

**RELATIONSHIP BETWEEN TRANSPORTATION BARRIERS, HEALTH RELATED  
QUALITY OF LIFE, COMMUNITY INTEGRATION, AND EMPLOYMENT RATES  
FOR INDIVIDUALS WHO USE POWER WHEELCHAIRS**

by

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BS Rehabilitation Sciences, University of Pittsburgh, 2006

Submitted to the Graduate Faculty of  
The School of Health and Rehabilitation Sciences in partial fulfillment  
of the requirements for the degree of  
Masters of Science

University of Pittsburgh

2008

UNIVERSITY OF PITTSBURGH

THE SCHOOL OF HEALTH AND REHABILITATION SCIENCES

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Currently, about 13% of the population ages 21-64 have a disability in the United States and approximately 1.7 million of people use a wheelchair for their mobility needs. Additionally, over 100,000 individuals in the United States use an electric-powered wheelchairs and the use of power wheelchairs has been associated with increased opportunities to participate in society for individuals with mobility disabilities. While assistive devices have facilitated participation, barriers still exist. Approximately 30% of individuals with disabilities reported facing difficulties in accessing transportation compared to 10% of individuals without disabilities and transportation was reported as the most significant barrier related to their work environment. Furthermore, the national employment rate for individuals with disabilities age 21-64 is roughly 38% while the rate of individuals without disabilities is about 80%.

The main objective of this study was to collect data from individuals who use power wheelchairs or scooters. Data were collected and analyzed on variables of transportation barriers, employment, community integration, and health related quality of life. One hundred and two individuals consented to participate in this study.

Significant correlations were found between health related quality of life and community integration scores (Community Integration Questionnaire). Individuals who are employed have a significantly better HRQoL than individuals who are unemployed. No significant differences were found on the basis of self-reported transportation difficulties.

Employment rates for persons who use power wheelchairs are related to the individual's health related quality of life. While previous research has shown that independent transportation is essential to employment for persons with disabilities, this study has shown that individuals who do not experience self-reported transportation difficulties have no difference in employment rates than individuals who experience transportation difficulties.

## TABLE OF CONTENTS

|  |           |
|--|-----------|
| <b>ACKNOWLEDGEMENT</b> .....   | <b>x</b>  |
| <b>1.0 INTRODUCTION</b> .....  | <b>1</b>  |
| <b>1.1 DISABILITY IN THE UNITED STATES</b> .....   | <b>1</b>  |
| <b>1.2 INDEPENDENT TRANSPORTATION</b> .....  | <b>3</b>  |
| <b>1.3 LEGISLATION REGARDING EMPLOYMENT AND TRANSPORTATION<br/>FOR INDIVIDUALS WITH DISABILITIES</b> ..... | <b>4</b>  |
| <b>1.4 EMPLOYMENT AND EDUCATION RATES FOR PERSONS WITH<br/>DISABILITIES</b> .....                          | <b>6</b>  |
| <b>1.5 QUALITY OF LIFE AND DISABILITY</b> .....  | <b>7</b>  |
| <b>1.6 COMMUNITY INTEGRATION</b> .....   | <b>8</b>  |
| <b>1.7 SIGNIFICANCE OF STUDY</b> .....   | <b>10</b> |
| <b>1.8 SPECIFIC AIMS</b> .....   | <b>10</b> |
| <b>2.0 METHODS</b> .....   | <b>13</b> |
| <b>2.1 STUDY DESIGN</b> .....  | <b>13</b> |
| <b>2.2 SUBJECTS</b> .....  | <b>13</b> |
| <b>2.3 STUDY PROTOCOL AND INSTRUMENTATION</b> .....  | <b>15</b> |
| <b>2.4 DATA MANAGEMENT</b> .....   | <b>23</b> |
| <b>2.5 METHOD FOR STATISTICAL ANALYSIS</b> .....   | <b>24</b> |

|            |  |           |
|------------|--|-----------|
| <b>3.0</b> | <b>RESULTS .....</b>   | <b>27</b> |
| <b>3.1</b> | <b>DEMOGRAPHICS .....</b>  | <b>27</b> |
| <b>3.2</b> | <b>SPECIFIC AIM 1: TRANSPORTATION, EMPLOYMENT, AND<br/>COMMUNITY INTEGRATION .....</b>                 | <b>32</b> |
| <b>3.3</b> | <b>SPECIFIC AIM 2: HEALTH RELATED QUALITY OF LIFE, COMMUNITY<br/>INTEGRATION, AND EMPLOYMENT .....</b> | <b>42</b> |
| <b>3.4</b> | <b>SPECIFIC AIM 3: EMPLOYMENT .....</b>  | <b>45</b> |
| <b>4.0</b> | <b>DISCUSSION .....</b>  | <b>50</b> |
| <b>4.1</b> | <b>LIMITATIONS .....</b>   | <b>56</b> |
| <b>4.2</b> | <b>FUTURE STUDIES .....</b>  | <b>58</b> |
| <b>4.3</b> | <b>IMPLICATIONS FOR REHABILITATION COUNSELORS.....</b>   | <b>60</b> |
| <b>5.0</b> | <b>CONCLUSION .....</b>  | <b>62</b> |
|            | <b>APPENDIX A: DEMOGRAPHIC QUESTIONNAIRE .....</b>   | <b>63</b> |
|            | <b>APPENDIX B: TRANSPORTATION QUESTIONS.....</b>   | <b>66</b> |
|            | <b>APPENDIX C: COMMUNITY INTEGRATION QUESTIONNAIRE .....</b>   | <b>68</b> |
|            | <b>APPENDIX D: HEALTH RELATED QUALITY OF LIFE VARIABLES .....</b>                                      | <b>71</b> |
|            | <b>APPENDIX E: ADDITIONAL FIGURES .....</b>  | <b>72</b> |
|            | <b>BIBLIOGRAPHY.....</b>   | <b>79</b> |

## LIST OF TABLES

|  |    |
|--|----|
| <b>Table 1:</b> Outcome Score Indicator .....  | 21 |
| <b>Table 2:</b> Data Reduction Key .....   | 22 |
| <b>Table 3:</b> Demographic Information.....   | 28 |
| <b>Table 4:</b> Socioeconomic Data .....   | 29 |
| <b>Table 5:</b> Disability Income Received.....  | 32 |
| <b>Table 6:</b> Transportation Usage .....   | 34 |
| <b>Table 7:</b> Method of Payment for vehicle.....   | 35 |
| <b>Table 8:</b> Transportation Difficulties.....   | 35 |
| <b>Table 9:</b> Employment Status versus Transportation Difficulties .....                   | 36 |
| <b>Table 10:</b> Community Integration Scores by Transportation Difficulties.....            | 41 |
| <b>Table 11:</b> Community Integration Scores by Primary Means of Transportation.....        | 41 |
| <b>Table 12:</b> Health Questions .....  | 42 |
| <b>Table 13:</b> Demographic Variables by Employment Status .....                            | 44 |
| <b>Table 14:</b> Employment Status and Community Integration Scores .....                    | 44 |
| <b>Table 15:</b> Health Related Quality of Life by Employment Status .....                   | 49 |
| <b>Table 16:</b> Comorbid Conditions and Employment Status Before and After Age Control..... | 49 |
| <b>Table 17:</b> Relationship between Health Questions and Comorbid Conditions.....          | 77 |
| <b>Table 18:</b> Breakdown of the Method of Transportation.....                              | 78 |



## LIST OF FIGURES

|   |    |
|---|----|
| <b>Figure 1:</b> Reason for Employed Other Than Full-time .....             | 31 |
| <b>Figure 2:</b> Breakdown of Number of Days Leaving Home.....              | 34 |
| <b>Figure 3:</b> Transportation Difficulties by Employment Status .....     | 37 |
| <b>Figure 4:</b> Primary Means of Transportation by Employment Status ..... | 38 |
| <b>Figure 5:</b> Primary Means of Transportation by Household Income .....  | 39 |
| <b>Figure 6:</b> Employment Status by Highest Degree Earned .....           | 46 |
| <b>Figure 7:</b> Household Income by Employment Status .....                | 47 |
| <b>Figure 8:</b> Histogram of Age .....                                     | 72 |
| <b>Figure 9:</b> Histogram of Disability .....                              | 73 |
| <b>Figure 10:</b> Employment Status.....                                    | 74 |
| <b>Figure 11:</b> Household Income.....                                     | 75 |
| <b>Figure 12:</b> Transportation Difficulties by Household Income .....     | 76 |

## **ACKNOWLEDGEMENT**

I am extremely appreciative for the opportunity to have strengthened my education, and expanded my horizons, at the Human Engineering Research Laboratories and the Department of Rehabilitation Science and Technology. The opportunities that have been given to me during my career at RST have been wonderful, and for this I will always be thankful. To my advisor, Dr. Michael Pramuka, whose door was always open to answer my questions and offer his encouraging support throughout my entire educational experience, I am tremendously grateful. I must also extend my gratitude to the other members of my thesis committee, Dr. Michael McCue and Dr. Rory Cooper for their assistance and their guidance.

Finally, I must also thank my family and my friends for all of their support and their words of wisdom they have given me during my graduate career. To my friends, thank you for making my time in Pittsburgh truly special and for enduring my relentless excitement about the Pirates and the Penguins (and for always accepting my requests to go to so many games). To my family, you have been my rock and were always there for me no questions asked. I am sincerely grateful for the love you have given me and am thankful to have you in my life...you mean the world to me.

## **1.0 INTRODUCTION**

### **1.1 DISABILITY IN THE UNITED STATES**

According to the 2006 United States Disability Status Report, approximately 13% of the population ages 21-64 have a disability and about 15% of individuals age five years and older have a disability (Rehabilitation Research and Training Center on Disability Demographics and Statistics, 2007). Kaye, Kang, and LaPlante (2000) stated there were an estimated 6.8 million people using assistive devices (e.g. wheelchair, crutches, and canes) for their daily mobility needs in the United States, with almost 1.7 million of these individuals using wheelchairs. The remaining 5.1 million individuals who use canes, crutches, and walkers today may be future wheelchair users. As McNeil (1993) reported, between 1980 and 1990 alone, the use of wheelchairs increased over 96 percent. Kaye et al. also reported that roughly one-third of individuals who use an assistive device for their mobility require some human assistance to complete their Activities of Daily Living such as eating, bathing, dressing and transferring, while less than one percent of individuals who do not use mobility assistance devices need some human assistance. Additionally, two-thirds of individuals who use assistive technology for mobility have some limitation in their Instrumental Activities of Daily Living (Kaye, Kang, and LaPlante). Examples of Instrumental Activities include balancing a check book, grocery shopping, and preparing meals. Davis (1997) found that roughly between fifteen and twenty percent of individuals in the United States have a disability that interferes with some life activity.

As the population in the United States ages, the incidence of disability will increase; this is illustrated by Lipson and Rogers (2000) who stated that people with disabilities are the largest minority group in the United States. Individuals with progressive disabilities or with high levels of impairment, or for individuals with disabilities who can no longer use a manual wheelchair, an electric-powered wheelchair can provide an increase in functional mobility and increased independence (Ding and Cooper, 2005; Buning, Angelo, & Schmeler, 2001; Evans, 2000). Jones and Sanford stated the usage of electric-powered wheelchairs is over 100,000 in the United States alone (1996).

The use of powered wheelchairs has been associated with increases in self-esteem and increased opportunities to participate in society (Buning, Angelo, & Schmeler; Evans; and Miles-Tapping & Mann, 1994) while another study has shown the prescription of a power wheelchair had a lesser impact on their mobility issues than was expected (Jedeloo, de Witte, Linsen, Schrijvers, 2000). However, this study did not did not assess other factors that may have influenced the results such as environmental barriers (Miles-Tapping & Mann; Mclain, Cram, Wood, & Taylor, 1998). In another study conducted by Patrick, Kinne, Engelberg, and Pearlman (2003), they found people with disabilities have a perceived lower quality of life due to environmental barriers and biases based upon the disability, but the addition of powered mobility has allowed individuals to become more independent by allowing them to travel farther, thereby increasing their independence (Davies, DeSouza, & Frank, 2003).

## 1.2 INDEPENDENT TRANSPORTATION

In today's society, transportation is vital for individuals to be a productive member of society; this is true for individuals with and without disabilities. Unfortunately, though, many barriers can exist for individuals who use wheelchairs and who want to participate in activities outside their home with one of the biggest obstacles being transportation. A person with a disability may live in the same home for many years and have the ability to adapt and make accommodations specific to their needs. This is not true, however, for transportation as individuals cannot depend on taking the same bus on a regular basis (Tanner, Zura, Chen, Gregory, Becker, Thacker, et al., 1990). Additional problems with transportation may include lack of curb cuts, subway turnstiles, or the height of the first step on a public bus (Tanner, Zura, Chen, Gregory, Becker, Thacker, et al.). A survey conducted in 2000 by the National Organization on Disabilities found approximately 30% of individuals with disabilities reported facing difficulties in accessing adequate transportation compared to 10% of individuals without disabilities (United States General Accounting Office, 2003)

A national of 336 individuals who use wheelchairs for their mobility needs found that 28% reported being drivers and 68% reported being car or van passengers and 21% indicated that they used a public bus system and 35% reported the used para-transit. Sixty percent of this population used power wheelchairs or scooters (Fitzgerald, Songer, & Rotko, 2004; Fitzgerald, Songer, & Schneider, 2006; Rotko, Songer, & Fitzgerald, 2005; Songer, Fitzgerald, & Rotko, 2004).

Several studies focusing on transportation usage for individuals who use powered wheelchair have been conducted in the United Kingdom. Belcher and Frank conducted a study

on individuals who use power wheelchairs to determine problems with transportation (Belcher & Frank, 2004). Twelve percent of the individuals who use transportation were involved in an accident and twenty percent of the participants felt unsafe at times during transportation. They also found eighty-two percent of the participants use transportation compared to the 70% found in previous studies (Donaldson, 2003; Sanderson, 1999). Transportation options evaluated in this study included para-transit, private cars, taxis, ambulances, local authorities that provide services to individuals with disabilities to take them to school, and other. Thirty-three percent of individuals who use power wheelchairs use cars as a means of transportation while 75% of those who use manual wheelchairs travel in cars (Belcher & Frank).

Transportation has been observed to be important to individuals when considering the functional evaluation of a wheelchair (Mills, 2002; Routhier, 2003). Independent transportation may allow a person to be more active in the community and increase their perceived quality of life. However, the needs and concerns of the person are not always shared or considered (Pierce, 1997). With so many problems in transportation for individuals who use wheelchairs, a better solution needs to be addressed.

### **1.3 LEGISLATION REGARDING EMPLOYMENT AND TRANSPORTATION FOR INDIVIDUALS WITH DISABILITIES**

The Rehabilitation Act of 1973, as amended, the Americans with Disabilities Act (ADA), and the New Freedom Initiative (NFI) were passed into law with the intent to provide equal access in community participation to all individuals with disabilities. Section 504 of the

Rehabilitation Act prohibits discrimination in programs that receive federal funding on the basis of disability (U.S. Department of Justice, 2005). The ADA was passed into legislation in 1990 and covers five areas: employment, public services, public accommodations, telecommunications, and miscellaneous. Specifically, Title I prohibits employers from discriminating against qualified individuals with disabilities with respect to hiring, firing, compensation, and other privileges of employment (U.S. Department of Justice, 2007). Title II extends the parameters of Section 504 of the Rehabilitation act as it prohibits discrimination in programs and activities of the state and local governments and ensures equal opportunity and access for all persons with disabilities (U.S. Department of Justice, 2007). Transportation provisions covered by Title II include city buses, subways, commuter rails, and public rail transit (U.S. Department of Justice, 2007).

