work and non-work domains, the participants continually adapt, adjust to, and accept decline in their functioning as they age with disability. This was a significant source of stress, especially for those who had experienced a high degree of self-reliance in the past. Some with congenital disabilities seemed saddened to have to deal with being more limited after years of overcoming and enjoying a good quality of life that for the most part did not focus on their limitations. As they experience non-visible consequences of their disabling conditions, they struggle with when and how to share this information with others, especially at work. The need and desire to be viewed as capable makes them reluctant to disclose aspects of their disabilities that are not readily apparent to their colleagues. They have strived to maintain identities of normalcy, and some have distanced themselves from disability. In many cases, this has carried over into their leisure lifestyles, with

some participants being reluctant to take part in adaptive recreation with others who have disabilities.

### **Identity: A Reflection of Relationship with Self and Others**

The significance of identity was the most surprising finding. I had anticipated that the relationship with one's self would be a factor in decisions related to self-care--that the negative ways that people with disabilities have been viewed and excluded throughout history had influenced how participants feel about themselves. Still, I had not anticipated that identity would emerge as the most significant construct. However, in retrospect, it makes perfect sense. Both work and leisure choices influence identity, and both are influenced by identity. Many people identify themselves through their work, and leisure is a space to develop, re-create, or construct identity. However, when as an individual with a disability one works and plays in settings dominated by nondisabled people, one has to have a way of viewing oneself as capable, and because we are all taught to believe that disability and ability are mutually exclusive, we have to deny (or at least minimize) one to be the other. These conflicting messages can be a source of frustration and require constant identity negotiation.

Gill (1997) stated that Erik Erikson "stands out among personality theorists for his focus on identity development as an essential life task" (p. 40). According to Corey (1982), Erikson's theory of human development posits that individual and social development take place together, and identity is a "combination of what one feels one is and what others take one to be" (p. 49). Corey asserted that at each of the eight life stages, individuals must strive to establish

equilibrium between themselves and their social world. He noted, “To a large extent, our lives are the result of choices we make at each of these stages” (p. 49).

As persons with disabilities, the participants in this study have faced challenges throughout their lives that may have made it harder for them to define themselves in positive terms. It was difficult to get participants to describe specific events in their childhood interactions, and most were even more reserved when it came to questions about their adolescence. Comments about being “resilient” or tending to “forget bad things” suggest that some participants may have had an especially difficult time early on. However, they have developed healthy relationships, established careers, and contributed to their communities. Of note is the fact that most of them spoke of their parents, especially mothers, as being willing to let them test their abilities and learn their boundaries.

The responses of participants with congenital disabilities suggested that as they moved from childhood and through adolescence, they wanted to belong in the larger community, the dominant culture; they wanted to fit in. They had encountered other people with disabilities, but they did not feel they had much in common with these individuals; rather than fostering these relationships, they moved away from them. Their efforts were rewarded by a good degree of acceptance by people without disabilities throughout most of their lives.

The integration of disability identity appeared to be important to the adjustment to disability and to perceptions of participants’ quality of life. For example, Irene considers her getting involved in wheelchair sport shortly after her accident as a key factor in her overall adjustment to this life-changing event. Craig, whose pre-injury identity was also closely linked to his physicality and sport participation, reported that he took up wheelchair tennis, briefly, and

then went on to other interests. He has no friends with disabilities and continues to express considerable grief over the loss of abilities more than two decades after his injury.

However an individual comes to disablement, through birth, illness, or trauma, the acceptance of disability as a part of one's identity seems an important step in developing a positive outlook about one's self and one's life, especially as he or she ages. According to Henderson and Bryan (2004), if persons with permanent disabilities do not accept their conditions by the end of middle adulthood, they are prone to "lapse into continual depression" (p. 77). Interestingly, three of the four participants in their 40's seemed to have the hardest time embracing a disability identity. They grew up in a time when there was no talk of disability pride, and people with disabilities essentially had only two choices: de-emphasize their differences and overcome or associate with disability and be excluded. Although deemphasizing their differences from the general population has served them well in terms of their careers and relationships, they are now expressing an interest in connecting with other people with disabilities who may share some of the same challenges as they age.

