ASSESSING THE INFLUENCE OF WHEELCHAIR ON INDIVIDUALS WITH SPINAL CORD INJURY USING A MEASURE OF PARTICIPATION

by

Eliana Chaves Ferretti
B.S OT, Federal University of Sao Carlos, 1995
MS, University of Pittsburgh, 2003

Submitted to the Graduate Faculty of
School of Health and Rehabilitation in partial fulfillment
of the requirements for the degree of
Ph.D. in Rehabilitation Science and Technology

University of Pittsburgh

2007
This dissertation was presented

by

Eliana C. Ferretti

It was defended on
September 7th, 2007

and approved by

Michael L. Boninger, MD
Shirley Fitzgerald, PhD
Rosemarie Cooper, A.T.P
David Gray, PhD

Dissertation Advisor: Rory A. Cooper, PhD
The purpose of the first study was to investigate the effect of manual and power wheelchairs on the frequency of community activities of individuals with varying levels of spinal cord injury (SCI). One hundred and five individuals with SCI who use wheelchairs for mobility provided participated in the final analysis. A written survey that recorded assistive technology (AT) usage in daily activities, called Participation Survey/Mobility (PARTS/M), was distributed among clients from Pittsburgh and Saint Louis. Results showed that individuals who use power wheelchairs visit their friends and dine out much less than individuals who use manual wheelchairs. In addition, individuals with tetraplegia reported going to the doctor’s office less frequently than individuals with paraplegia. Therefore, individuals with SCI with varied level of injury and different mobility devices, experience different types of frequencies of public places and community participation.

The purpose of the second study was to investigate the effect of wheelchairs, the physical and social barriers on community participation among individuals with SCI. One hundred and five individuals with SCI who use wheelchairs for mobility participated in the data analyses. A written survey, called Facilitators and Barriers Survey/Mobility (FABS/M) was distributed among clients from Pittsburgh and Saint Louis. Results showed that a greater number of individuals with tetraplegia who use power wheelchairs (TP) reported that lack of personal assistance as a perceived social barrier that limits their participation in their place of employment.
when compared to those individuals with paraplegia who use manual wheelchairs (PM), individuals with paraplegia who use power wheelchairs (PP) and individuals with tetraplegia who use manual wheelchairs (TM). A greater number of individuals with TM and PM reported that the place of employment does not limit them compared to those PP and TP. In addition, a greater number of individuals with PP and TP indicated that lack of personal assistance as a perceived social barrier that limits their participation in the grocery store when compared to those with PM and TM. Furthermore, the perceived influence of the physical environment on participation in activities within the home and community was also demonstrated.

The purpose of the third study was to investigate if the acquisition of new manual and power wheelchairs delivered by specialized AT clinic will change the frequency of participating in activities within the community of individuals with SCI and reduce the number of perceived limitations to participation over time. No significant difference between participants who received new wheelchairs delivered by specialized AT clinic and those who have received new equipment from a non-specialized AT clinic on the perception of frequency of community activities, satisfaction of community activities and number of physical and social barriers were found. The process of wheelchair service delivery has been shown to play an essential role in wheelchair related outcomes. However, the wheelchair service delivery may just be one of the factors that affect the individual’s community participation.

The purpose of the fourth study was to investigate if there is a correlation between mobility characteristics (distance traveled, speed, number of starts and stops and drive time) and the frequency of community activities of individuals with SCI as measured by the PARTS/M and data logger device. A significant negative correlation (r=-.783, p=.013) was found between number of start and stops during week days and community participation scores, indicating that
individuals who use power wheelchairs who have less number of starts and stops have higher level of community participation. A significant positive correlation ($r=.772$, $p=.015$) was found between daily drive minutes during week days and community participation scores, indicating that individuals who use power wheelchairs who drive their wheelchair more have higher level of community participation. In addition, in the manual wheelchair group, a significant positive correlation was found between speed during week days ($r=.760$, $p=.047$) and community participation, indicating that individuals who travel at a higher speed have higher levels of community participation.
# TABLE OF CONTENTS

PREFACE ................................................................................................................................................. 14  