The NFI was instituted in 2001 to increase and expand opportunities to participate in society and seek gainful employment for individuals with disabilities by developing innovative transportation solutions (United States Department of Health and Human Services [DHHS], 2001). The NFI also established the Interagency Council on Community Living (ICCL) under the Secretary of the Department of Health and Human Services. According to The White House progress report on the NFI, “employment is a key to independence, empowerment, and improved quality of life” (The White House, 2002, p. 10) and that “inadequate transportation inhibits employment for all people, but is an even greater barrier to people with disabilities” (The White House, 2002, p. 12). While these laws have been passed, the unemployment rates are still strikingly high for persons with disabilities.

## **1.4 EMPLOYMENT AND EDUCATION RATES FOR PERSONS WITH DISABILITIES**

Competitive employment has been described by many as a basic human right of individuals with disabilities and is fundamental to the health, both physical and psychological, of all individuals living in modern society (Chan, Cheing, Chan, Rosenthal, & Chronister, 2006; Chan, Reid, Roldan, Kaskel, Rahimi, & Mpofu, 1997; Perrone, Perrone, Chan, Thomas, 1997; Rubin & Roessler, 2000). Individuals who are unemployed have higher rates of depressive symptomatology and substance abuse than individuals who are employed (Rodriguez, Lasch, and Mead, 1997; Rodriguez, Frongillo, & Chandra, 2001). Additionally, individuals who are in poorer health are at an increased risk of leaving their jobs while people who are in better health and become unemployed have a higher probability of becoming reemployed (Riphahn, 1999).

While the psychological and physical benefits of employment have been documented, research has also shown that people with disabilities are less likely to be working than those without disabilities. One barrier to the ability to work is available transportation and the ability for the individual to use their transportation independently. Currently, the employment rates of individuals with disabilities age 21-64 is approximately 38% while the rate of individuals without disabilities is roughly 80% (Rehabilitation Research and Training Center on Disability Demographics and Statistics). Sixteen percent of individuals with disabilities are receiving Supplemental Security Income. Additionally, of the individuals who are unemployed, 9% of individuals with disabilities and 20% of individuals without disabilities are actively looking for work.



The education rates for individuals with disabilities are also lower than individuals without disabilities; 35% of people with disabilities have a high school diploma only, 28% have an Associates Degree or some college education, and 12% have a Bachelor's Degree or higher compared to 28%, 30%, and 30% of people without disabilities respectively (Rehabilitation Research and Training Center on Disability Demographics and Statistics).

According to Wehman, Wilson, Parent, Sherron-Targett, & McKinely (2000), transportation was reported as the most significant barrier related to their work environment. Another barrier to employment may be employers' attitude toward employees with disabilities as people with disabilities tend to have a lower perceived health related quality of life than individuals without disabilities. If people have a low perceived quality of life, they may be at an increased risk for losing their job.

## **1.5 QUALITY OF LIFE AND DISABILITY**

Quality of life (QoL) and health related quality of life (HRQoL) have received more focus over the past years due to advancements in medical care and assistive technology that allow individuals with severe disabilities to live independently longer. QoL has been described as "a subjective, multidimensional concept" that focuses on the individual's self-perception of their current status. (Cella & Bonomi, 1995 and Patrick & Erikson, 1993. As Cited in Bonomi, Patrick, Bushnell, & Martin, 2000). While there is no agreement on a single definition for QoL, several common themes have been identified. These themes are captured with the belief that an individual's health status, social well-being, and psychological well-being relate to their QoL.

Additional areas of interest in QoL include things such as safety of the environment in which they live and their current access to healthcare (Bonomi, Patrick, Bushnell, & Martin, 2000). HRQoL, in contrast, refers to an individual's QoL as it relates to disease or disability (Bonomi, Patrick, Bushnell, & Martin).

As previously stated, people with disabilities may have a perceived lower QOL due to environmental barriers and biases based upon the disability. The addition of powered mobility has allowed individuals to become more independent by allowing them to travel farther thereby increasing their independence (Davies, 2003), however, their independence can also be compromised because of an inability to dismantle and store their wheelchair in the automobile, creating the problem of requiring assistance from another individual (Frank, Ward, Orwell, McCullagh, & Belcher, 2000) .

## **1.6 COMMUNITY INTEGRATION**

Another area of interest for individuals with disabilities is community integration. Like quality of life, a clear definition of community integration has not been uniformly identified. Community integration research began with individuals with cognitive and psychiatric disabilities, but is expanding to all individuals with disabilities (McColl, Carlson, Johnston, Minnes, Shue, Davies, et al., 1998). As interest in community integration has spread, the ways in which researchers define and collect this concept has varied, but with some common underlying themes. The common themes that encompass many definitions of community integration focus on relationships with others, independence in activities and housing, and

participating in activities as a means to have something to do (McColl, Carlson, Johnston, Minnes, Shue, Davies, et al., 1998; Johnston & Lewis, 1991; Ittenbach, Bruininks, Thurlow, & McGrew, 1993).

Individuals with mobility disabilities may have an increased rate in social isolation, depression, or anxiety compared to individuals without mobility limitations from a decrease in opportunities to socialize, a key component in community integration (Simpson, 2005; Iezzoni, McCarthy, Davis, Siebens, 2001). After a person experiences a disability, return to community-based activity and return to home are important goals in rehabilitation (Willer, Ottenbacher, & Coad, 1994). While community integration is the end goal, the environment, social and physical, has a direct impact on successful reintegration after injury. According to Miller, Forwell, Noreau, Jongbloed, Procter, & Abramson (2006), the environment is defined as:

The dynamic and inseparable situational context that shapes what a person chooses to do, how successful and how satisfied they are in doing it. The environment can support people or constrain them in their performance of activities and thus has a powerful impact on community re-integration.

Therefore, the environmental factors that individuals with disabilities face may have an impact on an individual's ability to successfully participate in society, socially and productively.

## **1.7 SIGNIFICANCE OF STUDY**

As previously stated, transportation is extremely important for individuals to fully participate in society, especially for persons with disabilities. Independent transportation impacts an individual's ability to be competitively employed and to fully participate in society outside of the home. As a result, the ADA was created and passed with sections that cover employment and public transportation for individuals with disabilities.

Many studies have been conducted on the transportation usage for individuals with disabilities and the safety of passengers, who remain in their wheelchair during transport, but few studies have been conducted on the relationship between transportation barriers, health related quality of life, and employment for individuals who use power wheelchairs. Therefore it was proposed to examine this topic of transportation usage as it relates to community integration and employment for individuals who use power wheelchairs. If data shows strong correlation between independent transportation and employment and community integration, support for rehabilitation professionals to further evaluate transportation options would be stronger.

## **1.8 SPECIFIC AIMS**

The purpose of this study was to determine the relationship between transportation barriers, health related quality of life, and employment for individuals who use power wheelchairs. This study examined the relationship between independent transportation,

employment rates, health related quality of life, and community integration for individuals who use power wheelchairs. The following hypotheses were examined:

### **Specific Aim 1: Transportation, Employment, and Community Integration**

Determine the relationship between transportation and employment and community integration.

- **Hypothesis 1.A**

Power wheelchair users who do not experience difficulties with transportation will have higher rates of employment outside of the home or be enrolled in school than power wheelchair users who experience transportation difficulties.

- **Hypothesis 1.B**

Power wheelchair users who do not experience difficulties with transportation will have higher community integration than power wheelchair users who experience transportation difficulties.

### **Specific Aim 2: Health Related Quality of Life, Community Integration, and Employment**

Determine the relationship between health related quality of life and employment and community integration.

- **Hypothesis 2.A**

Power wheelchair users who have a higher health related quality of life will have higher community integration.

- **Hypothesis 2.B**

Power wheelchair users who are employed will have higher community integration than power wheelchair users who are unemployed.

### **Specific Aim 3: Employment**

**Compare and contrast demographic characteristics of individuals who are unemployed versus those who are employed.**

- **Hypothesis 3.A**

Power wheelchair users who are employed will have better health related quality of life power wheelchair users who are unemployed.

## **2.0 METHODS**

### **2.1 STUDY DESIGN**

This study was a cross-sectional design investigating independent transportation usage and its relationship with employment, health related quality of life (HRQoL), and community integration. Individuals were given a questionnaire to collect data on demographics, disability, automobile, and current transportation usage. The information collected from the questionnaires allowed for the comparison of scores among individuals with varying disabilities and duration and severity of disabilities. Institutional Review Board (IRB) approval was obtained from the University of Pittsburgh prior to any data collection. All subjects completed the informed consent process before participating.

### **2.2 SUBJECTS**

Eligibility criteria for this study were 1.) Use a power wheelchair or a scooter for mobility 2.) 18 years of age or older and. Participants were recruited through IRB approved brochures explaining the study sent to individuals already in the Human Engineering Research Laboratories Wheelchair Users Registry. This registry is a database of individuals located throughout the United States who have given the lab permission to contact them if a study comes

up for which they may be eligible and is for the lab's reference only. Personal information in the Wheelchair Users Registry is treated as confidential; access to this database is restricted to only the principal investigators and clinical coordinators. Clinical coordinators are given the eligibility requirements to determine who may be eligible for a particular study and then search through the Wheelchair Users Registry. Registry investigators or coordinators contact individuals who fit the eligibility criteria to participate in a particular study. Participants were also recruited through an IRB approved advertisement placed on the Human Engineering Research Laboratories Website and in their newsletter. This advertisement encouraged interested individuals to contact the investigators.

Once individuals contacted the investigators, the researchers were able to answer any questions that individuals may had. The researchers gathered an IRB approved packet which contained: a cover letter explaining the contents of the packet, a demographic questionnaire, a data questionnaire, a consent form, a reimbursement sheet, and a self-addressed stamped envelope. All study advertisements and the cover letter provided multiple means of contacting the research team should any additional concerns have arisen with the potential participants. Upon the receipt of the returned, signed consent form, data were collected. Individuals who were unable to complete the packet through the mail were able to complete the information through a telephone interview. Participants were considered to be enrolled once individual met inclusion criteria and informed consent was completed. Participants were reimbursed \$15.00 for completing the demographic and data questionnaire.



## **2.3 STUDY PROTOCOL AND INSTRUMENTATION**

Once participants signed the informed consent documents, data were collected. Data collected consisted of Demographic Information; Socioeconomic Status; Community Integration; Automobile Information; and Current Transportation. The following are the variables listed with descriptions of how these were measured.

### **Demographics**

Self-reported questions were asked about the person's age, ethnicity, gender, socioeconomics (including work status, years of education, type of health insurance and household income). Additional information was asked about the person's disability, years of disability, and comorbid conditions.

Specifically, the type of disability was determined by the answers individuals gave to the question: "What is your injury or diagnosis?" The date of onset, injury, or diagnosis was recorded following the question asking about the type of disability. For the purpose of this paper, disability was classified as progressive and nonprogressive and as congenital and acquired.

### **Socioeconomic Status**

Socioeconomic status was assessed by asking participants specific questions about their living environment, current work status, level of education, marital status, income, and health insurance. Current living environment was collected by asking if the person was living in a residence hall/college dormitory, hour/apartment/condominium, independent senior housing,

assisted living, nursing home, relative's home, or other. The education data were collected by asking individuals their number of years of formal education they have completed, ranging from 6 years to 17 years. The participants were also asked what the highest degree received with the options of high school diploma or GED, associate degree/vocational/technical school, bachelor degree, or graduate degree. To determine current works status, participants were asked to choose one of the following descriptions best captured their current work status: Working full-time, outside the home, Working full-time, inside the home, Working part-time, outside the home, Working part-time, inside the home, disabled: unable to work because of disability, unemployed: not able to find work in field I was trained, I choose not to be employed or am retired, or student. Employment was classified prior to data analysis as working outside the home, working inside the home, unemployed, or student. Due to small cell sizes, data were further classified into employed (working or student) or unemployed and household income was broken down into less than \$35,000 or great than \$35,000. Marital status was collected by asking respondents if they were single, married, or living with someone as if married and was collapsed to single and married/living together. Individuals were asked to describe their current health insurance by responding to the following statements: I do not have health insurance; Medicare or Medicaid; employer, spouse's/parent's employer, or previous employer; health insurance through personal monies; and other. Health insurance was categorized into Public (Medicare/Medicaid), Private (employer, personal monies, and appropriate other responses), or both prior to data analyses.

## **Employment**

Employment was further analyzed by asking participants who were not employed full-time if it was by choice, because of the economy, or because of the disability. Participants were also asked if they felt their disability has affected their income and if so, if their income was increased or decreased. Individuals were also asked if they receive disability and if so, to indicate if type, Supplemental Security Income, Social Security Disability Income, Workman's Compensation, or Other.

## **Automobile Information**

Participants were asked if they owned a modified converted van, and if so, how they paid for the van. A modified converted van was described to participants as a van that typically has a side or rear ramp and a lowered floor inside. The options subjects could choose for payment included Insurance; Vocational Rehabilitation; Veterans Administration; Personal monies; Other. If an individual responded other, they were asked to describe the other funding source. Individuals were also asked if they were dependent upon another person when using their vehicle and if cost is an issue when purchasing a vehicle, if it increases their independence.

## **Current Transportation**

We were interested in determining the means of transportation for individuals who use power wheelchairs and scooters. Individuals were asked on average, about how many days per week they left their home for any reason. The subjects were then asked how frequently they drove a motor vehicle, rode as a passenger in a private car or van, and rode as a passenger using local public transit. Responses ranged from Everyday or almost everyday; Once a week;

Occasionally (e.g. less than once a week); Seldom (e.g. less than once a month); Never. Data was collapsed into drive or ride (Everyday or almost everyday, once a week, or occasionally) or do not drive or do not ride (seldom, or never). Subjects were asked whether they transferred to the vehicle seat or remained in their wheelchair or scooter during travels. Transfer ability was also assessed by asking an individual if he or she requires assistance when transferring from their wheelchair or scooter to an automobile seat and from an automobile seat to their wheelchair or scooter. If an individual uses assistance they were asked if the transfer was completed with an assistive device, some human help, total human help, or not applicable. We also wanted to determine the primary means of transportation for individuals who use power wheelchairs and scooters; respondents were asked whether Private Car; Private Van; Public Bus or subway/train; Regular taxi; Specialized bus, van, or taxi service for people with disabilities (ex. Access); School Bus; or other were utilized. Barriers to transportation were assessed by asking if individuals have any difficulties in getting motor vehicle transportation that is needed and if so to describe the difficulties they have experienced.

### **Health Related Quality of Life**

Health Related Quality of Life (HRQoL) was assessed by the comorbidities an individual experiences by asking participants whether they had any additional problems. Nine specific comorbidities were used to assess HRQoL: pain, limited range of motion, weakness, balance problems, decreased endurance, paralysis, diminished sensation, mental health issues (e.g., depression or anxiety), and fatigue. Participants responded yes or no to having each comorbid condition. All positive responses (yes) were summed to obtain a total number of comorbid

conditions from zero to nine. This number was then dichotomized into few (0-4) and many (4-9).

HRQoL was also assessed by asking if participants additional health questions to determine the individual's present health.