Gill (1997) identified four types of disability integration "in disabled persons' discussions of who they are and where they belong" (p. 42). The first type includes the expectation that people with disabilities will be integrated into society through full participation in social, educational, and employment opportunities. All of the participants spoke of participating as fully as possible in these arenas throughout their lives. Some mentioned that social acceptance for friendship and dating was at times problematic. Others said they believed they had been discriminated against for work and promotional opportunities due to disability.

Gill's second type of integration, *coming home* involves connecting to and associating with the disability community. She noted several reasons that some individuals with disabilities avoid this. For example, they may feel that participating in disability-specific gatherings may indicate acceptance of society's tendency to deny access to the mainstream, or they may fear that such associations would result in stigmatization. These kinds of concerns were highlighted in the responses of my participants, particularly when describing their youth. Some referred to their desire to avoid being the handicapped kid or typical handicapped person. While they sometimes referred to themselves as having disabilities, they reserved the use of the term *handicapped* for describing people whose situations represent the more stereotypical, negative images of what it means to be a person with a disability. They spoke of such individuals as being unemployed, unmotivated and uninvolved in their communities.

*Coming together*, or the internal integration of sameness and differentness, is the third type of integration identified by Gill (1997). Gill proposed that the principal barrier to this kind of integration is "not at all in the disability, itself, but in the manner in which family members, professionals and other significant social figures framed the impact of disability for the disabled individual" (p. 43). The responses of participants confirmed the significant role of parents and teachers in how they viewed themselves in light of their disabilities. Those born with disabilities learned from the authority figures in their lives to deemphasize this aspect of their selves; to embrace it now, after so many years, is difficult. Decisions about how they incorporated disability identity were influenced by concerns about how they would be viewed not only by strangers and colleagues but also by those closest to them.

The final type of integration in Gill's (1997) work is *coming out*. This involves integration between one's "private knowledge of self and the ideal image we wish to present to others" (p. 45). Gill described this coming out process as "the last step toward disability identity" (p. 45). At this point, the individual is "sufficiently comfortable to be 'oneself' unwaveringly, regardless of the circumstances..." (p. 45). Princess, one of the older study participants, seems to be at this point in her identity formation. She stated, "As for now, I'm pretty comfortable with myself, so I don't put as much weight into whether people accept me as I am or not. It [s] apparent pretty quickly if someone can get past me being different."

The types of integration proposed by Gill (1997) are similar to the hypotheses of other scholars whose work concerns racial and ethnic minorities. For example, in his 1970 work (as cited in Hall, Freedle, & Cross, 1972, p. 4), Cross posited that there exists a series of well-defined stages in black identity development. In the *pre-encounter* stage, the individual views the world as "non-black, anti-black, or the opposite of black...and attitudes toward self are determined by the 'oppressor's logic'" (p. 5). In other words, the individual has a sense of self-hatred and inferiority. In the second stage, referred to as *encounter*, some experience begins to "slip by or even shatter the person's current feelings about himself and his interpretation of the condition of the Negro" (p. 5). In *immersion*, the third stage in Cross' hypothesis, the individual undergoes "a liberation from whiteness and an involvement in blackness" (p. 8). In this stage, the individual values those things relevant to blackness, such as involvement in black politics, and "feels an overwhelming attachment to all black people" (p. 8). These stages lead to the fourth and final stage of *internalization*, in which "the person defines himself as a black, adequate, and noninferior [sic] person" (p. 4). Both Cross' work concerning racial minorities

