

MANUAL VERSUS POWER WHEELCHAIR PROPULSION:  
QUALITY OF LIFE AND SELF-PERCEPTION

BY

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THESIS

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## ABSTRACT

The purpose of the present research study was to examine the effects of wheeled mobility devices on self-reported measures of community participation, quality of life and self-perception on the campus of the University of Illinois Champaign Urbana. The Craig Handicap Assessment Reporting Technique (CHART) and Rosenberg's Self-Esteem Scale were used to elicit information from research participants. A short demographic survey was also utilized to obtain other background information. The knowledge generated from this study will enhance our understanding of the psychosocial and environmental facilitators and barriers confronting wheelchair user's mobility and the extent to which manual and power chair are affected differently.

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## CHAPTER 1

### INTRODUCTION

Approximately 6.8 million non-institutionalized persons with disabilities (PWDs) use mobility devices in the United States (Kaye, Kang and LaPlante, 2002). Of these 6.8 million individuals, 1.6 million are wheelchair users (WCUs); with 1.5 million utilizing manual devices and approximately 155,000 using power wheelchairs (Kaye, Kang and LaPlante, 2002). With the impending “graying of society” due to the vast number of individuals from the baby-boomer generation entering retirement and turning age 65, the number of WCUs is expected to increase as well. Advances in medicine and technology have permitted individuals today to live longer than ever before, yet another factor contributing to the forecasted increase in PWDs and WCUs.

Many of the modern perceptions of PWDs can be traced back to the 1960s where PWD were more overtly discriminated against and stigmatized. In 1963, so-called “ugly laws” in American cities such as Chicago banned PWDs from public places. By virtue of having an observable or visible disability and presenting oneself in common public places such individuals would in turn be engaging in an act of civil disobedience. “No person who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object or improper person to be allowed in or on the public ways or other public places in this city, or shall therein or thereon expose himself to public view, under a penalty of not less than one dollar nor more than fifty dollars for each offense” (Kaveny, 2005).

While the challenges today are different than those faced during the days of the “ugly laws”, public access is still a problem on a number of different fronts. Even though the United States has implemented certain safeguards for PWDs, physical barriers abound, particularly for individuals who utilize wheelchairs as their primary mode of transportation. An overwhelming majority (93.0 percent) of wheelchair users report some form of activity limitation (Kaye, Kang and LaPlante, 2002). For two-thirds (66.1 percent), the limitation is severe enough to render them unable to perform their major activity (Kaye, Kang and LaPlante, 2002).

Whereas there have been good faith efforts made by some, there is clearly a preponderance of evidence showcasing the ineptitude of society as a whole in terms of built environment. Whether it is new construction or renovations, public transportation or parks and recreation, inaccessibility continues to be a major problem for many PWDs. The critical factor to real change, according to Harlan Hahn, a professor of political science at the University of Southern California, was that the definition of disability shifted from medical and economic perspectives, which view disabilities from the standpoint of functional and vocational limitations, to a socio-political perspective that focuses rather on the disabling qualities of the environment that limit the possible interactions of people with disabilities (Welch and Palames, 1995).

Although the passing of the Americans with Disabilities Act (ADA) in 1990 has improved conditions for WCUs considerably, disparities remain. For example, numerous studies suggest that WCUs report diminished quality of life (QOL) and reduced community/life participation levels compared to their able-bodied matched counterparts. There is evidence that personal characteristics and limitations of manual wheelchair (MWC) users with SCI reduce their capacity to propel their MWC, with a potential impact on community mobility (Lemay, 2009). These discrepancies have been attributed to the physical and psychosocial barriers WCUs encounter on a daily basis.

It is important to acknowledge that it is a combination of physical, attitudinal, communication and systematic barriers that prevent people with disabilities from leading active and independent lives (Ontario Health Promotion). Although barriers faced by PWDs tend to be easily identifiable, the experience of living with disability is complex and highly unique to the individual therefore multidisciplinary perspectives are often required to form effective interventions. For example, even those living with similar disabilities in similar environments may experience facilitators and barriers differently.

However, some researchers have identified common features of disability relating to quality of life and participation. Studies have revealed that severity of injury indirectly affects quality of life through its influence on community participation (Post et al., 1998; Dijkers, 1999). Although severity of disability can influence participation, even if PWD successfully remediate or adapt to the physiological changes in their bodies, there may be psychosocial barriers that

remain which can be equally detrimental to QOL and living independently. For example, psychosocial barriers like stigma, fear, and discrimination can be as detrimental to QOL as the physical and environmental features.

Because the experience of living with disability is often a function of a person's unique personal characteristics expressed through his or her own environment, different disability types may need different environmental supports to be successful. For instance, power and manual wheelchair users have different environmental needs. Whereas a manual wheelchair user may have the ability to transfer independently, a power wheelchair user may require the assistance of a Hoyer lift or other assistive devices. Consequently, it could be inferred that power wheelchair users are commonly viewed as being more disabled and therefore more likely to be stigmatized than manual wheelchair users. Moreover, it would also follow that power wheelchair users face more obstacles and barriers in achieving the same level of access and experience that many others take for granted, even manual wheelchair users.

In essence, this paper will consider the potential influence of environment on the lives of PWDs. Specifically researchers will examine differences in self-reported QOL and self-perception measures between manual and power wheelchair users through established survey tools (Craig Handicap Assessment and Reporting Technique (CHART), and Rosenberg's Self-Esteem Scale (RSES)). A secondary goal of this study is to determine if manual and power chair users score differently on these tools, identifying distinct environmental facilitators and barriers. Uncovering how PWDs feel will allow for addressing how these variables impact the lives of PWDs. It is our hope that these results will not only help to identify needs and improve services currently offered at UIUC but that this could be a first step in developing best practice guidelines or recommendations applicable to WCUs nationwide.

#### Research question/hypothesis

Question #1: Will individuals with acquired disabilities do to trauma and those with non-traumatic related disabilities score differently on survey tools measuring self-efficacy, cognitive independence, mobility, and social integration?

Hypothesis for research question #1: Individuals with non-traumatic injuries will have higher levels of self-efficacy, cognitive independence, mobility, and social integration than individuals with traumatic injury.

Question #2: What is the impact of mobility device (manual vs. power) on measures of self-efficacy, cognitive independence, mobility, and social integration?

Hypothesis for research question #2: Manual wheelchair users will have higher levels of self-efficacy, cognitive independence, mobility, and social integration than power wheelchair users.

## BACKGROUND OF STUDY

### 1.1 Wheelchair type

There is a vast array of wheelchairs available for individuals with mobility impairments. Although there are a number of subtypes or subcategories of wheelchairs in use today, wheelchairs as a whole can typically be broken down into the two aforementioned categories (power and manual). While severity of disability, may dictate use of a particular type of wheelchair, there are distinct advantages and disadvantages associated with these forms of mobility. Appropriately selecting, configuring and matching the right mobility device to meet the unique needs of the individual can profoundly impact one's ability to successfully navigate their physical and psychosocial environment. Ultimately wheelchair type can in and of itself present as a physical barrier to common societal practices and everyday experiences.