1.0 INTRODUCTION ................................................................................................................................. 16  

1.1 THE EFFECTS OF TYPE OF WHEELCHAIR AND LEVEL OF INJURY  
ON THE FREQUENCY OF COMMUNITY ACTIVITIES OF INDIVIDUALS WITH  
SPINAL CORD INJURY .......................................................................................................................... 19  

1.1.1 INTRODUCTION ............................................................................................................................. 19  

1.1.2 METHODS ...................................................................................................................................... 21  

    1.1.2.1 Subjects .................................................................................................................................. 21  

    1.1.2.2 Questionnaire ...................................................................................................................... 21  

    1.1.2.3 Data Analysis and Statistical Considerations ....................................................................... 22  

1.1.3 RESULTS ......................................................................................................................................... 23  

    1.1.3.1 Subjects .................................................................................................................................. 23  

    1.1.3.2 Demographics ...................................................................................................................... 24  

    1.1.3.3 Frequency of Community Activities ................................................................................. 24  

1.1.4 DISCUSSION .................................................................................................................................. 27  

1.1.5 STUDY LIMITATION ...................................................................................................................... 30  

1.1.6 REFERENCE .................................................................................................................................. 31  

APPENDIX A ........................................................................................................................................... 37
1.2 THE EFFECTS OF ENVIRONMENTAL BARRIERS ON DAILY ACTIVITIES OF INDIVIDUALS WITH SPINAL CORD INJURY

1.2.1 INTRODUCTION

1.2.2 METHODS

1.2.2.1 Participants

1.2.2.2 Questionnaire

1.2.2.3 Data Analysis and Statistical Considerations

1.2.3 RESULTS

1.2.3.1 Participants

1.2.3.2 Demographics

1.2.3.3 Perceived Physical and Social barriers in the home and community

1.2.3.4 Perceived influence of the physical environment on participation in activities within the home and community

1.2.4 DISCUSSION

1.2.5 STUDY LIMITATION

1.2.6 REFERENCE

APPENDIX B

APPENDIX C

1.3 THE INFLUENCE OF A WHEELCHAIR SERVICE DELIVERY ON COMMUNITY PARTICIPATION PERCEPTIONS OF INDIVIDUALS WITH SPINAL CORD INJURY

1.3.1 INTRODUCTION
1.4.2.1 Participants ................................................................. 105
1.4.2.2 Recruitment Procedures ........................................... 105
1.4.2.3 Protocol ....................................................................... 106
1.4.2.4 Questionnaire ............................................................. 106
1.4.2.5 Data logger ................................................................. 107
1.4.2.6 Reduction of Data logging Device Data ...................... 108
1.4.2.7 Data Analysis ............................................................. 110

1.4.3 RESULTS .......................................................................... 112
1.4.4 DISCUSSION ................................................................. 115
1.4.5 STUDY LIMITATION ...................................................... 118
1.4.6 REFERENCE ................................................................. 119

2.0 CONCLUSION ...................................................................... 124

APPENDIX H ........................................................................... 129
APPENDIX I ........................................................................... 132
LIST OF TABLES

TABLE 1. Results of Kruskal Wallis Test on Frequency of Community Activities for Four Groups (PP, PP, TM and TP).................................................................................................................................................. 25

TABLE 2. Results of Mann-Whitney Test on Items on Frequency of Community Activities for PM, PP and TM.................................................................................................................................................. 26

TABLE 3. Results of Mann-Whitney Test on Items on Frequency of Community Activities for PM, TM and TP.................................................................................................................................................. 26

TABLE 4. Results of Mann-Whitney Test on Items on Frequency of Community Activities for PP, TM and TP.................................................................................................................................................. 26

Table 5. Illustrates an example (with scores above and below for each answer) of the influence of the environment question in activities within the home and community............................43

Table 6. Scoring Explanation for the Influence of Environment on Participation in Activities. ..................................................................................................................................................................................................44

Table 7. Illustrates the percentages of social and physical barriers in the residence.......48

Table 8. Illustrate the percentages of social and physical barriers in the place of employment. ..................................................................................................................................................................................................48

Table 9. Illustrates the percentages of social and physical barriers in the grocery store. .48

Table 10. Illustrates the percentages of social and physical barriers in the doctor's office.49
Table 11. Illustrate the percentages of social and physical barriers in the religious institution.