and Gill's work related to persons with disabilities indicate that individuals who are members of marginalized groups tend to go through a process of self-acceptance that involves, initially, distancing themselves from their marginalized identities and other group members, and eventually coming to value their difference and the support that can be found among those who are members of the same marginalized group. Cross detailed a revised theory of black identity formation in *Shades of Black: Diversity in African American Identity* (1991). While the stages of identity development remained the same, he emphasized that the process did not necessarily begin with self-hatred (which he stated was a commonly held belief in early racial identity research) and that internalization, the final stage in both versions of his model, "is not likely to signal the end of a person's concern with nigrescence [or becoming black]" (p. 210). He noted that as one moves through life and has different experiences he or she may revisit some of the stages again. Cross also advised "there is no one way to be Black" (p. 149). This is true with the disability experience, too. Disability, like blackness is but one attribute of a person, and many factors influence the way and degree to which this is incorporated into one's self-perception.

The findings of the current study indicate that the lives of employed people with disabilities are the same as and different from their nondisabled colleagues. They had roles and responsibilities in both the work and family domains and had identities associated with these life spheres. They also had leisure identities and filled nonfamily relational roles such as friend. Further, their disabilities and issues related to self-care influenced how they saw themselves within these other spheres. Their identities within these other spheres (such as work, family, and leisure) contributed to their positive self-identities, which for some meant not embracing disability as a central part of how they viewed themselves. Reportedly, these identities and ways

of viewing themselves were greatly influenced by what they were taught about disability growing up and the tension between being an employed and capable person versus the “typical handicapped person” who does not work, does not have a family, and is not involved in typical social activities. Their perspectives, shaped by their experiences, have contributed to what they consider to be important elements in a quality life. Essentially, they desire the same things as their nondisabled peers: relationships, productivity, pleasure, and good health. Thus, family and friends, work, leisure, and self-care are part of a balanced life.

The methodological approaches to this study helped to bring out the complexities of living fully with disability. The subsequent findings indicated that disability and identity are integral parts of all life spheres, remaining with the participants as they cross from one border to another throughout the day. Further, just as in Clark’s (2000) research, they demonstrated spillover between work and non-work concerns and the importance of relationships in maintaining a sense of work-life balance.

### **Limitations**

One limitation of this study is that it involved a small number of participants. With only eight people, it is not possible to generalize the findings. I spoke with each participant on only two occasions for a total average time of three hours per person. Given that most of our meetings took place after work or during their lunch hours, the participants were tired and rushed, and so was I. Additionally, although I had an opportunity to see the participants’ workspaces and some of the ways they used those spaces to convey who they are (e.g., displaying leisure-related artifacts in their work areas), I was only minimally able to observe

interactions with colleagues. Consequently, I was not able to obtain the depth of information necessary to generate a theory about the role of workplace social inclusion in employed people with disabilities' management of work-life concerns.

It is worth noting that I observed little interpersonal interaction among any workers in these workplaces; the physical layout of the work areas and the minimal amount of shared space such as break rooms that also housed copy machines and other work equipment seemed to make these workplace leisure spaces less appealing. When I specifically asked about the use of break rooms, for example, participants reported that these spaces were rarely utilized. Randel and Ranft (2008) defined workplace social inclusion as “the extent to which employees have informal social ties with coworkers and feel as if they belong and are socially included by others in the workplace” (p. 213). Although I was not able to spend significant time observing workplace interactions, I did get an understanding of participants' perceptions of belonging in their workplace communities. Social inclusion is a key aspect in social wellness and is one of the six dimensions of wellness identified by the National Wellness Institute (NWI) (2004). Some of the elements of social wellness include having satisfying relationships, participating and contributing to one's community, and having supportive social networks through meaningful relationships with family, friends, colleagues, and others. Social wellness, along with the other dimensions of wellness--occupational, spiritual, physical, intellectual, and emotional--help individuals to maintain a sense of balance in their lives (NWI, 2004).