For purposes of this study, it is important to delineate some of the key differences between manual and power WCUs. A few common factors that may impact manual or power chair users differently include: traveling long distances, timing of traffic lights, condition of sidewalks, curb cuts and opening doors. Speed is another variable that has been shown to impact participation and socialization. The data showed a trend among manual wheelchair users indicating that participants who on average traveled faster tended to have a higher level of community participation (Cooper, Ferretti, Oyster, Kelleher and Cooper, 2012). When evaluating the specific content areas for manual wheelchair users, a significant positive correlation was found with increased speed and increased frequency of using transportation and socializing with others (Cooper, Ferretti, Oyster, Kelleher, and Cooper, 2012).

One common advantage of manual wheelchair use is the promotion or maintenance of physical fitness. Clinicians might be hesitant to prescribe a power wheelchair because a manual wheelchair can improve or maintain fitness, whereas a power wheelchair may invite deconditioning (Hastings, Robins, Griffiths and Hamilton, 2011). Other possible advantages associated with manual wheelchair use include: lighter weight, lower cost, less maintenance, greater portability, greater efficiency, increased maneuverability and easier to handle/operate. In addition, manual wheelchairs are typically more easily covered by insurance and payment providers. The single greatest disadvantage of manual wheelchair use is the possibility of contracting an upper body repetitive strain injury. The incidence of shoulder pain in people with SCI is higher than in their able-bodied counterparts, which can result in additional loss of functional independence (Hastings, Robins, Griffiths and Hamilton, 2011). A few other commonly cited disadvantages associated with manual wheelchairs (in comparison to power wheelchairs) are as follows: less stability, less comfort and typically require inflation of tires.

There are also pros and cons that should be considered in terms of power wheelchair use. The most commonly cited advantages of power chair use include: energy conservation, greater comfort, increased stability, more accessories and extra options. However, there are a number of disadvantages in terms of power chair use that seem to be more readily identifiable. Power wheelchairs provide less portability, weigh considerably more, require additional maintenance, provide for decreased maneuverability (especially on certain terrains) cost substantially more, and generally require more effort in terms of insurance coverage. Wheeled mobility devices can be expensive. Although a hospital version manual chair may cost only a few hundred dollars, a lightweight or ultra-lite manual chair costs at least \$1500, and high end electric wheelchairs can exceed \$20,000.

## 1.2 Environment

### a. Physical

The environment has a direct impact on the experience of disability, either as a positive or enabling force, improving the opportunities for people with disabilities to undertake activities and participate in the economic and social world, or a barrier to these pursuits. Research has shown that for mobility, the physical and social environments are seen as the most important

predictors of community participation. A study by Chaves et al. found that persons with SCI perceived wheelchairs as being the most significant factor limiting participation—even greater than their impairment (Oyster, Karmarkar, Patrick, Read, Nicolini and Boninger, 2011). Essentially, it is this combination of disability and environmental supports that may affect participation and QOL. If the level of community participation valued by a person is not affected because of favorable conditions (e.g., appropriate environmental adaptations, social support), it is likely that subjective well-being will not be affected, regardless of severity of injury (Miller et al., 2005; Dijkers, 1997).

#### b. Social

Psychosocial barriers may be experienced by children or persons with disabilities (C/PWDs), affecting their self-esteem and confidence, decision making and integration to mainstream society (Juliano-Soliman, 2010). Several of the commonly held beliefs about PWDs may actually serve as self-fulfilling prophecies, further denigrating the psyche of an already discounted group of individuals. When C/PWDs are treated as incapable of sustaining an existence on their own, they may in turn begin to exhibit such learned behaviors. Low expectations and the enablement of dependent behaviors can often time lead to the ubiquitous expression of co-dependency and helplessness, both of which serve as an immense detriment to C/PWDs.

Another component of the environment that influences participation and QOL is stigma. Among these perceived barriers, the social stigma attached with being a member of such a subgroup of individuals within society remains prominent. Historically, PWDs were seen as a burden and families oftentimes wanted to separate them from the nuclear family through means such as institutionalization. Further, many words commonly used for insults today were based in large part on disability or came from ideals related to disabled people. While there is considerable variation in terms of the stigma experienced by individuals within the greater disability community, highly dependent upon where one lives, this remains a disruptive force which further complicates things for an already marginalized group of individuals.

Currently, wheelchair users encounter stigma through simply being ignored or treated as if they do not even exist. Citing Stigma, in which Erving Goffman describes people with

disabilities as being viewed by society as not quite human, Hahn argues that it is this failure to meet the twentieth-century Western values of physical attractiveness and individual autonomy that permits society to set disabled people apart (Welch and Palames, 1995). In many instances, wheelchair users are seen as incompetent or somehow incapable of managing things for themselves. There is a stereotypical image of what an individual in a wheelchair should look like or how they should act. Wheelchair users as a homogenous and unified group of individuals are generally looked at as a liability in society today. According to the Department of Social Welfare and Development, the stigma attached to the person makes him a person with disability, such as negative hansenites, arrested TB patients, recovered drug addicts/alcoholic, released prisoners and mendicants (Juliano-Soliman, 2010).

### 1.3 Universal design

“Universal design means the design of products, environments, programmes and services to be used by all people to the greatest extent possible without the need for adaptations or specialized design. This shall not exclude assistive devices for particular groups of persons with disabilities where this is needed” (Juliano-Soliman, 2010). Universal design is a plausible alternative to the restriction of physical space; a prudent resolution to many of the physical barriers which continue to plague a great deal of individuals. This concept promotes the ideal of breaking down barriers to physical accessibility on a number of different levels. For example, the concept of universal design allows for pregnant women to navigate an environment with greater ease, individuals with height limitations can more easily utilize space, the elderly are able to more safely utilize their environment, and individuals recovering from surgery can more easily ambulate within a given space, in addition to a host of other constructive outcomes. As one can easily see, the concept of universal design is actually quite beneficial for all Americans, not only PWDs and WCUs. Schools, businesses, public and private venues alike, can all benefit from the flexibility offered by universal design. In terms of the promotion of respected principles and valued standards we cherish in the United States of America, the ability to remain independent and autonomous to the greatest extent possible remains near the top of the list. Universal design pushes these principles and ideals to the forefront in everyday life.

As a result of failed efforts to enact lasting change within society, many barriers remain. PWDs continue to experience many different forms of barriers on a regular basis. Whether it is the absence of a curb cut to allow equal access to sidewalks or an inaccessible wing to a major building on college campuses nationwide, stereotypes or prejudicial thinking, the struggle remains. For public-policy changes to be effective, the attitudes that lead to the marginalization of people with disabilities must be addressed equally along with functional changes in the physical environment (Welch and Palames, 1995). While it is beyond the scope of this article to cover the many barriers faced by PWDs and/or WCUs, it is helpful to entertain a brief overview of some of the most common barriers in order to put things into perspective in terms of this study.