Table 12. Illustrates the percentages of social and physical barriers in restaurants.

Table 13. Illustrates the percentages of social and physical barriers in movie theaters.

Table 14. Illustrate the percentages of social and physical barriers in shopping malls.

Table 15. Illustrate the percentages of social and physical barriers in clothing stores.

Table 16. Illustrates the percentages of social and physical barriers in parks.

Table 17. Percentages of influence of the physical environment on participation in activities within the home.

Table 18. Illustrate the percentages of influence of the physical environment on participation in activities within the community.

Table 19. Illustrates the scores of perception of frequency of community participation (FCP), satisfaction of community participation (SCP) and functional limitations (Participation and Access limitations) of community participation by the four groups over time.

Table 20. Shows results from all participants on correlation between community participation scores and average daily distance, speed, number of stops/starts and active minutes during the week and weekend.

Table 21. Illustrates the correlations between mobility characteristics and community participation of manual and power wheelchair users.
LIST OF FIGURES

Figure 1. Illustrates a flowchart for participation in the study. ........................................ 78

Figure 2. Illustrates Frequency of Community Participation (FCP) scores by the four groups over
time ........................................................................................................................................ 80

Figure 3. Illustrate Satisfaction of Community Participation (SCP) scores by the four groups over
time ........................................................................................................................................ 82

Figure 4. Illustrate functional limitations (participation limitations) scores by the four groups over
time ........................................................................................................................................ 84

Figure 5. Illustrate functional limitations (access limitations) scores by the four groups over time.
.................................................................................................................................................. 85

Figure 6. Shows the data logger mounted to the spoke of a manual wheelchair. ........ 108

Figure 7. Illustrates the power data logger device.. ................................................................. 108
I would like to thank all my dissertation committee, Dr Cooper, Dr Boninger, Rosemarie Cooper, Dr Fitzgerald and Dr Gray. The support and guidance that each of you has given me over the years is immeasurable and I will be forever grateful!! Dr Fitzgerald, thank you for offering your expertise in research design and statistical analysis. Your inputs have been invaluable. It has been a privilege working with Dr Boninger. His initiative, energy, and vision have inspired me in many ways. Especial thanks to Rosemarie Cooper, I enjoyed the time that you were working at HERL not only for the learning experience but because of the friendship that has grown over the years. Dr Gray, you have a great team. Denise Curl and Kerri Morgan have been playing an important role in this project. Denise and Kerri were always available and provided me with the sources that I needed to start entering and analyzing data.

Special thanks are reserved for my dissertation advisor Dr. Rory Cooper. Dr Cooper, I could not have asked for a better mentor. Words will probably not express my gratitude for all you have done for me. Thank you for your patience, understanding, and support when times were difficult. Thank you for always having 1 minute to discuss any of my doubts, although our discussions ended up longer than that. You always had the right answers and the sources that I needed. You have contributed to all that I have learned about leading research, being a mentor and advisor, and have show me the magnitude of the rehabilitation science and technology field. Besides that, you have been a supportive and genuine friend who has shared your understanding
about the importance of balancing family and work. Dr Cooper, I have you as an example of hard work and I will be forever grateful for all this immeasurable learning experience!!!

I would also like to thank all of the staff and students whom I have met during my time at the HERL, who have provided me with not only their knowledge and wisdom, but with their friendship. Special thanks for Paula Stankovic, Christine Heiner, Annmarie Kelleher, Emily Zipfel, Fabrisia Ambrosio, Yusheng Yang, Ian Rice, Amol Karmarkar, Dine Collins, Michelle Tolerico, Garrett Grindle, Rachel Cowan, Ana Souza, Hongwu Wang and Harshal Mahajan.