Another limitation of the study is that all of the participants were persons with mobility impairments; I had anticipated more variety in the types of disabilities participants would have. For example, I anticipated that some participants would be individuals who were visually

impaired or persons with amputations, in addition to those whose mobility is impaired by orthopedic or spinal disabilities. Had there been greater variety in the kinds of disabilities experienced by participants, the findings might have been different. For example, the employment history of for individuals with visual impairments, includes the establishment of long-standing professional organizations (Kudlick, 2001); this is not the case among employed people with other types of disabilities. thus, these workers might have had different work experiences than the participants who took part in this study. Likewise, those who acquire disability through war-related injuries have tended to be viewed differently than others with disabilities (Gerber, 1994). These individuals have been referred to as heroes; they often do not identify with the disability community and may know little about their rights or resources to help with employment and quality of life following their disablement.

Finally, this study is limited by the fact that I conducted this research in a college town and had no budget to compensate participants. Consequently, I attracted individuals with higher levels of educational attainment and higher income levels than most employed persons with disabilities in the U.S. They also all worked in what would be considered professional jobs.

### **Theoretical and Practical Implications**

A number of theoretical and practical implications can be drawn from the findings of this project. Theoretically, the findings of this study provide support for Clark's (2000) work/family border theory. Participants who demonstrated a strong work ethic and values most like those of their nondisabled colleagues and supervisors seemed to be provided more support to manage work and non-work concerns and more opportunity for professional growth. Additionally, those

most willing to share their personal needs with their supervisors, enhancing their awareness of the self-care/disability domain of participants' lives, seemed to fare better than participants who expected others to understand their needs without sharing this kind of information. Further, the roles and responsibilities the participants held in the various domains of their lives also influenced their priorities, their sense of inclusion in their workplace communities, and their sense of balance. For example, participants who had children expressed more tension around maintaining work and family obligations than did those who did not have children. The parents in this study reported less personal leisure time and the tendency for leisure to center around family. Consistent with Clark's theory, relationships, roles, and responsibilities seemed to be critical to the successful management of work-life concerns. For example, the willingness of family members and friends to assist with transportation to and from work helped participants who did not drive or whose modified vehicles were unavailable to get to and from the job as needed.

Some participants occasionally worked at home, and others worked overtime at the office, missing family mealtimes. Still, those with families reported that the needs of their family members were of the utmost importance, and they expressed this to their colleagues and supervisors. Artifacts including such things as family photos and decorative items reflecting leisure interests also demonstrated that participants' home life influenced them at work; they served as reminders that these individuals, like their nondisabled colleagues, regularly cross the borders, as Clark puts it, of the home and work domains. Further, the participants' responses indicated that leisure/friends and disability/self-care were also important life domains. For

example, all of the women spoke of friends who were “like family,” and they made a conscious effort to maintain these relationships. Moreover, all of the participants indicated that issues related to disability/self-care were present to some degree in all of the domains of their lives. They engaged in various methods of self-management to minimize the impact their conditions had on work performance and leisure participation.

There are several practical implications of this study. For one, the participants indicated factors that seemed important in understanding how some individuals with disabilities choose to live their lives. For example, many of them have disabilities that claimed the lives of several of their peers in their youth. I believe this may have affected participants’ gravitation to the dominant group in at least two ways. One way is that as their disabled peers died, these young people had fewer options for friendship within an already limited subgroup of society; the dominant group offered greater numbers from which to choose or be chosen. Additionally, they may have on a subconscious level sought out able-bodied peers who lived, hoping that they would, too.

When Marie mentioned that “there were lots of boys” at summer camp and “they just didn’t live,” I asked if she thought the fact that peers were dying influenced relationships made at summer camp. She replied that although she and the other campers never talked about it, “Certainly every year, you noticed who wasn’t there.” If they did not talk about it among themselves, where would they have processed the feelings that they had about this reality? For many, times spent in these kinds of settings were the only times that they were with other children like themselves. How does the loss of a friend, or several friends, to a condition that he or she also has influence a person’s, a child’s, attitude toward life? When I asked Marie about

her own mortality, given that she has a progressive condition that often results in premature death, she replied that she does not really think about dying but rather about what special events she might miss in the life of her own child.