#### 1.4 University of Illinois at Urbana-Champaign (UIUC)

In contrast, the University of Illinois at Urbana-Champaign (UIUC) is an institution that has led the way in breaking down barriers for PWD through advocacy, accessibility, recreation, and research. Under these ideal circumstances students with disabilities at UIUC have historically thrived. Consequently the atmosphere at the UIUC offers a unique environment to study the physical and psychosocial features that facilitate or inhibit mobility, community participation and QOL in students who are wheelchair users.

Researchers paid special consideration to the fact that the UIUC has a rich history of rehabilitation and disability rights advocacy. Many of the firsts in terms of disability rights and accessibility standards for PWDs actually took place at the UIUC; curb cuts and accessible buses for example. “The first serious effort to address building design as an issue for people with disabilities was a 1958 conference sponsored by the President's Commission on Employment of the Handicapped, the National Easter Seal Society, and the American National Standards Institute (ANSI), a private standard-setting body that called for the development of voluntary standards for the design of accessible buildings. With a grant from the Easter Seal Foundation, these standards were developed by Timothy Nugent at the Rehabilitation Center at the University of Illinois with oversight by a committee of representatives from government, advocacy, health, trade, and professional associations. Published and distributed in 1961 under the title A117.1 Making Buildings Accessible to and Usable by the Physically Handicapped, the new standard

described "in precise and practical terms, the minimal features required to remove the major barriers that prevent many persons from using buildings and facilities and became the first scientifically developed design guideline on accessibility in the world" (Welch and Palames, 1995). Dr. Timothy Nugent and fellow colleagues at UIUC continued to forge ahead with a number of related issues, serving as true pioneers and waging an uphill battle for the rights of PWDs.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 Disability defined

Disability is indeed a multifaceted and dynamic construct, something which cannot be fully understood in isolation. There is no universally accepted definition of disability; as illustrated by the World Health Organization's (WHO's) primary definitions, which were in large part devised by doctors. In order to come to a better understanding of this construct and the interplay between key sub constructs, a clear distinction must be made between disability and its many forms. According to the WHO, disability is any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being. The WHO defines another form of disability known as impairment, as any loss or abnormality of psychological or anatomical structure or function. While handicap is generally seen as any disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfillment of a role that is normal for that individual (Snyder, Parsons, Valovich McLeod, Bay, Michener and Sauers, 2008). In a larger sense, Persons with Disabilities (PWDs) include those who have long – term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (Juliano-Soliman, 2010).

“Personal characteristics, as well as environmental ones, may be enabling or disabling, and the relative degree fluctuates, depending on condition, time, and setting” (Andreson, 2006). Disability is a contextual variable, dynamic over time and circumstance. For example, on a societal level, institutions and the built environment were designed for a limited segment of the population. Researchers should explore new ways of measuring and assessing disability in context, taking into account the effect of physical, policy, and social environments, and the dynamic nature of disability over the lifespan and across environments.

#### 2.2 Models of disability

The most commonly used conceptual models of disability intervention and research in the United States (medical model and social model) have regularly been looked at as helpful tools,

serving to advance the cause of researchers and practitioners throughout the health professions. These models have often been used to facilitate the development of assessment tools. Each model serves a need within different respective health arenas, allowing for varied perspectives in terms of the care offered. These models allow medical professionals to carry out a standardized process of identification and implementation of treatment strategies, ultimately improving the lives of PWDs. In terms of assessing the interplay between the construct of disability and a host of other variables contributing to the manifestation of such construct, these tools are a crucial piece of the puzzle.

Further, these models of disability serve as a “common, international language with the potential to facilitate communication and scholarly discourse across disciplines and national boundaries, to stimulate interdisciplinary research, to improve clinical care, and ultimately to better inform health policy and management” (Jette, 2006). Each former model of disability has contributed to the current views of disability, helping to empower individuals and promote patient-centered observation, critical analysis, and evidence-based practice (EBP). EBP can be viewed as the “conscientious, explicit, and judicious use of current best evidence” that incorporates clinical expertise, the patient's values, and best available evidence when caring for patients (Snyder, Parsons, Valovich McLeod, Bay, Michener and Sauers, 2008).

While there has been a significant transformation in terms of commonly held views on disability, the medical model has generally served as the starting point from which people have chosen to address issues related to disability. The medical model became popular when society shifted from a reliance on priests and religious officials to a greater focus on the expertise of doctors and medical professionals. This model posits that disability is a tragedy and the person is ultimately the problem or even a victim of circumstance. “Disability is the result of a physical condition, which is intrinsic to the individual (it is part of that individual’s own body), may reduce the individual's quality of life, and causes clear disadvantages to the individual” (Cooper et al 2012). In contrast to other models, the medical model is based purely on a person’s deficit or impairment. In this model, PWDs fill the “sick role”, consequently becoming exempt from social responsibilities and obligations. The resultant exemption from social responsibilities and

obligations only serves to further feed into a cyclical self-perpetuation of the stereotypical role PWDs are expected to play in society.

This model holds that the medical professional is in charge and pushes PWDs into a passive role as patients. Under the medical model framework, disability is not the norm and is therefore seen as a negative rather than an accepted individual difference. The individual is seen as the impairment, dehumanizing the person and generally not looking at the positive aspects that could be offered through such life experiences and diversity. The aim of a medical approach is to cure or make PWDs more “normal”, all while making the implicit assumption that there is something wrong with the individual to begin with. Disability simply isn’t a normal part of the common societal experience when viewing things through the lens of the medical model. Nevertheless, the purview of disability has expanded and people are beginning to look beyond these traditionally held beliefs. There has been a shift in mentality regarding disability and the medical model has been replaced with the social model of disability, and a number of other closely-related models.

The social model was developed in response to the medical model of disability. This model tends to focus solely on environmental factors contributing to disability. In this model, disability is not thought of as an attribute of the individual; instead the onus is placed on society. Society is viewed as the main contributing factor in disabling PWDs. This model of disability maintains that the attitudes and other features of an unwelcoming environment are truly the crux of the problem. In essence, the environment is what causes or amplifies how “disabled” a person is through its facilitators and barriers. Disability simply would not exist within a fully developed society, a society that puts things on a level playing field. The ultimate goal of the social model is self-determination, allowing an individual to determine his or her own lifestyle. This model holds that disability is ultimately the product of attitudinal, institutional, and physical barriers that exist within society, each of which lead to discrimination and an uneven playing field for the disabled minority.