To my family whose love and support make all things possible...thanks for your endless prayers... mãe, pai, without you, I wouldn’t have gotten this far. Thanks for being a wonderful mom and dad...thanks for also being a wonderful grandmother and grandfather...thanks for inspired me in everyday of my life...thanks for always being there when I needed. Sincere thanks for my sister Sandra, my brother in law Elvio, my brothers Huguinho and Ricardo and my sisters in law, Flavia, Ive, Susana, Suzi and Suzeli. Cannot forget to mention my mother and father in law, Cacilda and Mario Ferretti for prayers, love and support. Sincere thanks for Sheila Ingham and overflowing thanks to Regiane and Pedro Andrade for their endless kindness and support. The best friends!!! My most sincere gratitude to the one who shared every moment of my journey at Pitt and of my personal life, my loved husband Mario. Thank you for your patience, understanding, support, and love. You have been great and I love you very much! Missing you! To my son, Mario Antonio, you are the greatest gift ever! I love you so much...missing you a lot...more than you will ever imagine...in a bit I will be with you!!
1.0 INTRODUCTION

The perception of disability has been evolving greatly in international circles within the last decade. The World Health Organization’s (WHO) International Classification of Functioning, Disability and Health (ICF; WHO, 2001) emphasizes what people do on a daily basis as opposed to what they have the ability to do.\textsuperscript{1} Thus, disability has not only been related to physical or mental limitations, but more so, has been considered a dysfunction of the interaction between an individual and his environment.\textsuperscript{2} In this framework, the environment is composed of physical and social factors. The physical factors are defined as having the availability of resources, as such, accessibility of streets, buildings, transportation and medications. The social factors are composed by attitudes of others, public priorities, policies and availability of services. The latter, encompasses the individual’s ability to assess assistive technology (AT) devices.\textsuperscript{2} AT may be defined as “any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.”\textsuperscript{3}

People with spinal cord injury (SCI) rely on AT, especially manual and power wheelchairs to compensate for mobility needs and therefore, accomplish daily activities.\textsuperscript{4, 5} Therefore; the function of people with disabilities is affect by technology and the physical environment as much as by their physiological impairments.\textsuperscript{6, 2} With this in mind, wheelchairs and the physical environment are assumed to affect the extent to which an individual perform daily activities
and untimely, participates in the community. Hence, the outcome of wheelchairs on community participation represents an important area of research. In addition to providing information that is likely to directly affect care, these studies will also provide data necessary for further studies designed to optimize the use of mobility aides in individuals with SCI.

The purpose of section one was to investigate the effect of manual and power wheelchairs on the frequency of community activities of individuals with SCI. The purpose of section two was to investigate the effect of wheelchairs, the physical and social barriers on community participation among individuals with SCI. The specific aims were to: 1) Determine the most common social and physical barriers that individuals with SCI rank as the most limiting for community participation; 2) Determine if differences exist between individuals that use manual and power regarding the frequency of social and physical barriers on community participation and 3) Determine if specific characteristics of the social and physical environment (such as stairs, curb cuts etc.) are reported as facilitators or barriers to participation and if this differs by wheelchair type.

The purpose of section three was to investigate if the acquisition of new manual and power wheelchairs delivered by specialized AT clinic will change the frequency of participating in activities within the community of individuals with SCI and reduce the number of perceived limitations to participation. It was hypothesized as measured by the Participation Survey/Mobility (PARTS/M), when compared to those who have not received new equipment from a non-specialized AT clinic, both manual and power wheelchair users who receive new equipment from specialized AT clinic will show that: 1) frequency of participating in community activities will increase; 2) satisfaction in participation will improve and 3) perception for the number and types of limitations to participation will decrease. The purpose of section four was to investigate if
there is a correlation between mobility characteristics (distance traveled, speed, number of
starts and stops and drive time) and community participation of individuals with SCI as
measured by the PARTS/M and data logger device.

REFERENCE

1. World Health Organization. ICIDH-2: International Classification of functioning,
   Disability and Health. Final draft, full version. Geneva: world Health Organization,


4. Scherer M, Cushman L. Measuring subjective quality of life following spinal cord
   injury: a validation study of assistive technology device predisposition assessment.