Questions taken from the questionnaire to determine HRQoL:

1. In general, would you say your health is:  
<sub>1</sub>                      <sub>2</sub>                      <sub>3</sub>                      <sub>4</sub>                      <sub>5</sub>  
Poor                      Fair                      Good                      Very good                      Excellent
2. Compared to other people your own age, would you say your health is:  
<sub>1</sub>                      <sub>2</sub>                      <sub>3</sub>                      <sub>4</sub>                      <sub>5</sub>  
Poor                      Fair                      Good                      Very good                      Excellent
3. How satisfied are you with your present health?  
<sub>1</sub>                      <sub>2</sub>                      <sub>3</sub>                      <sub>4</sub>                      <sub>5</sub>  
Not at all                      Not very                      Neither satisfied                      Somewhat                      Extremely  
satisfied                      satisfied                      nor dissatisfied                      satisfied                      satisfied
4. How often do health problems stand in the way of your doing the things you want to do?  
<sub>1</sub>                      <sub>2</sub>                      <sub>3</sub>                      <sub>4</sub>                      <sub>5</sub>  
Never                      Seldom                      Sometimes                      Often                      Always

Questions 1-3 were reversed so that a lower score was reflective upon better HRQoL. After scores were reordered, responses from the additional health questions were collapsed into negative (response 4 or 5), neutral (response 3), and positive (response 1 or 2).

The total number of comorbid conditions was added to expanded responses from the four additional questions to create one HRQoL variable with a score ranging from 4 to 29, with lower scores indicating a better HRQoL. Total number of comorbid conditions and collapsed scores from additional problems were also analyzed separately, in addition to the overall HRQoL.

## **Community Integration**

Community integration was assessed using The Community Integration Questionnaire (CIQ). The CIQ consisted of 15 items and was designed to allow individuals with a traumatic brain injury self assess their level of community integration in three specific areas: home integration, social integration and productive activity (Willer, 1994). The CIQ was developed for individuals with traumatic brain injury and is validated for this population. Test-retest reliability has been established (coefficient=0.91) (Willer, 1990).

The CIQ can be used with other disability populations by changing traumatic brain injury specific wording to general disability terms. For example, question 10 responses were changed from “mostly with friends who have head injuries” to “mostly with friends who have disabilities.”

Several scoring methods are available for the CIQ (Dijkers, 2000; Brain Injury Resource Foundation, 1991). Each version computes a home integration score, a social integration score, and a productivity score. The productivity score is broken down into a job/school variable that can be computed differently. The following scoring syllabus was used to compute the job/school variable.

Sample Job/School Calculation Table:

| JOB/SCHOOL   | Score |
|--|-------|
| Not working, not looking for work, not going to school, no volunteer activities  | 0     |
| Volunteers 1 to 4 times a month AND not working, not looking for work, not in school                                       | 1     |
| Actively looking for work AND/OR volunteers 5 or more times per month  | 2     |
| Attends school part-time OR working part-time (less than 20 hours per work)  | 3     |
| Attends school full-time OR works full-time  | 4     |
| Works full-time AND attends school part-time OR Attends school full-time AND works part-time (less than 20 hours per week) | 5     |

In the event that an individual was retired and was attending school part time, the school answer was used to determine the job/school variable. Higher scores on the Community Integration Questionnaire indicate a higher community integration.

**Table 1:** Outcome Score Indicator

| Measure                           | Indicator     |
|-----------------------------------|---------------|
| Health Related Quality of Life    | Lower Better  |
| Home Integration                  | Higher Better |
| Social Integration                | Higher Better |
| Productivity                      | Higher Better |
| Total Community Integration Score | Higher Better |

**Table 2: Data Reduction Key**

| Variable  | Original Measure   | Transformed Measure  |
|---|--|--|
| Disability  | Spinal Cord Injury – Tetraplegia<br>Multiple Sclerosis<br>Other<br>Cerebral Palsy<br>Spinal Cord Injury – Paraplegia<br>Muscular Dystrophy<br>Rheumatoid Arthritis<br>Post-polio<br>Spina Bifida<br>Spinal Muscular Atrophy<br>Amputee | Progressive OR<br>Nonprogressive<br><br>And<br><br>Congenital OR Acquired              |
| Marital Status  | Single OR Married OR<br>Living with someone as if married  | Single OR<br>Married or Living with  |
| Health Insurance  | Do Not Have Health Insurance OR<br>Medicare/Medicaid OR Employer/Spouses<br>Employer/Previous Employer OR Personal<br>Monies OR Other  | Public<br>Private<br>Both  |
| Health Questions  | Poor OR Fair OR Good OR Very Good OR<br>Excellent  | Negative OR Neutral OR<br>Positive   |
| Comorbidities   | Summed score from 1-9  | Few OR Many  |
| Household Income  | Less than \$10,000<br>\$10,000-15,000<br>\$15,000-20,000<br>\$20,000-25,000<br>\$25,000-35,000<br>\$35,000-50,000<br>\$50,000-75,000<br>Greater than \$75,000  | Less than \$35,000<br>Greater than \$35,000  |
| Employment  | Unemployed OR Employed Full-time Outside the<br>Home OR Employed Part-time Outside the Home<br>OR Employed Full-time Inside the Home OR<br>Employed Part-time Inside the Home OR Student   | Employed/Student OR<br>Unemployed  |
| Race  | Caucasian OR African American OR Hispanic<br>OR American Indian/Alaska Native OR Native<br>Hawaiian/Pacific Islander   | Caucasian OR<br>Noncaucasian   |
| Drive Private Vehicle/<br>Ride as Passenger<br>Private/ Ride as<br>Passenger Public | Everyday/Almost Everyday OR Once a week OR<br>Occasionally OR Seldom OR Never  | Drive/Ride OR Do Not<br>Drive/Do Not Ride  |
| Primary Means of<br>Transportation  | Private Van OR Access OR<br>Public Bus OR Private Car OR Other or Taxi   | Public<br>Private  |
| Degree  | High School Diploma/GED OR Associate<br>Degree/Vocation/Technical School OR Bachelors<br>Degree OR Graduate Degree   | High School Diploma/GED<br>OR ADeg/Voc/Tech<br>School OR Bachelors<br>Degree or Higher |



## 2.4 DATA MANAGEMENT

As completed packets were received, the information was reviewed to ensure that the consent was properly completed and there was no missing information in the questionnaire. All records were tracked in detail throughout the data collection process. These records were located in an electronic tracking sheet and included the date the packet was received, the date of entry into the computer database, and the date of reimbursement.

All information was kept confidential by collecting all identifiable information in the demographic questionnaire and in the reimbursement form. Data collected in the data questionnaire contained no identifiable data and was given an identification number that was linked to the identifiable information and was kept only in the electronic tracking. All forms with identifiable information were kept in a separate folder in a locked file cabinet labeled by subject initials while unidentified information was stored in a different file cabinet labeled by the subject identification number. Data were entered into a Microsoft Access database by identification number to eliminate identifiable information to maintain confidentiality of participants.

## 2.5 METHOD FOR STATISTICAL ANALYSIS

Data from each packet were manually entered into and organized a Microsoft Access database. Once the information for the packets was entered into the Access program, SPSS was used to analyze the data. SPSS is a software program specifically for statistical analysis; SPSS Version 14.0 was used for this study (SPSS Inc.). Frequencies were run to check distributions for all variables. Alpha levels were set at 0.05 a priori.

### **Specific Aim 1: Transportation, Employment, and Community Integration**

Determine the relationship between transportation and employment and community integration.

#### **Hypothesis 1.A**

**Power wheelchair users who do not experience difficulties with transportation will have higher rates of employment outside of the home or be enrolled in school than power wheelchair users who do not experience transportation difficulties.**

Chi Square statistics were used to determine differences for categorical variables (experience difficulties and primary means of transportation) by employment status and household income.

#### **Hypothesis 1.B**

**Power wheelchair users who do not experience difficulties with transportation will have higher community integration than power wheelchair users who do not experience transportation difficulties.**

Community integration scores and days per week individuals left their home were normally distributed among the 102 subjects. T-tests were used to determine the relationship between categorical variables (experience difficulties and primary means of transportation) and continuous variables (community integration and days a week leaving home). A Pearson Correlation was run to determine if there is a relationship between days a week leaving home and community integration scores.

### **Specific Aim 2: Health Related Quality of Life, Community Integration, and Employment**

Determine the relationship between health related quality of life and employment and community integration.

#### **Hypothesis 2.A**

**Power wheelchair users who have a higher health related quality of life will have higher community integration.**

Community integration scores were normally distributed. A Spearman Rho Correlation was used to determine the relationship between ordinal (HRQoL) and continuous variable (community integration).

#### **Hypothesis 2.B**

**Power wheelchair users who are employed will have higher community integration than power wheelchair users who are unemployed.**

To determine if individuals who are employed and individuals who are unemployed are comparable, chi square statistics were run for categorical variables (gender, race, marital status,

progressive disability, acquired disability) and t-tests were run for continuous variables (age, years since injury or diagnosis). Individuals who are employed are significantly younger than individuals who are unemployed and were therefore controlled for in subsequent analyses. No significant differences between employment statuses were found in any other demographic variable. An analysis of covariance (ANCOVA) was used to determine whether there were differences in community integration scores between those who are employed and those who are unemployed while controlling for age.

### **Specific Aim 3: Employment**

Compare and contrast demographic characteristics of individuals who are unemployed versus those who are employed.

#### **Hypothesis 3.A**

**Power wheelchair users who are employed will have better health related quality of life than power wheelchair users who are unemployed.**

Descriptive statistics (means and percentages) were run to gain frequencies in order to describe the population characteristics of individuals who were unemployed. To determine if these characteristics differed from individuals who were employed, a Univariate Analysis of Variance was run in each of the comorbid conditions and each health question, and overall health related quality of life, while controlling for the age difference between individuals who are employed and those who are unemployed.

## 3.0 RESULTS

### 3.1 DEMOGRAPHICS

One hundred and two individuals who use power wheelchairs or scooters for mobility throughout the United States consented to participate in this study. The mean age of all participants was  $51.2 \pm 13.5$  years and years since injury or diagnosis of  $29.0 \pm 17.5$  years. Fifty-three percent of the population was male ( $n=54$ ) and 89% were Caucasian ( $n=91$ ). The disabilities represented in this population included tetraplegia (26%,  $n=26$ ), multiple sclerosis (18%,  $n=18$ ), other (13%,  $n=13$ ), cerebral palsy (13%,  $n=13$ ), paraplegia (8%,  $n=8$ ), muscular dystrophy (7%,  $n=7$ ), rheumatoid arthritis (6%,  $n=6$ ), post-polio (5%,  $n=5$ ), spina bifida (2%,  $n=2$ ), spinal muscular atrophy (2%,  $n=2$ ), and amputation (2%,  $n=2$ ) with the majority of the population (70.6%,  $n=72$ ) having an acquired disability. Ninety-three subjects stated they use a power wheelchair, 13 use a scooter, and 16 use a manual chair in addition to powered mobility. Eighty-five percent ( $n=87$ ) of the participants use a power chair most frequently, 10% ( $n=10$ ) use a scooter, and 5% ( $n=5$ ) use a manual wheelchair more frequently than their power wheelchair. On average, the participants have been using a wheelchair for  $20.3 \pm 13.7$  years. Table 3 displays the demographic data for all subjects.

**Table 3: Demographic Information**

| Demographic Measure              | % (n) or mean (standard deviation) |
|----------------------------------|------------------------------------|
| Age                              | 51.2 (13.5)                        |
| Years since injury or diagnosis  | 29.0 (17.5)                        |
| <b>Gender</b>                    |                                    |
| Male                             | 52.9 (54)                          |
| Female                           | 47.1 (48)                          |
| <b>Race</b>                      |                                    |
| Caucasian                        | 89.2 (91)                          |
| Non-Caucasian                    | 10.8 (11)                          |
| <b>Disability</b>                |                                    |
| Spinal Cord Injury – Tetraplegia | 25.5 (26)                          |
| Multiple Sclerosis               | 17.6 (18)                          |
| Other                            | 12.7 (13)                          |
| Cerebral Palsy                   | 12.7 (13)                          |
| Spinal Cord Injury – Paraplegia  | 7.8 (8)                            |
| Muscular Dystrophy               | 6.9 (7)                            |
| Rheumatoid Arthritis             | 5.9 (6)                            |
| Post-polio                       | 4.9 (5)                            |
| Spina Bifida                     | 2.0 (2)                            |
| Spinal Muscular Atrophy          | 2.0 (2)                            |
| Amputation                       | 2.0 (2)                            |
| <b>Disability Prognosis</b>      |                                    |
| Progressive                      | 44.1 (45)                          |
| Nonprogressive                   | 52.9 (57)                          |
| <b>Disability</b>                |                                    |
| Acquired                         | 70.6 (72)                          |
| Congenital                       | 29.4 (30)                          |

Forty-seven percent of the sample population is married or living with someone as if married (n=48). Thirty-seven percent (n=37) have a high school diploma or GED, 21% (n=21) have an associate degree or vocational or technical school, and 42% (n=42) have a bachelors degree or higher. Thirty-three percent are employed (n=34) and 81% (n=83) receive disability income. Fifty-five percent of the population has an income level less than \$35,000 (n=56) and 90% believe their disability affected their income (n=92). Of the 90 subjects who believed their

income was affected by their disability, 91% (n=84) believe their disability decreased their income and 9% (n=8) believed their disability increased their income. Ninety-nine percent of the population has health insurance: Public (62%, n=63), Private (18%, n=18), or both (19%, n=19).

Table 4 shows the socioeconomic data of the study population.

**Table 4: Socioeconomic Data**

| Socioeconomic Status Measure               | % (n) or mean (standard deviation) |
|--|------------------------------------|
| <b>Marital Status</b>                      |                                    |
| Single                                     | 52.9 (54)                          |
| Married or Living with Someone             | 47.1 (48)                          |
| <b>Education<sup>1</sup></b>               |                                    |
| High School Diploma/GED                    | 37.0 (37)                          |
| Associate Degree/Vocation/Technical School | 21.0 (21)                          |
| Bachelors Degree or Higher                 | 42.0 (42)                          |
| <b>Employment</b>                          |                                    |
| Unemployed                                 | 66.7 (68)                          |
| Employed                                   | 33.3 (34)                          |
| <b>Disability Income</b>                   |                                    |
| Receive                                    | 81.4 (83)                          |
| Do Not Receive                             | 18.6 (19)                          |
| <b>Household Income</b>                    |                                    |
| Less than \$35,000                         | 54.9 (56)                          |
| Greater than \$35,000                      | 45.1 (46)                          |
| <b>Disability Affected Income</b>          |                                    |
| Yes  | 90.2 (92)                          |
| No   | 9.8 (10)                           |
| <b>Health Insurance<sup>2</sup></b>        |                                    |
| No Health Insurance                        | 1.0 (1)                            |
| Public                                     | 62.4 (63)                          |
| Private                                    | 17.8 (18)                          |
| Both                                       | 18.8 (19)                          |

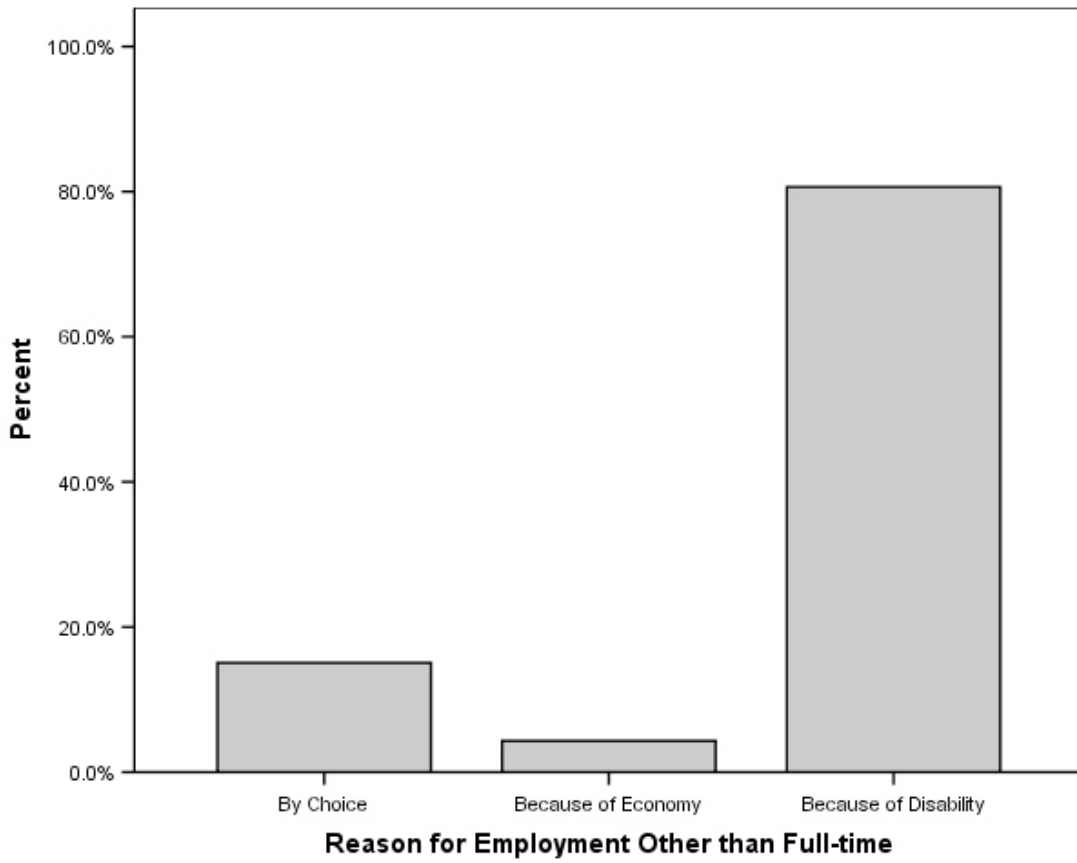
1. Missing 2

2. Missing 1

Thirty-four individuals (33%) were employed, with seven of these individuals (7%) being employed full time. Of those individuals who were not employed full time (n=95), 15% were not employed full time by choice (n=14), 4% because of the economy (n=4), and 81% because of their disability (n=77). Reasons for employment other than full time is also represented in Figure 1.