It has long been known that the medical and social models of disability both contribute to a better understanding of the disability phenomenon. Nevertheless, each theoretical framework is incomplete and only offers a limited view of disability when utilized independently. Both models

of disability have shortcomings and fail to incorporate key components when it comes to realization of disability. The social model places a strong emphasis on society and socially-constructed problems for PWDs. While bringing the environment into focus, this model seems to diminish the complexity of the concept of disability and the multifaceted nature of the variables that contribute to its manifestation. In a similar vein, the medical model is shortsighted in terms of taking all variables into account. The medical model attributes disability entirely to the individual, losing sight of the host of variables related to environmental manifestations of the construct. Disability needs to be assessed and treated by taking into account both individual and environmental perspectives. As a result of advances in research and a greater focus on evidence-based practice (EBP), new models of disability have materialized. The most modern models of disability are predicated on health and wellness, whereas older models tended to focus on disability and deficiency.

The disablement model, which was developed in the 1960's and later published in 1969, was indeed quite progressive for its time and still is comparable to the most current models of disability. Disablement models provide benefits to health professions through organization of clinical practice and research activities; creation of a common language among health care professionals; facilitation of the delivery of patient-centered, whole-person health care; and justification of interventions based on a comprehensive assessment of the effect of illness or injury on a person's overall health-related quality of life (Snyder, Parsons, Valovich McLeod, Bay, Michener and Sauer, 2008). This model was seen as a success in large part because it effectively reshaped disability, more broadly looking at the concept as a product of change. Whereas, the previous focus was generally placed on physical limitations, Nagi's disablement model focuses more so on the interaction between individual and environment.

In the disablement model, Saad Nagi defines disability as the expression of a physical or mental limitation in a social context. According to Nagi, "Disability represents the gap between a person's intrinsic capabilities and the demands created by the social and physical environment—a product of the interaction of the individual with the environment" (Nagi, 1976). Hence, disability can be thought of as a construct that includes a person and the environment within which they live in the context of an individual's capabilities versus the demands of that social and physical environment. In order to truly understand why someone becomes or does not

become disabled, consideration must be given to both the capacities of the individual (a function of active disease, impairment, or functional limitations or a combination of these) and the capacities of the individual in relation to the social situations (Snyder, Parsons, Valovich McLeod, Bay, Michener and Sauers, 2008).

The International Classification of Functioning, Disability and Health (ICF) is another example of a modern theoretical framework intended to address disability. The ICF has rapidly become a guiding model for disability research, showing disability as a dynamic interaction between health conditions (e.g., stroke, multiple sclerosis), activity limitations (e.g., inability to ambulate without a power wheelchair), and environmental (adapted parking spots, availability of Accessible transportation buses) and personal (ability to drive) contextual factors (Noreau and Boschen, 2010). The ICF model places an emphasis on function rather than condition or disease. This model of disability has shifted the focus from an emphasis on disability to an emphasis on level of health, taking into account the many different contributing factors leading to such phenomena.

The ICF attempts to mainstream disability, considering current societal trends including the “graying of the population,” which will lead to many more people experiencing such an ordeal throughout the duration of their lifetime. This model looks at the complex interplay between the condition, the environment, and personal factors contributing to disability. At the same time, the ICF also realizes each individual is unique and that the experiences related to any given condition will vary from person to person. While physical, sensory, intellectual, or psychological variations, may cause individual functional limitations or impairments, these do not have to lead to disability unless society fails to take into account and include people regardless of their individual differences (Dell Orto, A.E. & Power P.W. , 2007) . Isolation and exclusion prevents full participation in society, and thus leads to disability.

The ICF attempts to come to a better understanding of the complex interaction of variables that lead to disability and disablement. Many of the modern disability frameworks were built upon the ideal of a shift from dependency to self-determination. A shift in societal thought and attitudes on disability eventually leads to the notion that PWDs should realize the concepts of empowerment, advocacy and consumer control, while also working to remove environmental

barriers and improve their lives. As a result of this shift in philosophical mindset regarding disability, PWDs are now responsible for directing their own care. Nowadays, PWDs are in charge of hiring and firing assistants, attendants, and other personnel needed for assistance in activities of daily living (ADLs).

### 2.3 Research purpose

The purpose of this research study is to examine the effects of wheeled mobility devices on self-reported measures of community participation, quality of life and self-perception on a large university campus. In order to facilitate a better understanding of this study, readers should focus on utilizing the social model framework in order to disseminate concepts, recognize definitions, and more fully realize the construct of disability. Taking into account the complexity of disability and advances in modern perspective, this study will focus specifically on theoretical assumptions posited in the ICF and disablement models. The ICF and disablement models more closely place PWDs at the forefront, considering a multitude of possible alternatives to disabling conditions. The knowledge generated from this study will enhance our understanding of what social and environmental factors impact WCUs mobility and the extent to which manual and power chair users may be affected differently.

## CHAPTER 3

### METHODOLOGY

This study utilized a cross-sectional survey design from a convenience sample.

#### 3.1 Participants

The University of Illinois at Urbana-Champaign Institutional Review Board (IRB) approved this research study. Research participants included UIUC students who were also wheelchair users. WCUs were recruited from the Department of Rehabilitation and Educational Services (DRES) and Nugent Hall. Additional recruitment of study participants was facilitated through researcher contacts. Students were recruited through word of mouth and informed that their willingness to participate is completely voluntary; they were also informed that their ability or willingness to participate in this study will in no way, shape, or form affect grades and/or relationship with faculty/staff at UIUC. The inclusion criteria included: (a) having a traumatic or non-traumatic disability, (b) using manual, power or power assist wheelchair as primary source of mobility, (c) current student at UIUC, (d) 18 years of age or older.

Overall, thirty-nine participants were recruited into this study. Eight research participants failed to return the survey or fully complete all sections of the questionnaire. 53.8% or (21) of the research participants were males. While 46.2% or (18) of the research participants were females. Participants ranged from 19-31 years of age. The following wheelchair brands were utilized by participants: Invacare, Quickie, Top-End, Permobil, Per4Max, Eagle, Ranger X, Quantum, Balder, and Pride. Research results dictated that 43.6% or (17) participants fell into the traumatic disability type category. 56.4% or (22) research participants fit into the non-traumatic disability category. Participant's diagnoses were highly variable. Diagnoses ranged from the following: Amputee, Double-amputee, Paraplegia (complete, incomplete), Tetraplegia (complete, incomplete), Osteogenesis Imperfecta (O.I.), Cerebral Palsy (CP), Spinal AVM, Spina Bifida, Becker's Muscular Dystrophy, Spinal Muscular Atrophy (Type II), Transverse Myelitis, Stroke, Multiple Sclerosis, and Lyme Disease. All research participants were treated in accordance with UIUC and IRB standards in terms of treatment of human subjects.

#### 3.2 Outcome measures

For purposes of this study, researchers collected data via demographics forms and 2 survey questionnaires. The demographic form was utilized in order to gain background information on research participants, whereas the surveys were used to measure self-esteem, mobility, social integration, and cognitive independence. The surveys used were the Craig Handicap Assessment Reporting Technique (CHART) and the Rosenberg Self-Esteem Scale (RSES).