5. Hunt PC, Boninger ML, Cooper RA, Zafonte RD, Fitzgerald SG, Schmeler MR.
   Demographic and socioeconomic factors associated with disparity in wheelchair
   customizability among people with traumatic spinal cord injury. Arch Phys Med

1.1 THE EFFECTS OF TYPE OF WHEELCHAIR AND LEVEL OF INJURY ON THE FREQUENCY OF COMMUNITY ACTIVITIES OF INDIVIDUALS WITH SPINAL CORD INJURY

1.1.1 INTRODUCTION

Quality of life (QoL) in persons with spinal cord injury (SCI) has increasingly been a topic of interest within the last decade.\textsuperscript{1-3} The definition of QoL includes an individual’s satisfaction in specific areas of life such as work, social relationships, and being able to go where one desires to go, beyond their physical ability.\textsuperscript{4} Evidence suggests that compared to the general population, people with SCI might experience a slightly lower QoL.\textsuperscript{5} Research has documented that life satisfaction is greater for those who are involved in productive activities such as work, education, and recreation.\textsuperscript{6} Based on that, significant efforts have been made to characterize predictors of community participation and their importance to enhance QoL.

The term community participation is used to refer to returning to the mainstream of family and community life, engaging in normal roles and responsibilities, actively contributing to ones social groups and of society as a whole.\textsuperscript{7} The ability of people with SCI to successfully participate in the community and regain independence depends much on access to appropriate and adequate wheelchairs.\textsuperscript{8} Having an appropriate wheelchair can significantly influence how a person with a disability perceives life.\textsuperscript{9} Greater satisfaction with a wheelchair should result in enhanced use of that technology and contribute to a better subjective quality of life.\textsuperscript{10}

A study published by Hunt and colleagues\textsuperscript{11} using subjects from the Model Systems Database found that of individuals with SCI, 61\% used manual wheelchairs, 38\% used power wheelchairs and only 1\% used scooters or power-assisted wheelchairs. In line with that,
Biering-Sorensen et al.\textsuperscript{12} out of a sample of 236 participants, demonstrated that individuals with SCI are more likely to use manual wheelchairs (83.5\%) than power wheelchairs (27\%). Manual wheelchairs are more likely to be used by individuals with paraplegia whereas power wheelchairs are more likely to be used by individuals with tetraplegia.\textsuperscript{12} Most manual wheelchairs are considered smaller and lighter than power wheelchairs, making it possible to transfer and transport them into a car, maneuver in confined spaces, and negotiate curbs and stairs\textsuperscript{13}, either propelling them independently or with assistance. Manual wheelchair propulsion potentially benefits the wheelchair user’s cardiovascular fitness\textsuperscript{14} and upper extremity muscle strength.\textsuperscript{15} On the other hand, power wheelchairs can provide a means of independent mobility to people who are unable to self propel manual wheelchairs. They are also used by some individuals who are capable of propelling manual wheelchairs, but often need to travel considerable distances over hilly terrain or need to preserve energy and reduce the risk of repetitive strain injuries.\textsuperscript{16,17}

Although several studies have described the advantages and disadvantages of manual and power wheelchairs, no studies to date have related them to community participation. Most of the literature on wheelchairs is focused around issues of design, consumer preferences, abandonment, cost and policy.\textsuperscript{18-20} What is not known is how manual and power wheelchair users report different levels of participation in community activities. Therefore, the overall aim of this study is to investigate the effect of manual and power wheelchairs on the frequency of community activities of individuals with SCI.
1.1.2 METHODS

1.1.2.1 Subjects

Multi-site Institutional Review Board (IRB) approval was obtained prior to initiation of the study. One hundred and six individuals from Pittsburgh and Saint Louis with SCI who use wheelchairs for mobility provided written informed consent. All participants had to be discharged from rehabilitation for at least one year and live in a community setting. Pittsburgh participants were recruited through research centers and through a specialized assistive technology (AT) clinic that uses a client centered multi-disciplinary team approach. Saint Louis subjects were recruited from research centers and rehabilitation centers. In both locations subjects were recruited via flyer or approached by clinical study coordinators, who asked if they were interested in participating.