Another factor indicated in the participants' responses is that some individuals view their situations as a medical issue. That is, they refer to themselves as "patients" with a particular condition. They acknowledge the presence of symptoms of disability but do not associate their own lives with the social, political, and historical experiences of persons with disabilities as an oppressed group. In his doctor's office, John, for example, clearly wanted to be treated as "not just a regular patient." He expressed the view that in order for his doctor to provide good care, he needed to understand that John was different.

I also suspect some participants feel more different at work than they admitted to me. The feeling of needing to work harder than their nondisabled colleagues came up when pilot-testing my interview questions with my friends who have disabilities, and this issue has been noted in the literature about employment and disability (e.g., Randolph, 2005). John initially said that he felt some pressure to work harder, and then quickly moved on by commenting that he does the best he can and hopes that everything will work out. It seemed Craig might work extra hard in part to be sure that his work is up-to-date in the event that he needs to take time off, but he denied this when I asked him about it directly. Hansen and Philo (2007) noted that in one of the authors' previous studies, respondents reported "a strong feeling of their only conditional acceptance in work, educational, and other public settings" (p. 498). More needs to be understood about how people with disabilities feel about work and about themselves in their workspaces, as work is at the core of identity for many people in our society.

Finally, it is clear that identity is fluid and multi-layered. The same individual feels differently about him or herself at different times. Whether a matter of impression management or simply a more positive outlook brought on by the chance to get away, I observed different presentations of self in my limited interactions with participants. I imagine if I had asked each of them to keep a journal for a period of time, noting when their sense of being disabled was heightened, the mere fact that they had been given such an assignment might result in their giving their disablement more thought than they typically would. As much as I found myself thinking about disability--theirs and mine--during the course of the project, I also had times when I did not experience that as a primary identity. There are notes in my journal that confirm I was a student, an instructor, a sister, an aunt, a neighbor, a woman, a person of color, a Christian, all while also being in a body that gets around in a non-typical way. It seemed that the aging body forced participants to re-consider the role of disability in how they view themselves. As they enter middle age, the goal is to achieve generativity and avoid stagnation (Erikson, 1998). According to Corey (1982), generativity was broadly defined by Erikson "to include a sense of creating through career, family, leisure-time activities, and so on" (p. 51). As one ages, physicality appears to be much less significant than connecting with people and contributing through work. This seems also to suggest that an individual's concept of work-life balance might change over time. Workers may consider some domains more important than others as they age, and what they want or need from each domain may change as the body changes, because one's identity cannot be separated from his or her body. An identity that more fully integrates disability may develop as they find it harder to keep up with their nondisabled leisure companions.

One practical application is for organizations that serve individuals with disabilities to create social networks for working people and for professional networks to reach out to members of the disability community. The men and women in this study are not stereotypical people with disabilities and they do not want to be associated with those negative stereotypes. In order to target such individuals, information should be sent to the disability service units and career service offices on college campuses and to various employers in the geographic area from which the social networks will be formed. By disseminating information through these channels, providers are more likely to attract educated, active, work-oriented people who might enjoy spending time together.

Four of the participants were aware of the public vocational rehabilitation program. Three had received funding for college training and/or assistance with vehicle modifications and personal care. Some of these individuals and others like them may benefit from services at this stage in their lives. For example, Marie has concerns about being able to afford the level of personal care she knows she will require and might benefit from meeting other working people who require similar care to see how they manage the cost or if they could share a caregiver. Benefits counseling might reveal the availability of work incentives that would enable Marie to meet her caregiver needs without additional stress. Changes in legislation, technology, and benefits programming create opportunity; the vocational rehabilitation system should be a reliable provider of information and do what it can to help eligible persons maintain employment and good quality of life for as long as possible.