This study utilized a demographics survey that included seven questions in regards to participant's gender, age, primary diagnosis, make of wheelchair, type of wheelchair, years in current wheelchair, and years of total wheelchair use. The questions were carefully designed to elicit necessary information applicable to adequately supplement the RSES and CHART tools respectively.

One of the most extensively used instruments to assess self-esteem is the Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1989). The Rosenberg Self-Esteem Scale (RSES) was employed for the purposes of this study. The RSES is made up of 10 items that refer to self-respect and self-acceptance rated on a 4-point Likert-type scale, ranging from 1 (totally disagree) to 4 (totally agree) (Albo, Nunez, Navarro and Grijalvo, 2007). Possible scores range from 10 to 40, with higher scores equating with higher levels of self-esteem and lower scores corresponding with lower levels of self-esteem. "The internal consistency of the scale was assessed with Cronbach's alpha. The values obtained in the first and the second administration were .85 and .88, respectively. The value of the test-retest correlation was .84" (Albo, Nunez, Navarro and Grijalvo, 2007). Reproducibility of this measure is good to excellent at 92% (Hastings, Robins, Griffiths, and Hamilton, 2011).

This study also made use of three sections of the Craig Handicap Assessment Reporting Technique (CHART). The CHART primarily assesses behaviors (e.g., number of hours of physical assistance, visits and communication with other people, and hours spent on activities) (Cooper, Ferretti, Oyster, Kelleher and Cooper, 2011). The three subscales used for purposes of this study were: cognitive independence, mobility and social integration. These sections were used in their entirety, as found in the original CHART documents. Each subscale consists of preselected questions to address the selected measures. There were a total of twenty questions to address the three selected measures. Each subscale had 100 points possible, totaling a maximum of 300 points. A maximum score of 100 points for each respective subscale is representative of

the typical score for a member of the general population without SCI. Test-retest reliability has been shown to have a Pearson reliability coefficient of .93 and a test-retest ICC of .83, indicating the CHART as a reliable measure of participation (Hastings, Robins, Griffiths, and Hamilton, 2011).

### 3.3 Study design/protocol

Each participant was interviewed via an in-person survey format. Upon agreement to participate in the study, the research assistant met with participants face to face to explain the purpose of the study in detail. Subjects were given the informed consent agreement and instructed to read it carefully and in its entirety, signing and dating after completion of the review. Subjects were then administered a demographics survey. The demographic information included the participants age, sex, primary diagnosis (reason for using wheelchair), make and type of wheelchair, number of years using current chair, and total number of year using a wheelchair. Researchers answered any questions present at the time of administration. All research subjects were given the informed consent and demographic form in person. Next, each survey (RSES and CHART) was given to the individual. Research participants who identified decreased time available to complete surveys utilized in this research study were given the option of completing the survey on their own time. Researchers offered to make arrangements to retrieve the survey if participants elected to take it on their own time. However, all data utilized for purposes of this study were collected in-person and at time of consent. After each section of the study, the researcher remained vigilant in asking if there were any questions and providing necessary clarification as needed. The researcher assisted individuals with more severe physical limitations in terms of filling out the surveys and writing down necessary information. The survey generally took most participants less than 1/2 hour to complete.

In order to provide for standardization of procedure, each survey was administered in the same fashion. Confidentiality was addressed through anonymously numbered surveys. There was no identity key created for any purpose, which served to further protect against linking participant survey numbers to their names. Participant's names were in no way tied to the data collected. In the event of e-mailed or electronic data submission, researchers agreed to only

document numbers on physical paper copies of the forms being utilized. Signed consent forms plus any contact information collected was stored separate from all survey data.

### 3.4 Data analysis

Scores for the 2 questionnaires and the demographics form were entered into the Statistical Package for the Social Sciences Windows version 18.0 for data analysis. The total and subscale scores from RSES and CHART were compared using a multivariate analysis of variance (MANOVA) between the participants in the manual verses power wheelchair type groups and the traumatic verses non-traumatic injury type groups. Alpha was set at .05.

## CHAPTER 4

### RESULTS

Twenty-one (53.8%) males and eighteen females (46.2%) participated in this study. Their mean age was 22.62 years (SD= 3.29). Among all participants, seventeen (43.6%) were traumatic injury type and twenty-two (56.4%) were non-traumatic injury type. Twenty-two (56.4%) participants were manual wheelchair users, while seventeen (43.6%) were power wheelchair users. The mean score for time spent in current wheelchair was 4.00 years (range, 0.5-23y), whereas the mean score for total years in wheelchair overall was 11.23 years (range, 0.8-24y).

This study found a main effect statistically significant difference between power and manual wheelchair users,  $F(4, 34) = 4.581, p = .005$ . Manual wheelchair users had significantly higher scores on RSES, CI, and Mobility measures compared to power wheelchair users,  $F(1, 37) = 4.260 - 17.184, ps < .05$ . Disability type (traumatic and non-traumatic) was not found to have a statistically significant impact in and of itself or on survey scores,  $F(4, 34) = .346, p = .845$ . ( $F(1, 37) = .007 - .897, p > .05$ ).