1.1.2.2 Questionnaire

The questionnaire used in this study was the Participation Survey/Mobility (PARTS/M). The PARTS/M was specifically designed to define participation in the same manner as the International Classification of Function and Disability (ICIDH-2).\textsuperscript{21} The PARTS/M is composed of 13 major life activities ranging from grooming to going to the doctor’s office.\textsuperscript{22} For this study, a subset of 11 questions were selected which we were felt to better describe community participation. Subjects were asked 8 questions related to their frequency of leaving home and three questions related to their frequency of leisure activities. Activities such as reading, playing cards, watching sports and playing board games were not included as there was a high probability that subjects were not leaving the house to perform them. Leaving home included traveling into the community performing tasks such as shopping or going to the
doctor. Leisure activities included going to the movies, going to the concert and dining out. The 8 questions on frequency of leaving home and the 3 questions on leisure activities are listed in Appendix A and represent instrumental activities of daily living. Subjects were able to respond to each question on an ordinal scale which was classified as never, less than once a month, 1-2 times a month, 1-2 times a week or more than twice a week. The reliability and validity of the PARTS/M have been completed by Gray et al. 21, 23

1.1.2.3 Data Analysis and Statistical Considerations

Data collected at both sites (Pittsburgh and Saint Louis) for participants was combined. All analysis was completed using SPSS software (13.0 SPSS, Inc.). To ensure manual and power wheelchair groups were comparable demographics were compared statistically. A student t-test was used for comparing variables that are continuous in nature (group by age and years post injury) and chi-square was used for variables that are categorical (group by gender, level of injury and marital status). The only significant difference found in demographics between individuals who use manual and power wheelchairs was the level of injury. Therefore, four groups were created to control for level of injury and wheelchair use: 1) individuals with paraplegia who use manual wheelchairs (PM), 2) individuals with paraplegia who use power wheelchairs (PP), 3) individuals with tetraplegia who use manual wheelchairs (TM), and 4) individuals with tetraplegia who use power wheelchairs (TP). One participant was removed from the analysis as he used a pushrim-activated power-assisted wheelchair, resulting in a final sample size of 105 subjects. A series of Kruskal-Wallis tests were conducted to examine differences between four groups (PP, PM, TM and TP) on the set of items related to the frequency of leaving home and leisure activities (Appendix A). Kruskal-Wallis test is
appropriate because is a nonparametric test for statistical significance used when testing more than two independent samples on ordinal data. The significance level was set \textit{a priori} at $< 0.05$. To follow significant results, pair wise comparisons between groups were conducted using the Mann-Whitney test. The Bonferroni correction was applied. Since there were six pair wise comparisons for each item, an alpha of $0.05/6$ or $0.008$ was used for each comparison.

1.1.3 RESULTS

1.1.3.1 Subjects

A hundred and six individuals provided informed consent; however, one was excluded as he was using a pushrim-activated power-assisted wheelchair, leaving 105 subjects for final analysis. Forty-nine individuals were from Pittsburgh and 56 were from Saint Louis. There were 84 men and 21 women with a mean age of 41 years ($\pm$ SD 11.37). Seventy six individuals were white, 23 were Black/African American, 3 were Asian/Pacific Islander and 3 classified themselves as other (Mestizo, Hungarian and Hispanic were the specification was provided). The average time post injury was 18 years ($\pm$SD 9.87). There were 41 individuals with tetraplegia, 58 with paraplegia, 3 did not know their injury level and 3 did not respond to the question. Seventy-six subjects used manual wheelchairs, 29 used power wheelchairs. Sixty-one participants used customizable manual wheelchairs, 10 used standard manual wheelchairs, 22 used customizable power wheelchairs, 5 used standard power wheelchairs and 7 were not possible to classify their type of wheelchair. Customizable manual wheelchairs were classified by a weight less than 14 kg (30lb) and have an adjustable axle position. Manual wheelchairs that do not have these features were classified as standard wheelchairs.\textsuperscript{11} Customizable power wheelchairs were the ones with programmable controls that had at least one of the following
features: 1) capable of accommodating advanced seating systems such as tilt-in-space or standing, 2) a suspension system, or 3) a high torque motor and stronger frame. A standard power wheelchair was the one with only programmable controls.\textsuperscript{11}