Table 5 displays the type of disability income the study population receives. Each individual may receive more than one time of disability income; 83 individuals receive disability income. Thirty-three responded they receive supplemental security income, 49 receive social security disability insurance, two are on workman's compensation, and 13 receive some other form of income. Five individuals receive both supplemental security income and social security disability insurance.





1. 95 individuals not employed full-time. Missing 2 responses

**Figure 1:** Reason for Employed Other Than Full-time

**Table 5:** Disability Income Received

| Disability Type <sup>1</sup>         | % (n)     |
|--------------------------------------|-----------|
| Supplemental Security Income         | 39.8 (33) |
| Social Security Disability Insurance | 59.0 (49) |
| Workman's Comp                       | 2.4 (2)   |
| Other                                | 15.7 (13) |

1. Out of 83 individuals who receive disability income: Missing 2
  - a. Percent is greater than 100 as each individual may receive more than one form of disability income. Five (5) people on SSI and SSDI

### **3.2 SPECIFIC AIM 1: TRANSPORTATION, EMPLOYMENT, AND COMMUNITY INTEGRATION**

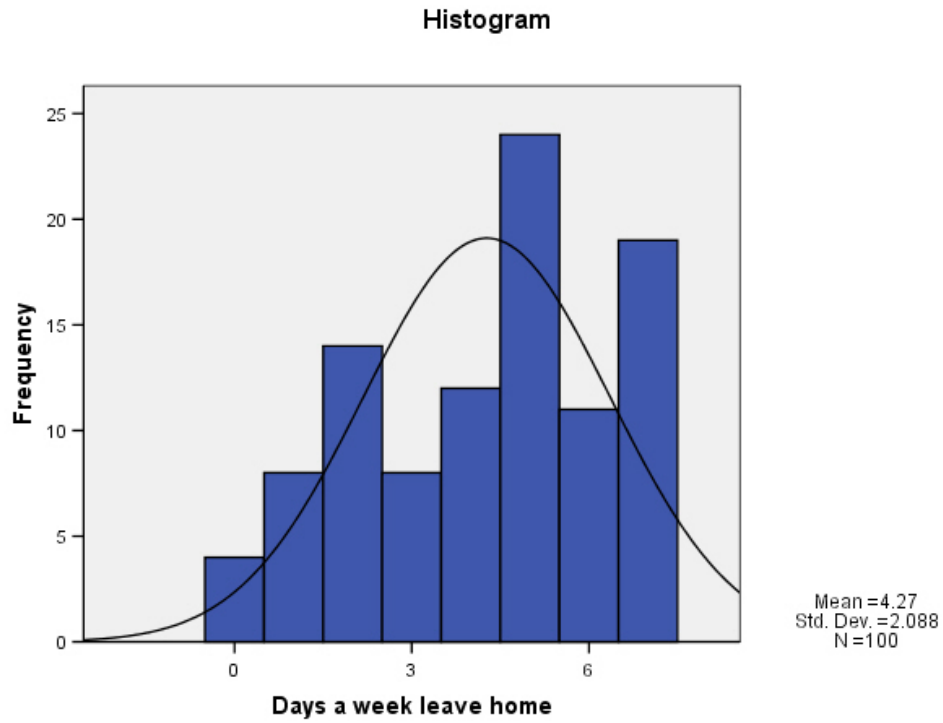
The average number of days the subjects left home was 4±2 and is also displayed in Figure 2. Transportation usage for this population was assessed and found that forty-six percent drove a private vehicle (n=47), 72% rode as a passenger in a private vehicle (n=74), and 31% used public transportation (n=32). Seventy-four percent used a private vehicle while 26% used some form of public transportation as their primary means of transportation.

The number of transportation methods participants used was also assessed. Three percent (n=3) of the population does not use any form transportation while 52% (n=53) used one mean of transportation, 37% (38) used two means, and 8% (n=8) used all three means of transportation. Twenty-six percent (n=26) use some sort of public transportation as their primary means while 74% (n=73) use private transportation as their primary means. Tables 6 display

breakdowns of transportation usage. Fifty-five percent (n=56) of the subjects required some assistance with transfers. For transfers from the users wheelchair to the vehicle seat, 9% (n=5) were independent, 27% (n=15) used an assistive device, 23% (n=13), used some human help, 27% (n=15) required total human help, and 14% (n=8) responded not applicable. For transfers from the vehicle seat to the users wheelchair 11% (n=6) were independent, 18% (n=10) used an assistive device, 21% (n=12) used some human help, 23% (n=13) required total human help, 23% (n=13) responded not applicable, and 3% (n=2) did not respond.

Individuals were asked if they were currently using a converted modified van and those who own this type of van were asked how they paid for the van. Forty-nine percent (n=50) stated they own a converted modified van and the method of payment for this vehicle included 66% (n=33) personal monies, 20% (n=10) Veterans Health Administration, 16% (n=8) vocational rehabilitation services, 16% (n=8) other, and 6% (n=3) insurance. Each individual may use more than one means of purchasing a vehicle. Table 7 displays the frequencies of vehicle payment method.

Thirty-eight percent (n=39) of the subjects stated they have some difficulty in getting the transportation they need. Of the subjects who stated they had difficulties, 55 responses were identified. The most common difficulties were limited transportation options or limited public transportation availability and the cost of transportation. Other themes of difficulties included scheduling transportation, accessibility, modifications, and accommodations for independent transportation, finding drivers for private vehicles, the time it takes to travel, reliability, drivers' attitudes toward individuals with disabilities, and having to travel in bad weather. Table 8 displays the frequency of subject responses regarding difficulties to independent transportation.



**Figure 2:** Breakdown of Number of Days Leaving Home

**Table 6:** Transportation Usage

|            | Driving Private Automobile<br>% (n) | Passenger Private Automobile<br>% (n) | Passenger Public Transportation<br>% (n) |
|------------|-------------------------------------|---------------------------------------|--|
| Use        | 46.1 (47)                           | 72.5 (74)                             | 31.4 (32)                                |
| Do not Use | 53.9 (55)                           | 27.5 (28)                             | 68.6 (70)                                |

**Table 7:** Method of Payment for vehicle

| Means of payment for modified van  | % Yes (n) <sup>1</sup> |
|------------------------------------|------------------------|
| Personal Monies                    | 66.0 (33)              |
| Veterans Health Administration     | 20.0 (10)              |
| Vocational Rehabilitation Services | 16.0 (8)               |
| Other                              | 16.0 (8)               |
| Insurance                          | 6.0 (3)                |

1. n=50

**Table 8:** Transportation Difficulties

| Transportation Difficulty   | Number of Responses <sup>*</sup> |
|---|----------------------------------|
| Limited Transportation Options and Public Transportation Availability | 12                               |
| Cost  | 11                               |
| Scheduling Transportation   | 9                                |
| Accessibility of Automobile/Modifications/Accommodations              | 8                                |
| Time Required to Travel   | 5                                |
| Finding Drivers for Private Automobile                                | 5                                |
| Reliability of Public Transportation                                  | 3                                |
| Negative Drivers Attitude   | 1                                |
| Traveling in Bad Weather  | 1                                |

\* Based upon individuals who reported transportation difficulties (n=39)

### **Hypothesis 1.A**

**Power wheelchair users who do not experience difficulties with transportation will have higher rates of employment outside of the home or be enrolled in school than power wheelchair users who do not experience transportation difficulties.**

A chi-square test was run to determine if there were differences in employment rates between those who have transportation difficulties and those who do not and between those who

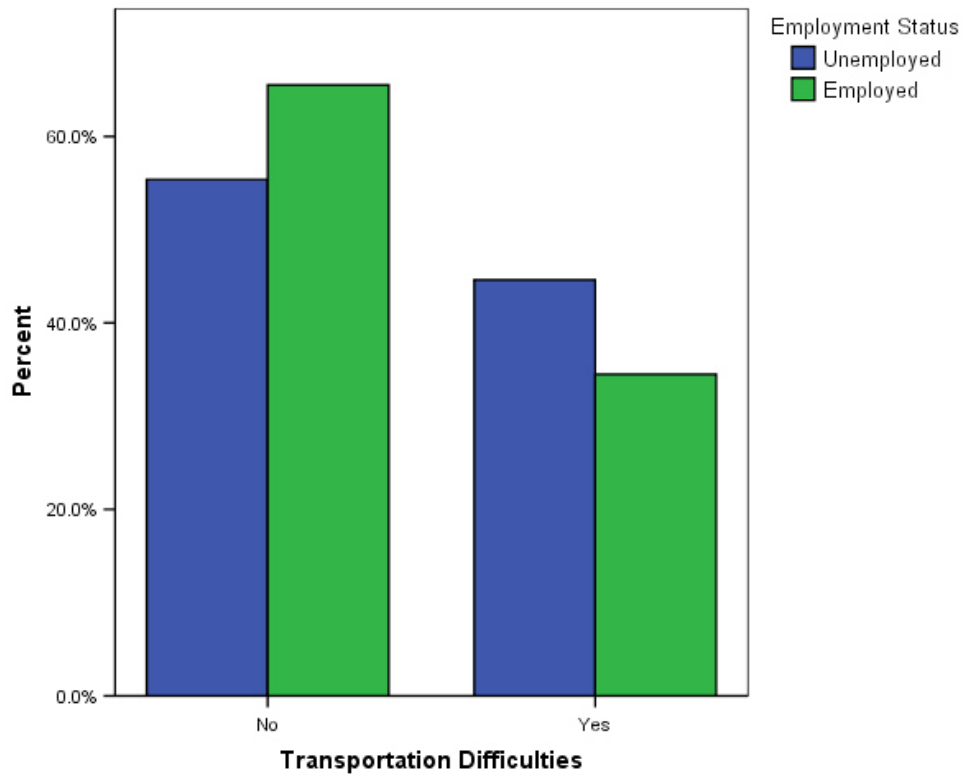
use public or private transportation as their primary means. There were no significant differences in employment between those who do not have any difficulties ( $p=0.357$ ). There were no significant differences between those who use public transportation and those who use private transportation ( $p=0.214$ ). Table 9 and Figure 3 represent the number of subjects who experience transportation difficulties as they relate to employment status and Figure 4 represents the breakdown of public and private transportation usage by employment status. Although not significant, individuals who use public transportation as their primary means have a higher percentage of people whose income is less than \$35,000 ( $p=0.072$ ) and is represented in Figure 5.

**Table 9:** Employment Status versus Transportation Difficulties

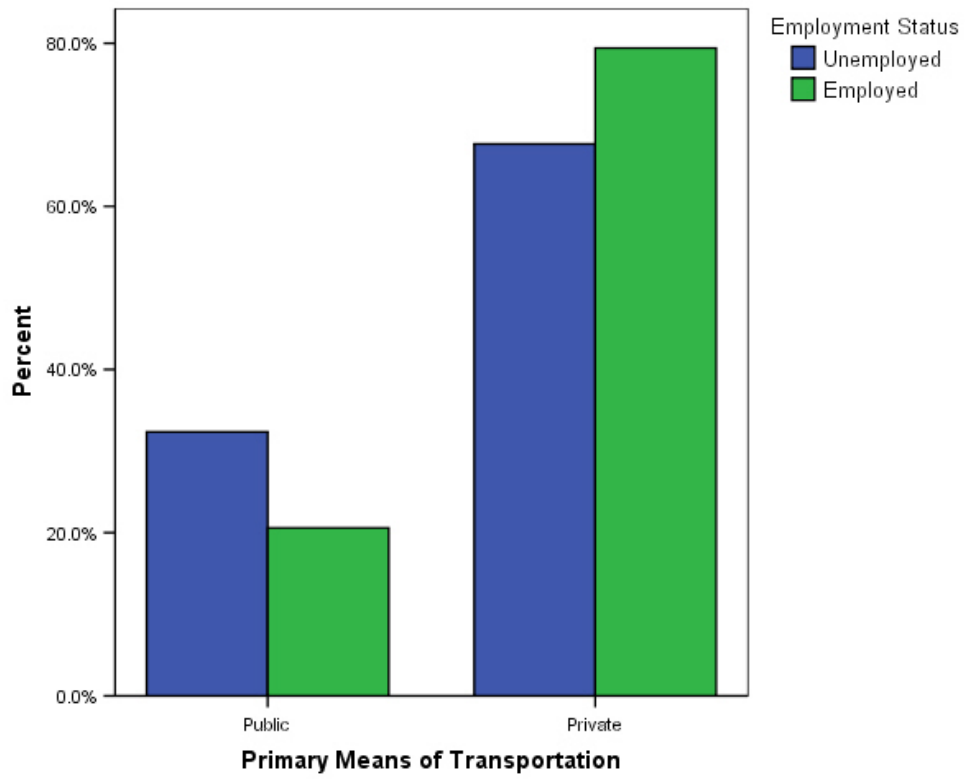
| Employment Status | Experience Transportation Difficulties | Don't Experience Transportation Difficulties |
|-------------------|--|--|
| Unemployed        | 44.6 (29)                              | 55.4 (36)                                    |
| Employed          | 34.5 (10)                              | 65.5 (19)                                    |