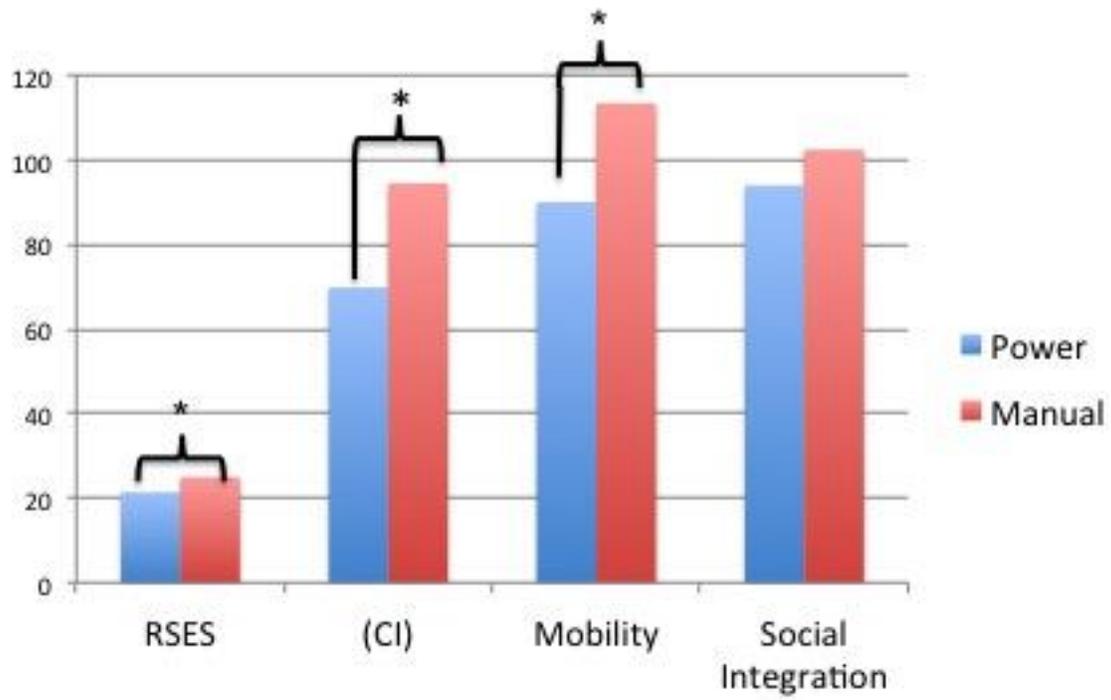
Table 1. Subject Characteristics

<b>Sex</b> N= 39	<b>Diagnosis</b> <b>(Disability Type)</b>  N= 39	<b>Age</b> N= 39	<b>Wheelchair</b> <b>Type</b> <b>(Manual/Power)</b>  N= 39	<b>Years in</b> <b>Current</b> <b>Chair</b>  N=39	<b>Total Years</b>  N= 39
21 Males (53.8%)	17 Traumatic Disabilities (43.6%)	Minimum= 19 years old	22 Manual W/Cs (56.4%)	Minimum= .50 years	Minimum= .80 years
18 Females (46.2%)	22 Non-traumatic Disabilities (56.4%)	Maximum= 31 years old	17 Power W/Cs (43.6%)	Maximum= 23.0 years	Maximum= 24.0 years
Valid Percent (Male) 53.8	Valid Percent (Traumatic) 43.6	Mean= 22.62 years	Valid Percent (Manual) 56.4	Mean= 4.00 years	Mean= 11.23 years
Valid Percent (Female) 46.2	Valid Percent (Non-traumatic) 56.4	Standard Deviation= 3.29	Valid Percent (Power) 43.6	Standard Deviation= 3.99	Standard Deviation= 6.82

Table 2: Mean Survey Scores

<b>Wheelchair</b> <b>Type</b>	<b>Mean Survey Scores</b>			
	<b>RSES</b>	<b>CHART 1</b> <b>(Cognitive Independence)</b>	<b>CHART 2</b> <b>(Mobility)</b>	<b>CHART 3</b> <b>(Social</b> <b>Integration)</b>
<b>Power</b>	21.35	69.88	89.97	93.94
<b>Manual</b>	24.96*	94.46*	113.39*	102.41

\* Statistically significant difference from Power wheelchair group p<0.05



**Figure 1 Mean survey scores**

\*statistically significant difference  $p < .05$

## CHAPTER 5

### DISCUSSION

This study investigated the relationship between disability type (traumatic vs. non-traumatic), and wheelchair type (manual vs. power) on measures of self-efficacy, cognitive independence, mobility, and social integration. Disability type (traumatic and non-traumatic) was not found to have a statistically significant effect on any of the dependent variables measured. However, a significant difference was found between power and manual wheelchair users on scores of self-efficacy, cognitive independence (CI) and mobility.

The statistically significant difference between power and manual wheelchair users (with manual wheelchair users scoring higher on all three variables) on the self-efficacy, CI, and mobility scales is consistent our hypothesis as well as previous literature. Researchers have shown manual wheelchair users to score higher relative to power wheelchair users on mobility, self-esteem and social integration scales (Cooper et al, 2012). The fact that no differences were found between manual and power chair users on the social integration component of the CHART was unexpected. However, it is possible that the wheelchair-friendly environment at the UIUC may have impacted the extent to which mobility, CI and self-esteem deficits impacted social integration. Despite scoring lower in some areas, power chair users are able to overcome these deficits because UIUC offers many opportunities for socialization that wouldn't occur as readily out in the general community/ environment. In essence UIUC levels the playing field for students with more involved physical disabilities in terms of accessibility, close proximity to friends, and other regularly occurring social opportunities.

Nevertheless, the literature continues to support the psychosocial and functional disparities that exist between power and manual wheelchair user. A recent study has shown that individuals with spinal cord injury, 1 year post injury, who are discharged in power wheelchairs, show a decline in physical function as a result of learned nonuse, while those discharged in manual wheelchairs demonstrate increased function (Hastings, Robins, Griffiths, and Hamilton, 2011). According to the CHART, mobility refers to the amount of time participants spend out of bed and out of the home, how well they can access their environment, and the availability of transportation (Hastings, Robins, Griffiths, and Hamilton, 2011). Previous research on mobility

objectively defined it as wheelchair skills and ability, performance time, and physical strain, which are all measures inherently rated higher for those who propel a manual wheelchair, and even higher for those with greater upper extremity function (Hastings, Robins, Griffiths, and Hamilton, 2011).

Researchers have shown similar findings to manifest when examining self-efficacy levels based on mobility device. In terms of self-efficacy, studies have shown that the easier it is for a person to self-propel their wheelchair, the more likely they may be willing to go more places and socialize with others (Cooper, Ferretti, Oyster, Kelleher and Cooper, 2011). These results are consistent with earlier studies that demonstrate persons able to self-propel their primary modes of transportation also exhibit higher levels of self-efficacy. Ultimately these studies have found participation and socialization to be highly correlated (Cooper, Ferretti, Oyster, Kelleher and Cooper, 2011)

Although not addressed in the original CHART, the revised CHART contains a sixth domain designed to assess “orientation”, entitled “Cognitive Independence” (Mellick, 2000). This added domain not only serves as a supplementary component used to measure constructs related to QOL and participation, but it also serves to strengthen overall findings. According to the WHO, “Orientation” involves the ability to orient oneself to his/her surroundings (Mellick, 2000). Once again, it was hypothesized that manual WCUs would perform at a higher level than power WCUs in terms of CI. The results of this study were consistent with our initial assumption that manual WCUs did indeed score higher than power WCUs when it came to the measure of CI. Both researchers’ rehabilitation background led to the belief that the assumed increase in physical activity and mobility experienced by manual WCUs would also lead to greater CI through means of healthier lifestyle and greater immune function.

### Implications/Clinical Application

This study has contributed to the advancement of literature examining the psychosocial differences between manual and power wheelchair users. There is clinical value in terms of the rehabilitation sciences seeking to help assimilate PWDs back into society. Physical therapists (PTs) and occupational therapists (OTs) alike can utilize these findings to better justify and endorse assistive technologies that endorse QOL as well. Specifically, therapists must consider

the extent to which power/ manual wheelchairs affect an individual's psychosocial experience before a prescription is made. Additionally, by looking at the interaction between person and environment, researchers and clinicians gain a clearer picture of the psychosocial environment PWD must navigate. Most importantly, the results of this study may help to elucidate what PWDs actually do in their lived environments, rather than the more stringent institutionalized settings they are often associated with. Furthermore, WCUs may benefit personally from the results of this study. Viewing how high achieving students with disabilities interact within their environments may help others in more restrictive settings to identify strategies to better manage psychosocial factors (mobility, self-esteem, and CI) impacting QOL.