Most of the participants are members of the baby boomer generation. Like their nondisabled peers, they wish to remain as active as possible. Often programs that target older

persons and persons with disabilities seem to be geared more toward those who are frail. Thus, they are not appealing to individuals, with or without disabilities, who have been and wish to remain active. Perhaps as we create products and spaces that attract baby boomers we will gain new insight into how to more effectively market to persons with disabilities, too. This also applies to the creation and marketing of leisure programs. Some people who have not felt a part of the disability community may find that they are more interested in connecting with others like themselves as they age. Consequently, adaptive leisure programs should consider how to attract these individuals, offering services by age group as well as disability type, when feasible. Further investigation about what it means to age with disability is needed in order to better plan for the work-life needs of America's aging workforce.

Finally, it would be short-sighted to think that all of the work-life concerns of employees with disabilities are related to their physical limitations. Similar to their nondisabled colleagues, the participants in this study were not immune to dealing with other challenges of living. For example, Ken spoke of the difficulty of trying to be a support to his aging mother who lives in another state, and Craig expressed concerns about moving in with his long-time girlfriend. These issues were not so much related to disability as they were to simply being human. Thus, they indicate the need for inclusive employee assistance programs (EAP's). Such corporate resources need to be provided in ways that are accessible to employees with disabilities.

### **Future Research**

There are several areas of research that would help to extend understanding of issues raised by my participants. The current study is one of few that have directly considered the

work-life balance (WLB) needs of persons with physical disabilities. Additional research is needed in this area. Future research about the work-life needs of people with physical disabilities should address the diversity that exists within the disability community. The needs of women with disabilities are not the same as those of disabled men. Persons with congenital disabilities have different needs than those who acquire disability later in life. The work-life needs of those who have children are different from those who do not, and those who are married have different needs than single people with disabilities. Additionally, because physical disability affects people of different races, ethnicities, religions, socio-economic status, and sexual orientations, future study of work-life issues will require that researchers consider the influence of intersecting identities on these individuals in their work and non-work lives. For example, Allison and Hibbler (2004) found that recreation agencies often unknowingly engage in organizational barriers that are unwelcoming or unappealing to ethnic minorities. Therefore, individuals with physical disabilities who are also ethnic minorities may have an especially difficult time in these settings. Further, those who have co-existing disabilities, for example, a mobility impairment and a psychiatric disability, may well have different work and leisure needs and experiences than someone who has just one disabling condition.

Research that considers workers' with disabilities access to and utilization of generic work/life resources, such as EAPs and employee wellness services (e.g., company-sponsored recreation programs), would be useful. While two participants spoke of using such resources, most did not use them, and had not thought to. Instead, they tried to handle their challenges on their own or through disability-specific resources. However, many of their work/life concerns

are the same as those of their coworkers, and these generic resources, if accessible and welcoming, could be very beneficial to their overall well-being.

Understanding what contributes to feelings of belonging and inclusion in the workplace is important in helping employers to attract and maintain a diverse workforce that can give them a competitive advantage. Research that helps to identify what is necessary to create welcoming environments in which workers feel safe to disclose disability or talk about other kinds of difference without losing the respect and support of those in their workplace communities would be beneficial to the American workforce as a whole.

As indicated by participants' comments, while leisure is "super important," it is also a source of stress. They are concerned about losing the ability to participate in favorite pastimes. Sites that claim to be accessible may not be well suited to the person's individual needs. The planning and physical excursion can make leisure outings less enjoyable. Thus, research on leisure as a source of stress would be worthwhile. A comparison of the stress management benefits of passive versus active leisure would be useful for these same reasons.

Another issue that warrants further study is how reliance on caregivers affects one's WLB. Many people with physical disabilities require assistance to perform activities of daily living such as getting dressed for work. Hiring and training assistants can be mentally and physically draining. When these helpers are not reliable, or worse, when they are abusive, it creates significant stress for the individual with a disability. Although the issue of abuse against people with disabilities is a newer area of research, the studies conducted so far indicate that "women with developmental disabilities have among the highest rates of physical, sexual and

emotional violence by spouses, ex-spouses, boyfriends, and family members...” (Emanuel, 2000, p. 6). Often, family and significant others are in the caregiver role.