1. N = 94 (MISSING 8 RESPONSES)

a.  $p = 0.357$

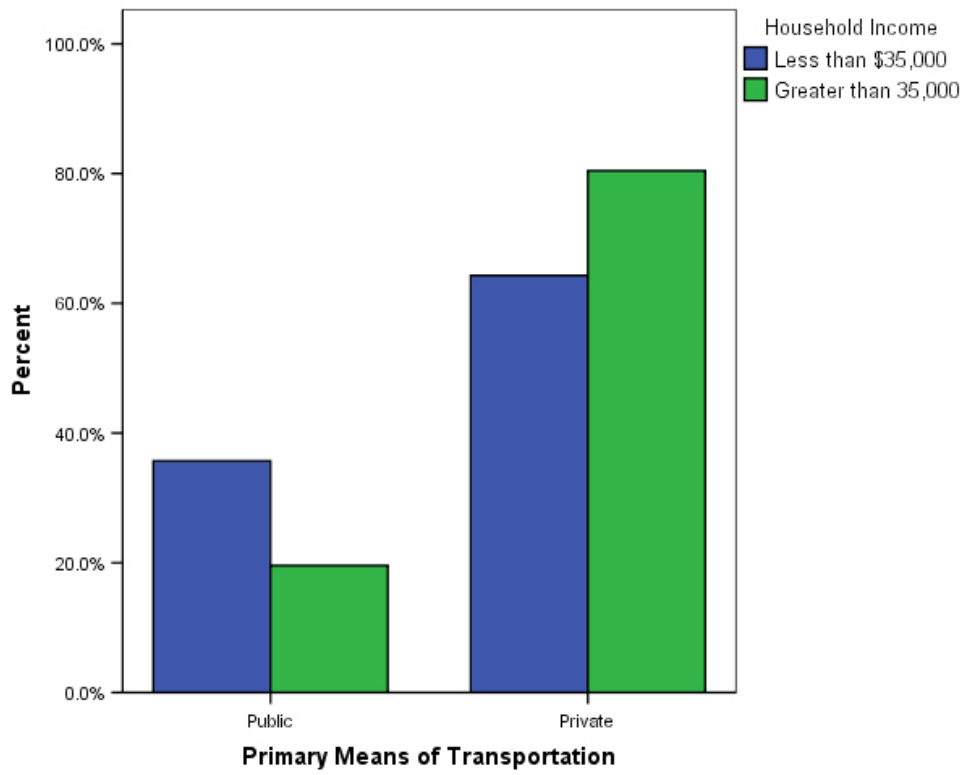


**Figure 3:** Transportation Difficulties by Employment Status



**Figure 4:** Primary Means of Transportation by Employment Status





**Figure 5:** Primary Means of Transportation by Household Income

## **Hypothesis 1.B**

**Power wheelchair users who do not experience difficulties with transportation will have higher community integration than power wheelchair users who do not experience transportation difficulties.**

A t-test was run to determine if differences in community integration exist between individuals who had difficulties with transportation and those who do not and between those who use public transportation and those who use private transportation as their primary means. No significant differences were found between those who do not have transportation difficulties and those who have transportation difficulties in community integration. Additionally, no significant differences were found between primary means of transportation in community integration scores. Tables 10 and 11 display the community integration scores and associated p-values by transportation difficulties and primary means. Individuals who experience transportation difficulties leave their home on average 3.9 days a week while those who do not experience difficulties leave on average of 4.5 days per week ( $p=0.177$ ). Similarly, individuals who primarily use private transportation and those who use public transportation both leave their home approximately 4 days per week ( $p=0.541$ ).

A Pearson correlation was calculated to determine if there was a relationship between days a week leaving the home and community integration scores. There was no significant relationship between days a week leaving the home and home integration ( $p=0.345$ ). Significant positive correlations were found between days a week leaving the home and social integration ( $p<0.001$ ,  $r=0.122$ ), Productive Activity ( $p<0.001$ ,  $r=0.635$ ), and total community integration scores ( $p<0.001$ ,  $r=0.488$ ).

**Table 10:** Community Integration Scores by Transportation Difficulties

| Community Integration Questionnaire<br>n (Std. deviation) | Overall Population<br>n=93 | Experience Transportation Difficulties<br>n=55 | Do Not Experience Transportation Difficulties<br>n=38 | p-value |
|---|----------------------------|--|---|---------|
| Home  | 4.1 (2.4)                  | 4.5 (2.4)                                      | 3.8 (2.5)   | 0.270   |
| Social  | 7.4 (2.1)                  | 7.4 (2.5)                                      | 7.4 (1.9)   | 0.987   |
| Productivity <sup>†</sup>                                 | 3.5 (1.8)                  | 3.1 (1.8)                                      | 3.6 (1.8)   | 0.283   |
| Total   | 15.1 (4.5)                 | 15.1 (5.0)                                     | 14.9 (4.4)  | 0.862   |

\* missing 9

† missing 1

**Table 11:** Community Integration Scores by Primary Means of Transportation

| Community Integration Questionnaire<br>n (Std. deviation) | Overall Population<br>n=101 | Public Transportation<br>n=29 | Private Transportation <sup>*</sup><br>n=73 | p-value |
|---|-----------------------------|-------------------------------|---|---------|
| Home  | 4.1 (2.4)                   | 4.3 (2.6)                     | 4.0 (2.3)                                   | 0.573   |
| Social  | 7.4 (2.1)                   | 7.1 (2.2)                     | 7.6 (2.0)                                   | 0.314   |
| Productivity  | 3.5 (1.8)                   | 3.3 (1.8)                     | 3.6 (1.8)                                   | 0.526   |
| Total   | 15.1 (4.5)                  | 14.8 (5.2)                    | 15.2 (4.2)                                  | 0.674   |

\* missing 1

### 3.3 SPECIFIC AIM 2: HEALTH RELATED QUALITY OF LIFE, COMMUNITY INTEGRATION, AND EMPLOYMENT

The average number of comorbidities for the subjects was  $4.6 \pm 2.2$ ; 42% had a few conditions while 58% had many. Twenty-five percent rated their health as positive, 27% as neutral and 38% negative and compared to other people their own age, 23% said their health was positive, 21% neutral, and 46% negative. Fifty-four percent said their satisfaction with their health was positive, 16% neutral and 30% negative. Additionally, 21% said their health rarely stands in the way of doing the things they want to do, while 32% were neutral and 47% stated their health frequently prevents them from participating in the things they want to. Responses to health questions are represented in Table 12.

**Table 12:** Health Questions

| Health Questions   | % Positive<br>(n) | % Neutral<br>(n) | % Negative<br>(n) |
|--|-------------------|------------------|-------------------|
| In general, would you say your health is:  | 24.5 (25)         | 37.3 (38)        | 38.2 (39)         |
| Compared to other people your own age, would you say your health is:                   | 22.5 (23)         | 31.4 (32)        | 46.1 (47)         |
| How satisfied are you with your present health?  | 53.9 (55)         | 15.7 (16)        | 30.4 (31)         |
| How often do health problems stand in the way of your doing the things you want to do? | 20.6 (21)         | 32.4 (33)        | 47.1 (48)         |

## **Hypothesis 2.A**

**Power wheelchair users who have a high health related quality of life will have higher community integration.**

A Spearman Rho Correlation was run to determine if there was a relationship between health related quality of life (HRQoL) and community integration (home, social, productivity, and total community integration). There is no significant correlation between HRQoL and home integration. Significant negative correlations were found between HRQoL and social integration ( $p=0.035$ ,  $r= -0.210$ ), HRQoL and productivity ( $p<0.001$ ,  $r= -0.412$ ), and HRQoL and total Community Integration Scores ( $p=0.012$ ,  $r= -0.245$ )

## **Hypothesis 2.B**

**Power wheelchair users who are employed will have higher community integration than power wheelchair users who are unemployed.**

We were interested in determining the characteristics of individuals who were unemployed. Individuals who are employed are significantly younger than individuals who are unemployed ( $p=0.005$ ). There were no significant differences in years since injury or diagnosis, gender, race, marital status, or disability status. Additionally, there were no significant differences in highest degree earned or household income by employment status. Demographic data are displayed for each group, employed and unemployed, in Table 13.

An analysis of covariance (ANCOVA) was run to determine if community integration scores differed between individuals who were employed and individuals who were unemployed while controlling for age. There are no significant differences in home integration and social integration between those who are employed and those who are unemployed. Individuals who

are employed have a significantly higher Productivity score and total community integration than individuals who are unemployed ( $p < 0.001$  and  $p = 0.021$  respectively). Table 14 displays means and standard deviations for each of the community integration scores.

**Table 13:** Demographic Variables by Employment Status

| Demographic Variable  | Overall Population<br>(n = 102) | Unemployed<br>(n = 68) | Employed<br>(n = 34) |
|-----------------------|---------------------------------|------------------------|----------------------|
| Mean Age*             | 51.2 (13.5)                     | 53.8 (12.8)            | 45.9 (13.6)          |
| Mean Disability years | 29.0 (17.5)                     | 28.75 (19.2)           | 29.6 (14.0)          |
| Percent Female        | 47.1 (48)                       | 47.1 (32)              | 47.1 (16)            |
| Percent Caucasian     | 89.2 (91)                       | 88.2 (60)              | 91.2 (31)            |
| Percent Progressive   | 44.1 (45)                       | 48.5 (33)              | 35.3 (12)            |
| Percent Acquired      | 70.6 (72)                       | 73.5 (50)              | 64.7 (22)            |
| Percent Single        | 52.9 (54)                       | 50.0 (34)              | 58.8 (20)            |

\*  $p = 0.005$

**Table 14:** Employment Status and Community Integration Scores

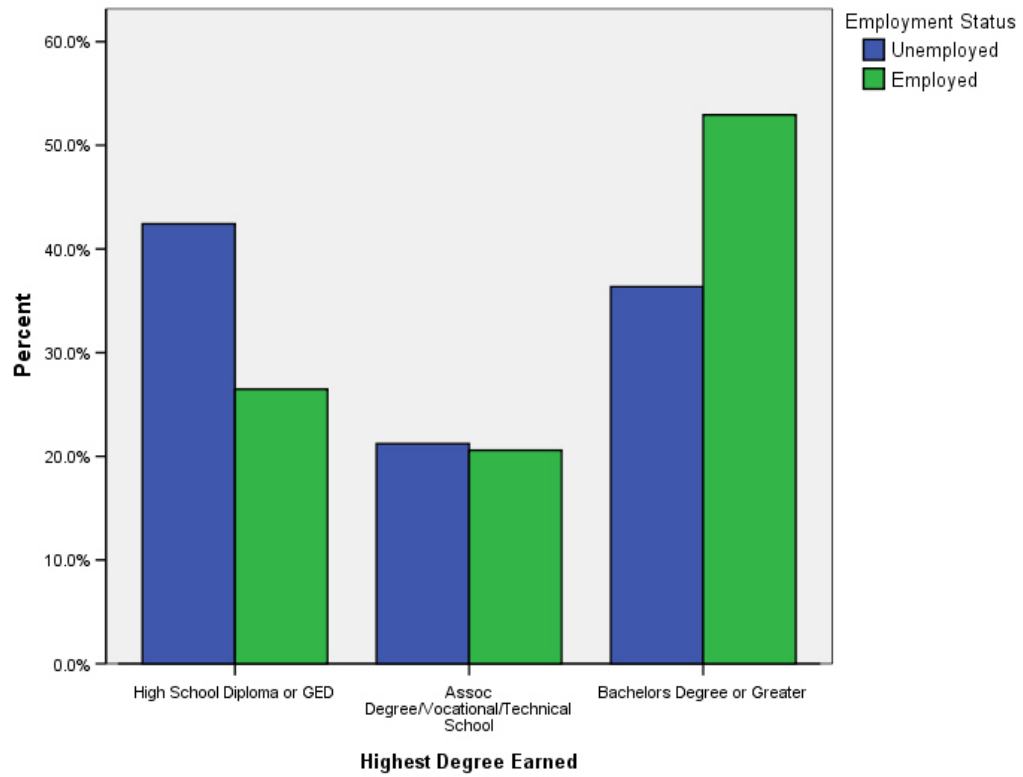
|                           | Overall Population | Employed   | Unemployed |
|---------------------------|--------------------|------------|------------|
| Home                      | 4.1 (2.4)          | 3.9 (2.1)  | 4.2 (2.6)  |
| Social                    | 7.4 (2.1)          | 7.6 (2.1)  | 7.3 (2.1)  |
| Productivity <sup>1</sup> | 3.5 (1.8)          | 5.2 (2.7)  | 2.7 (1.4)  |
| Total CI <sup>2</sup>     | 15.0 (4.5)         | 16.8 (4.0) | 14.2 (4.5) |

1.  $p$ -value (controlling for age)  $< 0.001$ ,  $r^2 = 0.456$

2.  $p$ -value (controlling for age) = 0.021,  $r^2 = 0.123$

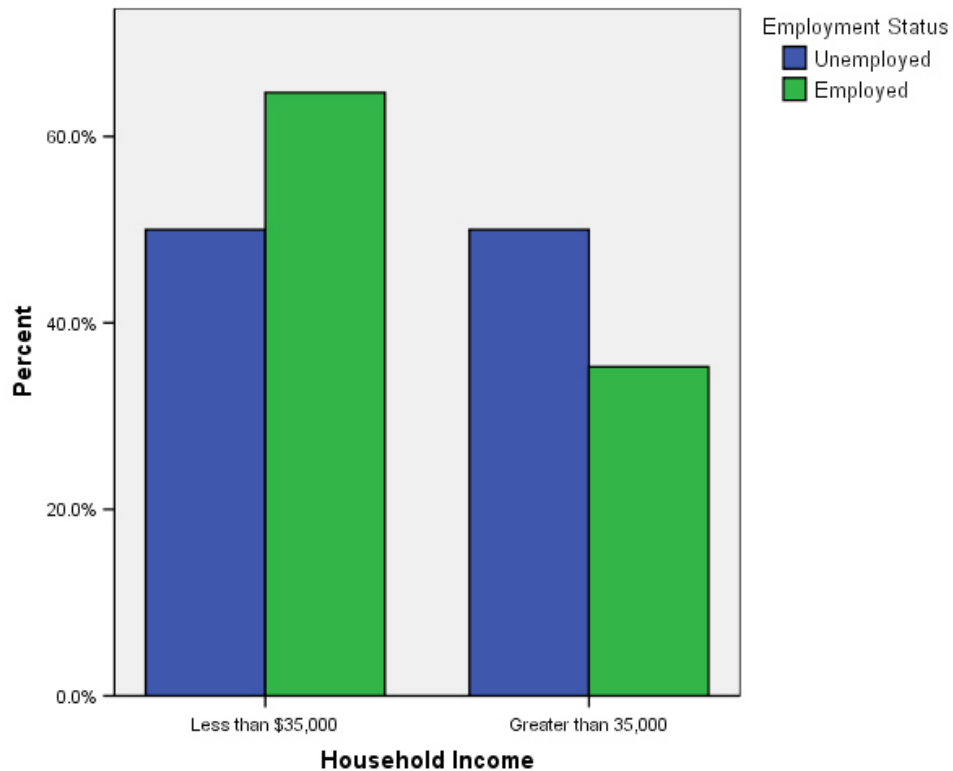
### **3.4 SPECIFIC AIM 3: EMPLOYMENT**

We were interested in determining the characteristics of individuals who were unemployed. As previously stated, individuals who are employed are significantly younger than individuals who are unemployed ( $p=0.005$ ). Chi-square tests were run to determine if there were differences in highest degree earned and household income between employment statuses. There is no significant difference in household income ( $p=0.159$ ) between individuals who are employed and those who are unemployed. Although not significant ( $p=0.221$ ), individuals with a bachelors degree or higher have a higher percentage of employment. Highest degree earned and household income compared to employment status are also displayed in Figures 6 and 7.