### Limitations of study

Study limitations impacting the overall generalizability of results include convenience sampling and sampling bias. The research was conducted at the UIUC which is an ideal environment for persons with disabilities and may not be representative of the general population. For example students have access to numerous academic, athletic, social, and medical resources that PWD in the general population simply do not have. The large concentration of wheelchair users in such a close proximity to one another is not representative of the US as well. Additionally, participants in this study may not be representative of a general population of WCUs nationwide. For example our participants were all pursuing higher education degrees and tend to be a highly motivated/ educated group with access to resources and support systems that the average person with a disability typically does not have. In essence, the study environment is that of a best case scenario for PWDs. It was interesting to note that significant differences emerged between power and manual wheelchair users despite the support and resources available to these students. This may suggest that a similar study performed on a general population of WCUs would find larger more pronounced discrepancies between power and manual wheelchair users.

Another possible limitation of this study is self-reported level of injury. The level of injury could have been reported inaccurately via recall bias. Researchers were not able to independently confirm the actual diagnosis of participants; it was not feasible to collect this information by looking at medical records or through other means. Injury information reported

by participants may have been incorrect due to changes after discharge (or last evaluation) or participant's lack of precise information about the injury severity.

An additional study limitation includes the possibility that research participants may have misinterpreted survey questions. Between the demographics form and survey tools, there were questions that needed clarification at times. Participants who failed to ask for clarification may have perceived the meaning of questions differently than those who asked for clarification.

Small sample size also limits the power of the findings. Ideal circumstances would provide for a minimum of 100-150 research participants. Because the study involved capturing outdoor mobility it was necessary to collect data under similar environmental or seasonal conditions. Additional recruitment may have required the study to be extended past spring which could have biased the results. Therefore, it was not possible to recruit additional study participants given the time restrictions.

Lastly, social desirability could have also played a role in how participants answered questions throughout this research study. It is commonly known within the greater disability community that there is generally a certain amount of segregation within the subgroups (power vs. manual WCU), leading to differentiation of PWDs as a whole. In turn, this may lead certain individuals to take ownership in their respective subgroup. For example, manual WCUs might have felt the need to answer questions representing themselves as more capable than their power wheelchair counterparts or vice versa.

## CHAPTER 6

### CONCLUSION

This study investigated the relationship between people with different types of disability (traumatic vs. non-traumatic), as well as wheelchair type (manual vs. power) on measures of self-efficacy, cognitive independence, mobility, and social integration. Researchers also focused efforts on identifying distinct environmental facilitators and barriers. Uncovering how PWDs feel will allow for addressing how these variables impact the lives of PWDs. In essence, this paper considered the potential influence of environment on the lives of PWDs. Study results indicated that there were no statistically significant differences between traumatic and non-traumatic disability injury groups. However, there was a significant difference between power and manual wheelchair users on scores of self-efficacy, cognitive independence (CI) and Mobility.

The results of this study point to the importance of taking a holistic approach toward rehabilitation and wellness throughout the lifespan. Living with a disability in and of itself has inherent barriers; promotion of key areas that facilitate wellness will help to lessen the burden experienced by individuals in each respective sub-population under study. Further research should continue to examine the interaction between persons with a variety of disabilities and the environments in which they live. Studies should also focus on finding ways to break down or lessen the impact of social and other environmental barriers threatening QOL. Furthermore, cross-disability studies should be used to determine if one's life experience is inherently related to the type of disability they have or if financial and other resources are more critical to successfully navigating life with a disability.

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APPENDIX A  
INFORMED CONSENT  
UNIVERSITY OF ILLINOIS  
AT URBANA-CHAMPAIGN

**Department of Kinesiology  
and Community Health**



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**Adult Informed Consent Agreement**

**Project title:** Manual vs. Power Wheelchair Propulsion: Quality of Life and Self-Perception

**Principal Investigator:** Ian Rice, Kinesiology and Community Health

**Co-Investigators:** Benjamin Salentine, Graduate Student Community Health

**What is the purpose of this study?**

The main purpose of the present research study is to examine the effects of wheeled mobility devices on self-reported measures of community participation, quality of life and self-perception on the campus of the University of Illinois Champaign Urbana. The knowledge generated from this study will enhance our understanding of what social and environmental factors impact wheelchair user's mobility and the extent to which manual and power chair users may be

affected differently. This research is conducted under the guidance of Assistant Professor Ian Rice of the Kinesiology and Community Health Department at the University of Illinois at Urbana-Champaign.

### **What is the purpose of this form?**

This consent form gives you the information you will need to decide whether to participate in the study. Please read the form carefully. You may ask any questions about the research, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When all of your questions have been answered, you can decide if you want to be in this study or not.

### **What will happen during the study and how long will it take?**

This is a survey study which will ask you about your experiences as a manual or power wheelchair user on the campus of the University of Illinois. Specifically we want to measure your feelings related to, community participation, self-sufficiency, and perceptions of quality of life based on your use of either a manual or power wheelchair.

Your involvement in this study will include one meeting with a researcher who will administer a consent form and survey. You may complete the survey with the researcher present or take it with you to complete on your own time. We will arrange to pick the survey up from you at your convenience. The survey will require approximately 1 hour of your time.

### **Do I have a choice to be in the study?**

If you decide to take part in the study, it should be because you really want to volunteer. You may choose not to take part at all. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. Your decision to participate, decline, or withdraw from participation will have no effect on your grades at, status at, or future relations with the University of Illinois.

### **What are the risks of this study?**

Risks involved in this investigation are minimal, limited to possible fatigue and boredom from completing the questionnaires. There is also a slight risk that the questions asked on the questionnaires may cause emotional or psychological discomfort, but this is not expected. We will also obtain some basic information like age, sex, primary diagnosis (reason for using wheelchair), make and type of wheelchair, number of years using your current wheelchair, and total number of years using a wheelchair.

### **What are the benefits of this study?**

The results of this study will not produce any direct benefits to you. This study will enrich our understanding of the factors that contribute to the quality of life, participation, and self-sufficiency in wheelchair users on the campus of U of I which may lead to improvements in services and therapeutic interventions nationwide.

**Compensation**

Participants will not be compensated for this study however your time and contribution is much appreciated!

**Who will see the information I give?**

The information you provide during this research study will be kept confidential to the extent permitted by law. To help protect and ensure your confidentiality, your name will not be tied to the data collected. All information, including this informed consent document and study results will be securely stored and accessible only to the primary investigator and researcher named in this study. At your request, a copy of your results will be given to you. It is expected that the results of this research will be presented at professional meetings and published in scientific journals. In those cases, your identity will not be made public.