A related area of research is the investigation of the leisure lifestyles of persons who provide professional or caregiver services to persons with disabilities. It would be interesting to understand the influence of these individuals’ leisure habits on the provision of services to those they serve. How might the work-life balance concerns of professionals such as vocational counselors influence the way they approach their work with consumers?

Research about what attracts individuals with disabilities to join segregated social support groups would also be useful. There are people similar to my participants who are more socially active in the disability community. While Gill (1997) and others have pointed out some of the reasons individuals might avoid association with the larger disability community, it would be interesting to learn more about what *attracts* people who are educated, and employed, to the disability community instead of or in addition to integration in the dominant culture. How might these individuals be a resource in welcoming those whose “coming out” process takes a little longer?

Finally, the employment rate for people with disabilities has remained at 30% for more than two decades (Chan, 2007). According to the Center for Disease Control (2001), 20% of working-aged citizens are reportedly disabled. Thus, for those who want to work and do not, the stress of being unemployed in a culture that focuses on employment is another concern.

Although these individuals may have more discretionary time than nondisabled people, it is not freely chosen but “enforced” (Olechnowicz, 2005) by their joblessness. Unemployment may be particularly frustrating for those who wish to work but for whom suitable employment is hard to

find in our highly technical, multi-tasking, team-oriented workplaces, or for whom needed job supports (such as job coaching, assistive technology, or personal assistance) cannot easily be provided. Research about the kinds of leisure or alternative work models that would best meet the needs of unemployed people might help to identify new opportunities for paid employment for individuals with physical disabilities.

### **Conclusion**

Although there have always been people with disabilities in our society, the process of individual and group identity is a difficult one. Incorporating a strong sense of disability into one's identity is counter to the messages we receive as members of a larger society that advises us to minimize our differences and focus on our strengths. Typically, this kind of message does not leave room for the possibility that one's differences may in fact *be* strengths. As a consequence of their differences, people with disabilities may be more creative problem solvers at work and more compassionate with their friends.

Most of the participants in this study began their careers after the passage of the ADA and therefore have benefitted from the opportunities and access it has afforded. Nevertheless, they have all had experiences where they were viewed as less capable of work and less interested in leisure simply because of their physical conditions. They have created full lives in many ways by denying a part of themselves. As more workers with disabilities come to value themselves and expect full inclusion in the employment and leisure arenas, perhaps more of us with disabilities will accept our whole selves sooner and enjoy the unique support of others like us.

One of the most memorable moments of this project came during my follow-up meeting with John, when we talked about the possibility of his using a wheelchair in order to play tennis with his wife. He expressed concern about what his kids would think and what other people would think if he spent any time at all using a wheelchair. I was in my wheelchair at the time, but he had also seen me use my crutches. I explained that I only use a chair sometimes--when I choose, because for me it is still a choice. His body was tense during this conversation, which may have been due in part to his having to travel for work the following day. All of a sudden, his face relaxed and his shoulders dropped and he asked, "You mean you just keep the wheelchair in your car and take it out when you want to use it?" He said this as if he had just discovered something he might want to investigate further. And I thought to myself: yes, it really is possible to have it all--work, leisure, and an identity as a capable person with a disability.

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**APPENDIX A.****INTERVIEW QUESTIONS**

1. Please describe your typical day.
2. What factors help you to feel connected to or included in your workplace community?
3. How does your current work setting compare to other places you have worked, in terms of connectedness and inclusion?
4. If you found that you had some downtime at work, how would you spend it with?
5. How important is work in your life? Why?
6. How important is leisure to you? Why? How do you maintain a sense of balance between your work and the rest of your life? What do you do for leisure? Who are your leisure companions?
7. Do you think your disability influences your work and leisure experiences? If so, in what ways?
8. Is there anything else you'd like to share about your experiences?

**APPENDIX B.**

**WORK ENVIRONMENT SUMMARY FORM**

**Date/Time:**

**Worksite (type, location, # of employees):**

**Workspace Layout**

**Observations**

**Interactions:**

**Artifacts:**

**Other:**