**Figure 6:** Employment Status by Highest Degree Earned





**Figure 7:** Household Income by Employment Status

### **Hypothesis 3.A**

**Power wheelchair users who are employed will have better health related quality of life than power wheelchair users who are unemployed.**

An Univariate Analysis of Variance was run to determine if there were differences in health related quality of life between those who are employed and those who are unemployed while controlling for age. Individuals who are employed have a significantly better HRQoL than individuals who are unemployed ( $p=0.002$ ,  $r^2=0.110$ ) and is displayed in Table 15.

Univariate Analysis of Variance tests were also run to determine if there were differences in responses to health questions and if individuals have specific comorbid conditions while controlling for age. There was no significant difference in the comparison of health to other people their age between those who are employed and those who are unemployed. Individuals who were employed rated their general health higher than individuals who were unemployed ( $p=0.047$ ,  $r^2=0.042$ ). Individuals who are employed are more satisfied with their health ( $p=0.001$ ,  $r^2=0.109$ ) and are less prevented by their health from doing activities they desire than those who are unemployed ( $p=0.001$ ,  $r^2=0.110$ ).

Individuals who are employed have overall fewer comorbid conditions than those who are unemployed ( $p=0.019$ ,  $r^2=0.059$ ). Additionally, individuals who are employed have significantly less pain than those who are unemployed ( $p=0.010$ ,  $r^2=0.073$ ). Individuals who are employed have significantly less weakness ( $p=0.005$ ,  $r^2=0.086$ ) and than those who are unemployed. Individuals who are employed have significantly less feelings of diminished sensation than those who are unemployed ( $p=0.028$ ,  $r^2=0.052$ ). Individuals who were employed had higher rates of paralysis ( $p=0.003$ ,  $r^2=0.096$ ) than those who were unemployed. No significant differences in levels of mental health issues, limited range of motion, balance problems. Although not significant, individuals who are employed have fewer feelings of decreased endurance and fatigue than those who are unemployed ( $p=0.083$  and  $p=0.111$  respectively). The number of individuals who responded to having comorbidities before and after controlling for age are represented in Table 16.

**Table 15:** Health Related Quality of Life by Employment Status

|                                | Overall Population | Employed   | Unemployed |
|--------------------------------|--------------------|------------|------------|
| <b>HRQoL Score<sup>1</sup></b> | 17.4 (4.9)         | 18.6 (5.0) | 15.0 (4.0) |

1. p-value (controlling for age) = 0.002,  $r^2=0.110$

**Table 16:** Comorbid Conditions and Employment Status Before and After Age Control

| % yes (n)                         | Overall Population<br>n=102 | Unemployed<br>n=68 | Employed<br>n=34 | p-value <sup>1</sup> | p-value |
|-----------------------------------|-----------------------------|--------------------|------------------|----------------------|---------|
| Pain <sup>*</sup>                 | 52.0 (53)                   | 61.8 (42)          | 32.4 (11)        | 0.005                | 0.010   |
| Limited Range of Motion           | 65.7 (67)                   | 67.6 (46)          | 61.8 (21)        | 0.560                | 0.487   |
| Weakness <sup>*</sup>             | 68.6 (70)                   | 77.9 (53)          | 50.0 (17)        | 0.004                | 0.005   |
| Balance Problems                  | 65.7 (67)                   | 67.6 (46)          | 61.8 (21)        | 0.560                | 0.875   |
| Decreased Endurance               | 59.8 (61)                   | 67.6 (46)          | 44.1 (15)        | 0.022                | 0.083   |
| Paralysis <sup>*</sup>            | 43.1 (44)                   | 39.7 (27)          | 50.0 (17)        | 0.327                | 0.003   |
| Diminished Sensation <sup>*</sup> | 49.0 (50)                   | 54.4 (37)          | 38.2 (13)        | 0.126                | 0.028   |
| Fatigue                           | 47.1 (48)                   | 52.9 (36)          | 35.3 (12)        | 0.094                | 0.111   |
| Mental Health Issues              | 13.7 (14)                   | 14.7 (10)          | 11.8 (4)         | 0.688                | 0.921   |

1. Uncontrolled

2. Controlling for age

## 4.0 DISCUSSION

The results of this study show a variety of outcomes in the relationship between transportation, employment, community integration, and health related quality of life. We were able to capture data from individuals with a variety of disabilities and from a large range of geographic locations across the continental United States. The majority of study participants have an acquired disability.

The population represented in this study was fairly active, leaving their home  $4\pm 2$  days per week, and a large number are currently using transportation services. We found that 97% of the study population used some form of transportation, compared to 82% and 70% by power wheelchair users previously reported (Belcher & Frank; Donaldson; Sanderson). Additionally, we found that 46% drove a private vehicle compared to 28% in a previous study (Fitzgerald, Songer, & Rotko, 2004; Fitzgerald, Songer, & Schneider, 2006; Rotko, Songer, & Fitzgerald, 2005; Songer, Fitzgerald, & Rotko, 2004).

We found that transportation does not have a significant relationship to an individual's employment status or level of community integration. This is not what researchers expected as previous studies have shown transportation barriers as limiting factors for employment. A possible explanation may be that subjects who were employed may not have needed vehicular transportation to get to their place of employment if the facility was close enough to access by traveling by wheelchair alone or if an individual is enrolled in an online educational program. Likewise, individuals may participate in leisure activities outside of the home at the neighbors

house so that travel by vehicle is eliminated. Individuals may not need transportation to go shopping as options such as online shopping and catalogue orders are alternatives that do not require an individual's travel to the store. Other barriers, besides transportation, are limiting individuals from being employed and transportation may not be that important to the subjects represented. Difficulties in transportation may not mean that the individual does not have transportation options, but rather traveling requires a lot of planning and support. Individuals who have a higher household income used private transportation more often than individuals who have a lower income. This may be possible as individuals who can afford public transportation may be more likely purchase a vehicle and increase their transportation options. Although not significantly different, individuals who experience transportation difficulties had a higher percentage of people whose household income was less than \$35,000.

Additional analyses of outcome measures by age and years since disability were completed. Age was broken down into ranges of 20-49.9 years and age 50.0 and older. Years since injury or diagnosis were stratified into 0-19.9 years, 20.0-49.9 years, and greater than or equal to 50.0 years. Upon further analysis of the outcome measures by age and by years since injury or diagnosis, individuals who were younger (ages between 20 and 49.9 years) had higher social integration and productive activity, as well as better health related quality of life. Additionally, individuals who have had their disability between 25 and 49.9 years had higher social integration and productive activity scores and better health related quality of life than individuals who have had their disability between 0 and 24.9 years. Individuals who have had their disability for 50 years or more also have better outcome scores than individuals who have had their disability between 0 and 24.9 years but not as much as individuals whose disability

years were between 25 and 49.9 years. These results may reflect a coping period after disability as well as a function of age.

According to Chaves, Boninger, Cooper, Fitzgerald, Gray and Cooper (2004), individuals with tetraplegia stated one limiting factor to independent transportation was the lack of equipment which may be a function of the overall difficulty in transporting a power wheelchair. These results could be related to the lack of funding for assistive technology and for transportation as evident by individuals with a higher household income using private transportation options more than individuals with a lower income.

Although community integration was not significantly different between individuals who experienced self-perceived transportation barriers and those who do not or those who use public transportation or private transportation as their primary means, Gray, Gould, and Bickenbach (2003) found that individuals with spinal cord injuries who have accessible transportation have an increased probability of participating in the community.

We also found no significant relationship between primary means of transportation and employment status or community integration. One possible explanation may be in the private means of transportation. Individuals who use a private vehicle as their primary means may solely be riding as a passenger in the vehicle and must find drivers to operate the vehicle. As a result, private means of transportation may not be more reliable than public transportation. Five individuals stated finding drivers as a major transportation difficulty. Anecdotally, one of these five individuals is currently working.

Our results support the findings of the United States General Accounting Office (2003) that 30% of individuals with disabilities face difficulties in transportation with 38% of our subjects reporting difficulties. Our population may have higher rates of problems as we were

focusing solely on individuals who use power wheelchairs while the national report looked at the entire disability population. There were several common themes in barriers to independent transportation. The most frequent responses were limited transportation options and limited public transportation availability and the cost of transportation. Additional problems were scheduling transportation and the accessibility of automobile, modifications, and accommodations needed for transportation. Although not significant, individuals who experienced transportation difficulties had higher scores on the home subscale of the community integration questionnaire. This may be explained by the idea that individuals who experience transportation difficulties leave their home less often than those who do not experience transportation difficulties. This is also supported by the significant correlations between days a week leaving home and social, productivity, and total community integration scores. As days a week leaving the home increases, so does social and productive integration and overall community integration. Although several items in the home subscale include items that may take place outside of the home such as grocery shopping, if an individual spends more time outside of there is a possibility that their home score could be lower than those who are home more frequently.

Overall, the study population rated their own health as fairly positive, however compared to people their own age, about one-half of the participants believe their health is worse than their peers. Likewise, about half of the participants also believe that their health prevents them from participating in the activities they wish to participate in. The correlations found suggest that individuals as individuals HRQoL increases, so will their community integration, socially and productively. Individuals who unemployed have significantly higher percentage of individuals who experience fatigue, however it was a function of age. Before controlling for age, no

significant differences in paralysis between power wheelchair users who are employed and power wheelchair users who are unemployed were found. After factoring in the age difference between the two groups, power wheelchair users who were employed had significantly higher rates of paralysis.

Individuals who are employed do not significantly differ in home and social integration from those who are unemployed. However, our results suggest that individuals who are employed have higher productivity scores and total community integration scores. These results are to be expected as these two variables take into consideration employment status. As a result, community integration scores may be confounded by the productivity variable. There is no evidence in these results to show that individuals who are employed are more active in the community than those who are unemployed.

The employment rate for the sample population was approximately 33% compared to 37% of all individuals with disabilities in the United States and 32% of individuals with physical disabilities (Rehabilitation Research and Training Center on Disability Demographics and Statistics). Additionally, the full-time employment rate for individuals with physical disabilities is 18% compared to our 7%. Likewise, the median household income for our population was between \$25,000 and \$35,000. The mean national average household income for individuals with physical disabilities is roughly \$34,000. Seventeen percent of individuals with physical disabilities receive SSI while we found that 40% of our participants receive SSI. The Rehabilitation Research and Training Center on Disability Demographics and Statistics also found that only 12% of individuals with physical disabilities hold a bachelors degree or higher while our study found that 42% of the participants have a bachelor's degree. The majority of participants are unemployed due to their disability. Ninety-one percent of the individuals who



believe they are unemployed because of their disability are also receiving some form of disability income (n=68). Additionally, 76% (n=57) of individuals who believe their disability impacts their ability to work full-time have an acquired disability.

Individuals who are employed have higher HRQoL, better self-perceived health, and less comorbidity. This is important because, while legislation prohibits an individual from losing their job based upon disability, as Riphahn found, individuals who have poorer health have a higher chance of losing their job. Surprisingly, decreased endurance and fatigue were not significantly different between individuals who are employed and those who are unemployed individuals. We are unable to tell if individuals who are employed have better health because of their employment status or if they were healthier before seeking employment, but these results support the idea that employment is fundamental to physical and psychological health (Chan, Cheing, Chan, Rosenthal, & Chronister; Chan, Reid, Roldan, Kaskel, Rahimi, & Mpofu, 1997; Perrone, Perrone, Chan, Thomas, 1997; Rubin & Roessler, 2000).

## 4.1 LIMITATIONS

While researchers have found interesting results, this study did have limitations. Some fundamental limitations were directly related to a questionnaire based study as the validity of studies that rely solely on the response of subjects is often influenced by forms of bias. Subjects were asked to respond to their current needs, however these needs may have recently changed and subjects may have not responded appropriately. Questionnaires can also very subjective as they rely on the subjects to pull from their feelings on the questions and without objective measures; it was difficult to compare subjects to one another in a uniform, standard fashion.

With respect to employment and transportation, distance from an individual's residence to their place of employment is unknown. Not all subjects may need vehicular transportation to get to work. We also had very few number of individuals (n=7) who are employed full time and there is a difference in being employed full-time versus part-time. There was also no control group available for comparison of data which could have made results stronger.

This study had two means of completing the questionnaire; subjects were given the option to complete the questionnaire over the phone or to manually complete a copy on paper and return it to researchers by mail. Although only one individual completed the questionnaire over the telephone, this variation may have affected the consistency throughout the study. If an individual wished to complete the questionnaire over the phone, a copy of the questionnaire was sent to the subject so they could follow along with the researcher. Individuals who completed questionnaires through the mail may have had questions or difficulty understanding certain sections of the survey and not all subjects were proactive enough, or wanted to pay for the long distance fees, to call and ask what he or she does not understand. As a result, subjects may have

skipped necessary questions. In general, people grow tired of answering long surveys so they may have skipped questions to finish the questionnaire. There were more missing data points with questions that appeared later in the questionnaire. Furthermore, the information was also manually entered into a computer database, which could allow for human error, despite regular information verification.

The Community Integration Questionnaire has been validated for individuals with traumatic brain injury, however psychometrics have not been conducted on other populations. Additionally, individuals were asked how often they go grocery shopping and who usually completes activities such as preparing meals in their household and does the normal everyday housework. While individuals may have responded that they do not complete these activities, it is possible that they chose not to rather than they cannot complete the activity. The questionnaire also did not specifically collect HRQoL and the variable was made using other data collected from the questionnaire. Additionally, no psychometric analyses have been conducted on the questionnaire sent to the participants, so there is no reliability or validity data available.

Several limitations exist due to the cross-sectional nature of the study. Researchers cannot determine a causal relationship between transportation and any of the variables of interest. For individuals who acquired their disability later in life, the researchers did not collect pre-injury work status and researchers do not know the previous work history of any of the subjects. According to Miller, Forwell, Noreau, Jongbloed, Procter, & Abramson, successful employment for individuals who acquire a spinal cord injury is positively associated with the ability to drive a car, more years since injury, younger age, being male, and having more years of education or being employed prior to injury (2006). Our results have suggested that being

younger and having more years of education are associated with employment, however we do not know when the individual received their education as compared to their injury and we do not know prior work history.

Overall, the study participants were recruited using the Human Engineering Research Laboratories Wheelchair Users Registry which is a national database of individuals who use mobility assistive devices. Individuals are recruited into the registry through conferences, educational seminars, national adaptive sporting events, and through previous participation in research at the Human Engineering Research Laboratories. Although our study had a high percentage of individuals who were unemployed, individuals who are employed and in the Registry may not have participated in this study due to time constraints. All participants could be viewed as active in the community and, as a result, the sample population may not be representative of all power wheelchair users in the United States.

## **4.2 FUTURE STUDIES**

Future studies that focus solely on the impact of transportation on employment may benefit the rehabilitation field. For individuals who have an acquired disability, these observations could take into account the pre-injury employment status and look at changes since injury or diagnosis. Additionally, studies that look at individuals enrolled in drivers training may be able to track changes pre and post the introduction of a new means of transportation. Questions specific to how transportation impacts an individual's ability to seek employment may also be utilized.

Additional studies may need to focus on a wider distribution of individuals who are employed full-time outside of the home. Having a high percentage of individuals who are unemployed may have affected the results. Future studies need to include individuals who use manual wheelchairs to get a better representation of individuals with mobility disabilities. Moreover, collecting additional work place barriers may shed light on the high unemployment rates for individuals with disabilities.

This study was mostly subjective. Future studies would be stronger if objective measures were added to subjective data collection. Although difficult to complete without inferring the researchers own opinion, having contact with each subject during data collection would cut down on variability of interpretation of questions. Additionally, better data collection tools for quality of life and community integration may also be employed and psychometrics of data collection tools should be conducted to ensure quality data is being collected.