**What if I have questions?**

If you have any questions about this research project, please contact: Dr. Ian Rice at 217-333-1807, email: [ianrice@illinois.edu](mailto:ianrice@illinois.edu)

If you have any questions about your rights as a participant in this study or any concerns or complaints, please contact the University of Illinois Institutional Review Board at 217-333-2670 (collect calls will be accepted if you identify yourself as a research participant) or via email [atirb@illinois.edu](mailto:atirb@illinois.edu)

---

I am 18 years of age or older. I have read and understand the above consent form and voluntarily agree to participate in this study.

Name of Participant (printed): \_\_\_\_\_

---

(Signature of Participant)

---

(Date)

You will receive a copy of this form.

APPENDIX B

DEMOGRAPHIC SURVEY

1) Are you Male or Female?

- Male
- Female

2) What is your age?

\_\_\_\_\_

3) What is your primary diagnosis (reason for using a wheelchair)?

---

---

4) What is the make of your wheelchair? (i.e. Quickie, Top-End, etc.)

---

---

5) What type of wheelchair do you use?

- Manual
- Power(front/mid/rear wheel)
- Power assist

6) How many years have you been using your current wheelchair as a mode of transportation?

\_\_\_\_\_

7) How many years have you been using a wheelchair as your mode of transportation overall?

\_\_\_\_\_

## APPENDIX C

### **Rosenberg Self-Esteem Scale** (*Rosenberg, 1965*)

The scale is a ten item Likert scale with items answered on a four point scale – from strongly agrees to strongly disagree. The original sample for which the scale was developed consisted of 5,024 High School Juniors and Seniors from 10 randomly selected schools in New York State.

Instructions: Below is a list of statements dealing with your general feelings about yourself. If you strongly agree, circle **SA**. If you agree with the statement, circle **A**. If you disagree, circle **D**. If you strongly disagree, circle **SD**.

- |   |    |   |   |    |
|---|----|---|---|----|
| 1. On a whole, I am satisfied with myself.  | SA | A | D | SD |
| 2.* At times, I think I am no good at all.  | SA | A | D | SD |
| 3. I feel that I have a number of good qualities.                                 | SA | A | D | SD |
| 4. I am able to do things as well as most other people.                           | SA | A | D | SD |
| 5.* I feel I do not have much to be proud of.                                     | SA | A | D | SD |
| 6.* I certainly feel useless at times.  | SA | A | D | SD |
| 7. I feel that I am a person of worth, at least on an<br>equal plane with others. | SA | A | D | SD |
| 8.* I wish I could have more respect for myself.                                  | SA | A | D | SD |
| 9.* All in all, I am inclined to feel that I am a failure.                        | SA | A | D | SD |
| 10. I take a positive attitude toward myself.                                     | SA | A | D | SD |

*Scoring: SA=3, A=2, D=1, SD=0. Items with an asterisk are reverse scored, that is, SA=0, A=1, D=2, SD=3. Sum the scores for the 10 items. The higher the score, the higher the self-esteem.*

**Craig**

**Handicap**

**Assessment**

**Reporting**

**Technique**

1. How much time is someone with you in your home to assist you with activities that require remembering, decision making, or judgment?

1 \_\_\_\_\_ Someone else is always with me to observe or supervise.

2 \_\_\_\_\_ Someone else is always around, but they only check on me now and then.

3 \_\_\_\_\_ Sometimes I am left alone for an hour or two.

4 \_\_\_\_\_ Sometimes I am left alone for most of the day.

5 \_\_\_\_\_ I have been left alone all day and all night, but someone checks in on me.

6 \_\_\_\_\_ I am left alone without anyone checking on me.

2. How much of the time is someone with you to help you with remembering, decision making, or judgment when you go away from your home?

1 \_\_\_\_\_ I am restricted from leaving, even with someone else.

2 \_\_\_\_\_ Someone is always with me to help with remembering, decision making, or judgment when I go anywhere.

3 \_\_\_\_\_ I go places on my own as long as they are familiar.

4 \_\_\_\_\_ I do not need help going anywhere

3. How often do you have difficulty communicating with other people?

1 \_\_\_\_\_ I almost always have difficulty.

2 \_\_\_\_\_ I sometimes have difficulty.

3 \_\_\_\_\_ I almost never have difficulty.

4. How often do you have difficulty remembering important things that you must do?

1 \_\_\_\_\_ I almost always have difficulty.

2 \_\_\_\_\_ Sometimes I have difficulty.

3 \_\_\_\_\_ I almost never have difficulty.

5. How much of your money do you control?
- 1  None, someone makes all money decisions for me.
- 2  A small amount of spending money is given to me periodically.
- 3  Most of my money, but someone does help me make major decisions.
- 4  I make all of my own money decisions (or if married, in joint participation with my partner).
6. On a *typical day*, how many hours are you out of bed?  hours
7. In a typical *week*, how many days do you get out of your house and go somewhere?  
 days
8. In the last *year*, how many nights have you spent away from your home (excluding hospitalizations)?
- None       1-2       3-4       5 or more
9. Can you enter and exit your home without any assistance from someone?
- Yes       No
10. In your home, do you have independent access to your sleeping area, kitchen, bathroom, telephone, and TV (or radio)?
- Yes       No
11. Can you use your transportation independently?
- Yes       No
12. Does your transportation allow you to get to all the places you would like to go?
- Yes       No
13. Does your transportation let you get out whenever you want?
- Yes       No
14. Can you use your transportation with little or no advance notice?

\_\_\_\_\_Yes                      \_\_\_\_\_No

15. Do you live alone?

\_\_\_\_\_Yes                      \_\_\_\_\_No

15a. (If you don't live alone) do you live with a spouse or significant other?

\_\_\_\_\_Yes                      \_\_\_\_\_No

15b. How many children do you live with? \_\_\_\_\_

15c. How many other relatives do you live with? \_\_\_\_\_

15d. How many roommates do you live with? \_\_\_\_\_

15e. How many attendants do you live with? \_\_\_\_\_

16. (If you don't live with a spouse or significant other) are you involved in a romantic relationship?

\_\_\_\_\_Yes                      \_\_\_\_\_No                      \_\_\_\_\_N/A

17. How many relatives (not in your household) do you visit, phone, or write to at least once a month? \_\_\_\_\_relatives

18. How many business or organizational associates do you visit, phone, or write to at least once a month? \_\_\_\_\_Associates

19. How many friends (non-relatives contacted outside business or organizational settings) do you visit, phone, or write to at least once a month? \_\_\_\_\_Friends

20. With how many strangers have you initiated a conversation in the last month (for example, to ask information or place an order)?

\_\_\_\_\_None

\_\_\_\_\_1-2

\_\_\_\_\_3-5

\_\_\_\_\_6 or more