As this was a questionnaire based study, subjects may have lost interest toward the end of a long questionnaire. Future studies may be stronger if the questionnaire was concise and took less of the subject's time and more engaging. Individuals may have felt burdened by having to complete the questionnaire by hand and return the forms by mail to the researchers. Future research studies could be conducted on-line, in conjunction with the paper based surveys, so that individuals could complete the forms on the computer and have the option to use assistive technology that may make completion of the questionnaire easier.

### **4.3 IMPLICATIONS FOR REHABILITATION COUNSELORS**

As employment is fundamental to successful rehabilitation, this research has implications for rehabilitation counselors. The overall employment rate of this population, and the population of people with disabilities in the United States, is low. In this study, we do not know if people are actively looking for work or seeking vocational rehabilitation services, which may have influenced the way individuals answered questions presented. This is important as there is a difference between individuals want to be competitively employed and those who are not currently seeking employment. Rehabilitation counselors must be aware of their clients desire to seek employment, as this may have an impact on vocational outcomes.

While this study did not find significant relationships between employment and community integration with transportation, this does not mean that transportation is not fundamental for individuals to be independent or become employed outside of the home. Only eight subjects reported using vocational rehabilitation services as a means of financing a private vehicle. While the question did not ask if they were using vocational rehabilitation to assist with the modification of the van, it is obvious that the majority of individuals purchased a private vehicle with personal monies and better funding sources for transportation need to be developed. Vocational rehabilitation counselors must be aware of their clients transportation options when they are examining the options for employment. If a client cannot get to the facility where the possible job is located, they will not be able to maintain that employment option.

Although legislation has been implemented to increase opportunities for persons with disabilities to seek gainful employment and to increase transportation opportunities, it is evident that not all laws are being complied with. The overall employment rates of persons with

disabilities are still strikingly low. Additionally, a large percentage of the study population is currently receiving a form of disability income, which may present as a disincentive to seeking employment.

Another key aspect of this study is that over half of the study population requires some assistance with their transfer activities. Ensuring that individuals who use wheelchairs maintain the health of their upper extremities must address transferring as a possible cause of pain and deterioration. Employment increases the number of transfers required throughout the day and about 75% of the subjects in this study need some form of assistance with vehicular transfers. Although our results did not show that transportation significantly affects employment, it is still an important consideration for gainful employment.

## 5.0 CONCLUSION

Employment and community participation are fundamental rights for all people regardless of disability status; and while legislation has been past to eliminate obstacles for participation, environmental barriers may limit opportunities for individuals who use power wheelchairs.

From this study, it was learned that employment rates for persons who use power wheelchairs are related to the individual's health related quality of life. While previous research has shown that independent transportation is essential to employment for persons with disabilities, this study has shown that individuals who do not experience self-reported transportation difficulties have no difference in employment rates than individuals who experience transportation difficulties. Future studies are needed to explore these findings over time and focus on barriers and facilitators to gainful employment for individuals who use power wheelchairs.



## APPENDIX A

### DEMOGRAPHIC QUESTIONNAIRE

Do you consider yourself Hispanic or Latino?

- \_\_\_\_\_ (1) Yes
- \_\_\_\_\_ (0) No (please go to question 7)

6a. If "Yes", would you describe yourself:

- \_\_\_\_\_ (1) Cuban
- \_\_\_\_\_ (2) Mexican
- \_\_\_\_\_ (3) Puerto Rican
- \_\_\_\_\_ (4) Other (please specify): \_\_\_\_\_

7. How would you describe your primary racial group?

- \_\_\_\_\_ (1) No Primary Group
- \_\_\_\_\_ (2) White Caucasian
- \_\_\_\_\_ (3) Black/African American
- \_\_\_\_\_ (4) Asian
- \_\_\_\_\_ (5) American Indian/Alaska Native
- \_\_\_\_\_ (6) Native Hawaiian/Pacific Islander
- \_\_\_\_\_ (7) Multi-racial
- \_\_\_\_\_ (8) Other (please specify): \_\_\_\_\_

8. In which type of housing do you live?

- (1) Residence hall/College dormitory
- (2) House/Apartment/Condominium
- (3) Senior housing (independent)
- (4) Assisted living
- (5) Nursing Home
- (6) Relative's home
- (7) Other (please specify): \_\_\_\_\_

9. Please circle the number of years of formal education that you have completed:

← 6 7 8 9 10 11 12 13 14 15 16 17 →

10. What is the highest degree you received?

- \_\_\_\_\_ (0) High School Diploma or GED
- \_\_\_\_\_ (1) Associate Degree/Vocation/Technical School
- \_\_\_\_\_ (2) Bachelors Degree
- \_\_\_\_\_ (3) Graduate Degree

11. Which statement best describes your **CURRENT** work status?

- \_\_\_\_\_ (0) Working full-time, outside the home
- \_\_\_\_\_ (1) Working part-time, outside the home
- \_\_\_\_\_ (2) Working full-time, inside the home
- \_\_\_\_\_ (3) Working part-time, inside the home
- \_\_\_\_\_ (4) Disabled: unable to work because of disability
- \_\_\_\_\_ (5) Unemployed: not able to find job in field that I was trained
- \_\_\_\_\_ (6) I choose not to be employed or am retired
- \_\_\_\_\_ (7) Student

12. If you are not employed full-time, please indicate the reason why:

- \_\_\_\_\_ (0) By choice
- \_\_\_\_\_ (1) Because of the economy
- \_\_\_\_\_ (2) Because of your disability
- \_\_\_\_\_ (-2) Not applicable because fully employed

13. Please indicate which best describes your marital status:

- \_\_\_\_\_ (0) Single
- \_\_\_\_\_ (1) Married
- \_\_\_\_\_ (2) Living with someone as if married

*One's financial situation and health insurance can influence one's health. Please check the response that best describes you.*

14. Your current approximate **total household** income per year is (**including spouse or other household income sources**):

- \_\_\_\_\_ (1) Less than \$10,000
- \_\_\_\_\_ (2) \$10,000 – 15,000
- \_\_\_\_\_ (3) \$15,000 – 20,000
- \_\_\_\_\_ (4) \$20,000 – 25,000
- \_\_\_\_\_ (5) \$25,000 – 35,000
- \_\_\_\_\_ (6) \$35,000 – 50,000
- \_\_\_\_\_ (7) \$50,000 – 75,000
- \_\_\_\_\_ (8) Greater than \$75,000

15. Do you feel that your disability has affected your income?

- \_\_\_\_\_ (0) No
- \_\_\_\_\_ (1) Yes → If yes, has your disability \_\_\_\_\_ (1) increased your income
- \_\_\_\_\_ \_\_\_\_\_ (2) decreased your income

16. Are you currently on disability?

- \_\_\_\_\_ (1) Yes
- \_\_\_\_\_ (0) No (please go to question 17)

16a. If yes, please state which type:

- \_\_\_\_\_ (1) SSI
- \_\_\_\_\_ (2) SSDI
- \_\_\_\_\_ (3) Workman's Compensation
- \_\_\_\_\_ (4) Other: \_\_\_\_\_

17. Please check the statement(s) that best describe you regarding health insurance:

- \_\_\_\_\_ (1) I do not have health insurance; I use my private money to pay for medical expenses.
- \_\_\_\_\_ (2) Health insurance is provided through Medicare or Medicaid.
- \_\_\_\_\_ (3) Health insurance is provided by my employer, my spouse's/parent's employer, or previous employer (i.e., Champus, Tri-Care).
- \_\_\_\_\_ (4) I have health insurance, but I pay for it through personal monies
- \_\_\_\_\_ (5) Other: \_\_\_\_\_

## APPENDIX B

### TRANSPORTATION QUESTIONS

1. On average, about how many days per week do you leave the home for any reason?  
\_\_\_\_\_ days
  
2. About how frequently do you **drive** a car or van or other motor vehicle?  
\_\_\_\_\_ (0) Everyday or almost everyday  
\_\_\_\_\_ (1) Once a week  
\_\_\_\_\_ (2) Occasionally (e.g. less than once a week)  
\_\_\_\_\_ (3) Seldom (e.g. less than once a month)  
\_\_\_\_\_ (-2) Never (Please skip to question #3)
  
- 2a. Approximately how many miles have you **driven** in the past week?  
\_\_\_\_\_ miles
  
- 2b. When you **drive**, do you transfer into a motor vehicle seat, or do you use your wheelchair/scooter as the seat? (please refer to the activity you do the majority of the time)  
\_\_\_\_\_ (0) I transfer to vehicle seat  
\_\_\_\_\_ (1) I use my wheelchair or scooter
  
3. About how frequently do you **ride as a passenger** in a **private car or van**?  
\_\_\_\_\_ (0) Everyday or almost everyday  
\_\_\_\_\_ (1) Once a week  
\_\_\_\_\_ (2) Occasionally (e.g. less than once a week)  
\_\_\_\_\_ (3) Seldom (e.g. less than once a month)  
\_\_\_\_\_ (-2) Never (Please skip to question #4)
  
- 3a. About how many miles have you ridden as a passenger in a car or van in the past week?  
\_\_\_\_\_ miles
  
- 3b. When you ride as a passenger, do you transfer into a motor vehicle seat, or do you use your wheelchair/scooter as the seat? (please refer to the activity you do the majority of the time)  
\_\_\_\_\_ (0) I transfer to vehicle seat  
\_\_\_\_\_ (1) I use my wheelchair or scooter

4. About how frequently do you **ride as a passenger** while using **local public transportation**, such as a public bus line, rapid transit, subway, or street car?

- \_\_\_\_\_ (0) Everyday or almost everyday
- \_\_\_\_\_ (1) Once a week
- \_\_\_\_\_ (2) Occasionally (e.g. less than once a week)
- \_\_\_\_\_ (3) Seldom (e.g. less than once a month)
- \_\_\_\_\_ (-2) Never (Please skip to question 5)

4a. Approximately, how many miles have you ridden as a passenger in public transportation in the past week?

\_\_\_\_\_ miles

4b. When you ride as a passenger, do you transfer into a motor vehicle seat, or do you use your wheelchair/scooter as the seat? (Please refer to the activity you do the majority of the time)

- \_\_\_\_\_ (0) I transfer to vehicle seat
- \_\_\_\_\_ (1) I use my wheelchair or scooter

5. In general, do you have any difficulties in getting the motor vehicle transportation that is needed?

- \_\_\_\_\_ (1) Yes
- \_\_\_\_\_ (0) No (Please skip to question 6)
- \_\_\_\_\_ (-2) Don't know

5a. What are these difficulties?

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6. How do you usually get to work or shopping, etc.? (i.e. What is your primary means of transportation?) (Check only one)

- \_\_\_\_\_ (0) Private Car
- \_\_\_\_\_ (1) Private Van
- \_\_\_\_\_ (2) Public Bus or subway/train
- \_\_\_\_\_ (3) Regular taxi
- \_\_\_\_\_ (4) Specialized bus, van, or taxi service for people with disabilities (ex. Access)
- \_\_\_\_\_ (5) School Bus
- \_\_\_\_\_ (6) Other

## APPENDIX C

### COMMUNITY INTEGRATION QUESTIONNAIRE

#### Home Integration:

1. Who usually does shopping for groceries or other necessities in your household?  
\_\_\_\_\_ (2) Yourself alone  
\_\_\_\_\_ (1) Yourself and someone else  
\_\_\_\_\_ (0) Someone Else
2. Who usually prepares meals in your household?  
\_\_\_\_\_ (2) Yourself alone  
\_\_\_\_\_ (1) Yourself and someone else  
\_\_\_\_\_ (0) Someone Else
3. In your home, who usually does normal everyday housework?  
\_\_\_\_\_ (2) Yourself alone  
\_\_\_\_\_ (1) Yourself and someone else  
\_\_\_\_\_ (0) Someone Else
4. Who usually cares for the children in your home?  
\_\_\_\_\_ (2) Yourself alone  
\_\_\_\_\_ (1) Yourself and someone else  
\_\_\_\_\_ (0) Someone Else  
\_\_\_\_\_ (3) Not Applicable—No children under 17 in the home
5. Who usually plans social arrangements such as get togethers with family and friends?  
\_\_\_\_\_ (2) Yourself alone  
\_\_\_\_\_ (1) Yourself and someone else  
\_\_\_\_\_ (0) Someone Else

#### Social Integration:

6. Who usually looks after your personal finances, such as banking or paying bills?  
\_\_\_\_\_ (2) Yourself alone  
\_\_\_\_\_ (1) Yourself and someone else  
\_\_\_\_\_ (0) Someone Else

Approximately how many times a month do you usually participate in the following activities *outside the home*?

7. Shopping

- \_\_\_\_\_ (2) 5 or more
- \_\_\_\_\_ (1) 1-4 times
- \_\_\_\_\_ (0) Never

8. Leisure activities such as movies, sports, restaurants, etc.

- \_\_\_\_\_ (2) 5 or more
- \_\_\_\_\_ (1) 1-4 times
- \_\_\_\_\_ (0) Never

9. Visiting with friends or relatives

- \_\_\_\_\_ (2) 5 or more
- \_\_\_\_\_ (1) 1-4 times
- \_\_\_\_\_ (0) Never

10. When you participate in leisure activities, do you usually do this alone or with others?

- \_\_\_\_\_ (0) Mostly alone
- \_\_\_\_\_ (1) Mostly with friends who have disabilities
- \_\_\_\_\_ (1) Mostly with family members
- \_\_\_\_\_ (2) Mostly with friends who do not have disabilities
- \_\_\_\_\_ (2) With a combination of family and friends

11. Do you have a best friend with whom you confide?

- \_\_\_\_\_ (0) No
- \_\_\_\_\_ (1) Yes

Integration into Productive Activities

12. How often do you travel outside the home?

- \_\_\_\_\_ (2) Almost every day
- \_\_\_\_\_ (1) Almost every week
- \_\_\_\_\_ (0) Seldom/never (less than once per week)

13. Please choose the answer below that best corresponds to your current (during the past month) work situation:

- \_\_\_\_\_ (1) Full-time employment (more than 20 hours per week)
- \_\_\_\_\_ (2) Part-time employment (less than or equal to 20 hours per week)
- \_\_\_\_\_ (3) Not working but actively looking for work
- \_\_\_\_\_ (4) Not working, not looking for work
- \_\_\_\_\_ (5) Not applicable, retired due to age

14. Please choose the answer below that best corresponds to your current (during the past month) school or training program situation:

- \_\_\_\_\_ (2) Full-time
- \_\_\_\_\_ (1) Part-time
- \_\_\_\_\_ (0) Not attending school or training program)
- \_\_\_\_\_ (3) Not applicable, retired due to age

15. In the past month, how often did you engage in volunteer activities?

- \_\_\_\_\_ (2) 5 or more
- \_\_\_\_\_ (1) 1-4 times
- \_\_\_\_\_ (0) Never



## APPENDIX D

### HEALTH RELATED QUALITY OF LIFE VARIABLES

Additional Problems - Please check all that apply to you:

- |  |   |
|--|---|
| <input type="checkbox"/> Pain                    | <input type="checkbox"/> Decreased Endurance (ex. tiredness, fatigue)     |
| <input type="checkbox"/> Paralysis               | <input type="checkbox"/> Diminished Sensation (ex. touch, pressure, pain) |
| <input type="checkbox"/> Limited Range of Motion | <input type="checkbox"/> Mental Health Issues (ex. depression, anxiety)   |
| <input type="checkbox"/> Weakness                | <input type="checkbox"/> Balance Problems                                 |
| <input type="checkbox"/> Fatigue                 |   |

#### Health Information

- In general, would you say your health is:  

|                                       |                                       |                                       |                                       |                                       |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>4</sub> | <input type="checkbox"/> <sub>5</sub> |
| Poor                                  | Fair                                  | Good                                  | Very good                             | Excellent                             |
- Compared to other people your own age, would you say your health is:  

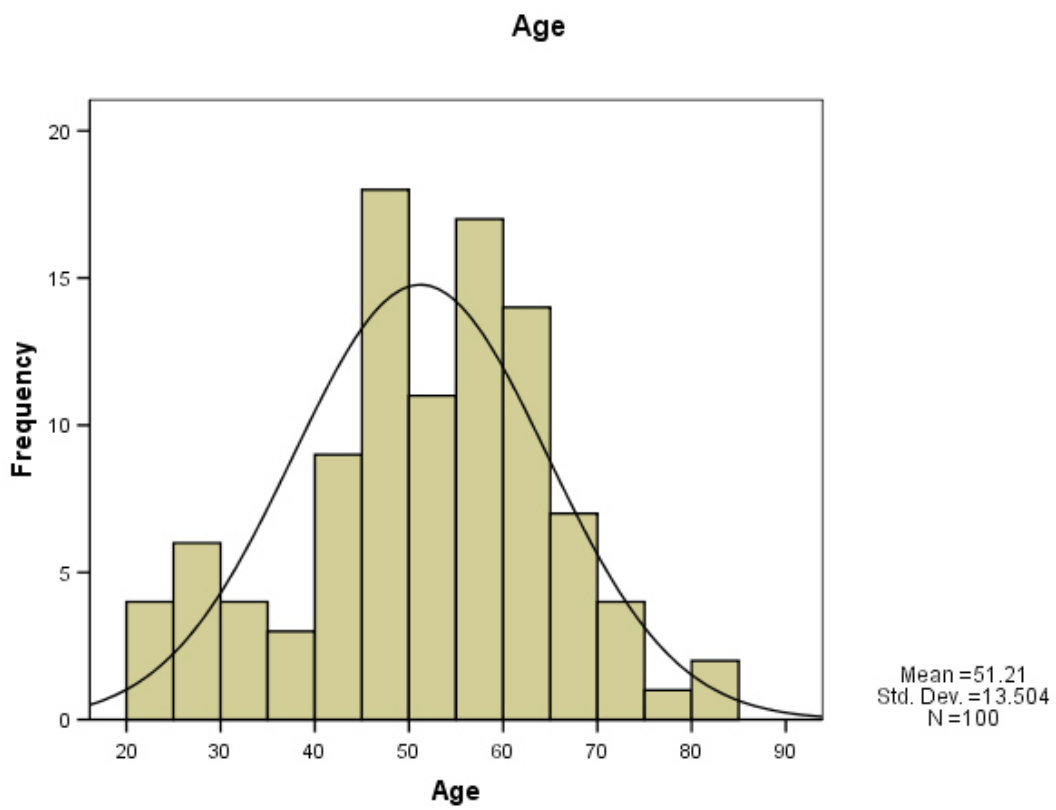
|                                       |                                       |                                       |                                       |                                       |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>4</sub> | <input type="checkbox"/> <sub>5</sub> |
| Poor                                  | Fair                                  | Good                                  | Very good                             | Excellent                             |
- How satisfied are you with your present health?  

|                                       |                                       |                                       |                                       |                                       |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>4</sub> | <input type="checkbox"/> <sub>5</sub> |
| Not at all satisfied                  | Not very satisfied                    | Neither satisfied nor dissatisfied    | Somewhat satisfied                    | Extremely satisfied                   |
- How often do health problems stand in the way of your doing the things you want to do?  

|                                       |                                       |                                       |                                       |                                       |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>4</sub> | <input type="checkbox"/> <sub>5</sub> |
| Never                                 | Seldom                                | Sometimes                             | Often                                 | Always                                |

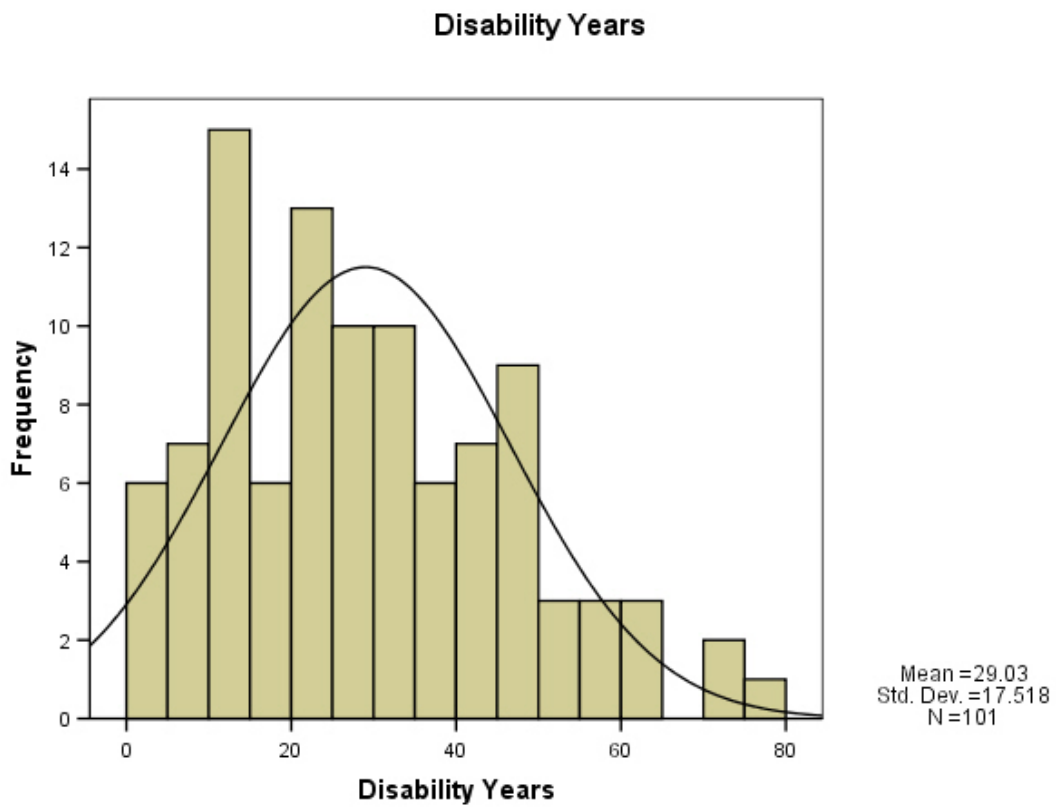
**APPENDIX E**

**ADDITIONAL FIGURES**



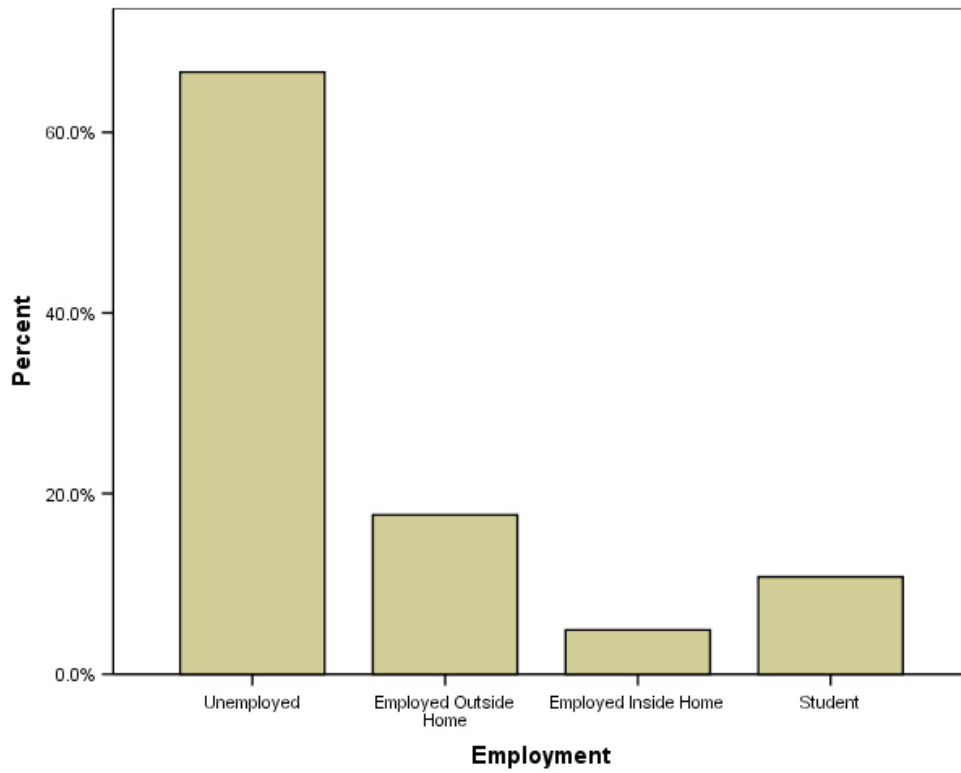
**Figure 8:** Histogram of Age for 100 Subjects

\*Two missing data points

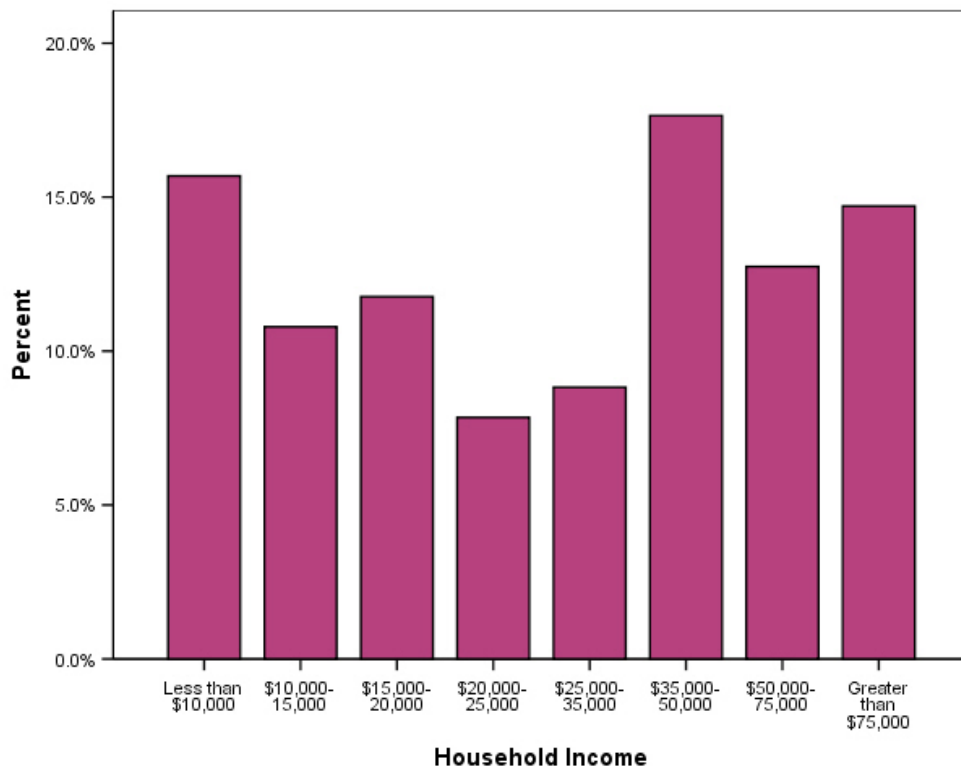


**Figure 9:** Histogram of Disability Years for 101 subjects

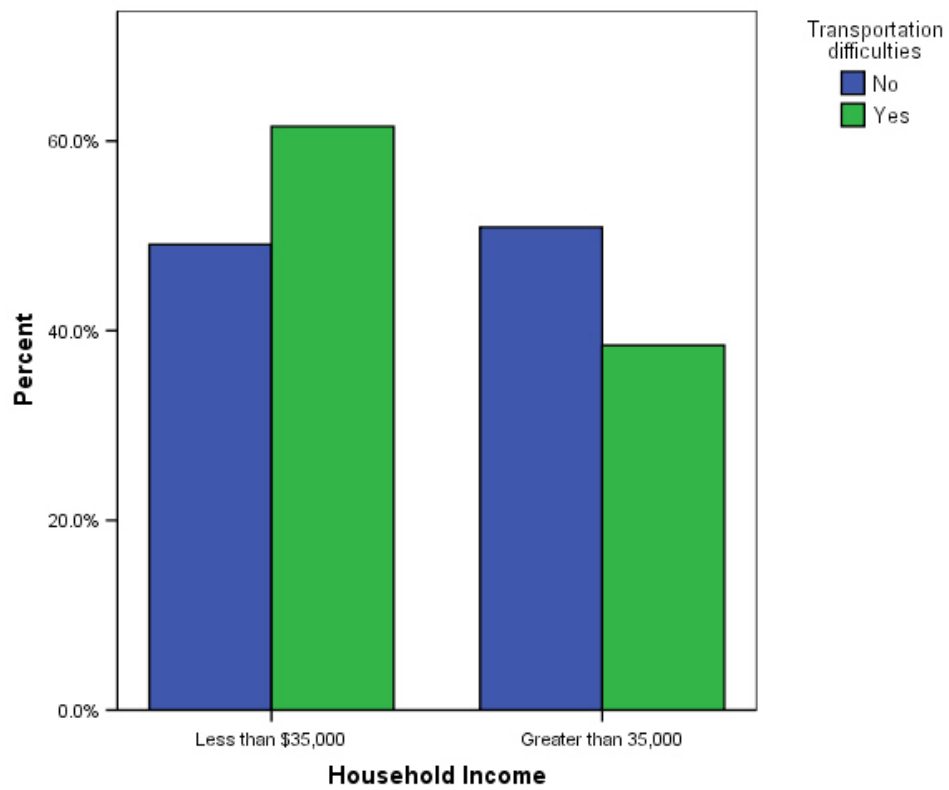
\*One missing data point



**Figure 10:** Employment Status



**Figure 11:** Household Income



**Figure 12:** Transportation Difficulties by Household Income

**Table 17:** Relationship between Health Questions and Comorbid Conditions

| Health Questions   | Some (0-4)<br>(n=43) | Many (5-9)<br>(n=59) |
|--|----------------------|----------------------|
| In general, would you say your health is <sup>1</sup>  |                      |                      |
| Positive   | 17                   | 8                    |
| Neutral  | 19                   | 19                   |
| Negative   | 7                    | 32                   |
| Compared to other people your own age, would you say your health is <sup>2</sup>                   |                      |                      |
| Positive   | 15                   | 8                    |
| Neutral  | 16                   | 16                   |
| Negative   | 12                   | 32                   |
| How satisfied are you with your present health <sup>3</sup>  |                      |                      |
| Positive   | 30                   | 25                   |
| Neutral  | 7                    | 9                    |
| Negative   | 6                    | 25                   |
| How often do health problems stand in the way of your doing the things you want to do <sup>4</sup> |                      |                      |
| Positive   | 13                   | 8                    |
| Neutral  | 20                   | 13                   |
| Negative   | 10                   | 38                   |

1.  $p < 0.001$  (significant differences between number of comorbid conditions and 1-4)
2.  $p = 0.004$
3.  $p = 0.006$
4.  $p < 0.001$

**Table 18:** Breakdown of the Method of Transportation

| <i>TRANSPORTATION</i>    |              | <i>Use Public<br/>Transportation</i> | <b>Do Not Use Public<br/>Transportation</b> |
|--------------------------|--------------|--------------------------------------|---|
| Do Not Ride as Passenger | Do Not Drive | 29                                   | 3   |
|                          | Drive        | 16                                   | 22  |
| Ride as Passenger        | Do Not Drive | 21                                   | 2   |
|                          | Drive        | 8                                    | 1   |



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