1.1.3.2 Demographics

The only significant difference found in demographics between individuals who use manual and power wheelchairs was the level of injury (p= 0.00). Out of 58 individuals with paraplegia, eighty-nine percent (n=52) used manual wheelchairs and only 11% (n=6) used power wheelchairs. Out of 41 individuals with tetraplegia, 50% (n=21) used manual wheelchairs and 50% (n=20) used power wheelchairs. Six participants were not possible to classify, either type of wheelchair or level of injury was missing.

1.1.3.3 Frequency of Community Activities

When the four groups (PM, PP, TM and TP) were compared on the set of items related to the frequency of leaving home and leisure activities, significant results were found for four items: going to doctor’s office (p=.00), going to post office (p=.03), going to friend’s home (p=.02) and dining out (p=.01) (see Table 1). Significant differences (at the .008 level) were also found between PM and PP on frequency of visits to a friends home (p=.005) and dining out (p=.004), with a higher frequency for those using manual wheelchairs (see Table 2). Significant differences (at the .008 level) were found between individuals with PM and TP on frequency of visits to a friends home (p=.005), with a higher frequency for those with paraplegia who use manual wheelchairs (see Table 3). In addition, significant differences (at the .008 level) were found between individuals with PP, TP (p=.005) and TM (p=.001) on
frequency of visits to doctor’s office, with a higher frequency for those individuals with paraplegia (see Table 2 & 4).

TABLE 1. Results of Kruskal Wallis Test on Frequency of Community Activities for Four Groups (PP, PP, TM and TP).

<table>
<thead>
<tr>
<th>FREQUENCY COMMUNITY ACTIVITIES</th>
<th>MEAN RANK</th>
<th>P &lt;.05</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping for groceries</td>
<td>55.94</td>
<td>34.83</td>
</tr>
<tr>
<td>Shopping for clothes</td>
<td>54.11</td>
<td>29.33</td>
</tr>
<tr>
<td>Going to pharmacy</td>
<td>52.44</td>
<td>44.00</td>
</tr>
<tr>
<td>Going to bank</td>
<td>55.39</td>
<td>31.42</td>
</tr>
<tr>
<td>Going to doctor’s office</td>
<td>51.71</td>
<td>79.08</td>
</tr>
<tr>
<td>Going to post office</td>
<td>57.38</td>
<td>41.50</td>
</tr>
<tr>
<td>Going to friend’ home</td>
<td>58.67</td>
<td>25.00</td>
</tr>
<tr>
<td>Going to movie</td>
<td>52.29</td>
<td>39.83</td>
</tr>
<tr>
<td>Going to concert</td>
<td>47.88</td>
<td>47.25</td>
</tr>
<tr>
<td>Dine out</td>
<td>54.10</td>
<td>19.25</td>
</tr>
</tbody>
</table>
TABLE 2. Results of Mann-Whitney Test on Items on Frequency of Community Activities for PM, PP and TM.

<table>
<thead>
<tr>
<th>FREQUENCY COMMUNITY ACTIVITIES</th>
<th>MEAN RANK</th>
<th>P&lt;.008</th>
<th>MEAN RANK</th>
<th>P&lt;.008</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Para Manual</td>
<td>Power</td>
<td></td>
<td>Tetra</td>
</tr>
<tr>
<td>Going to doctor’s office</td>
<td>27.81</td>
<td>44.17</td>
<td>0.011</td>
<td>21.75</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>11.79</td>
<td></td>
</tr>
<tr>
<td>Going to post office</td>
<td>30.51</td>
<td>20.75</td>
<td>0.149</td>
<td>14.25</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>13.93</td>
<td></td>
</tr>
<tr>
<td>Going to friend’ home</td>
<td>31.55</td>
<td>11.75</td>
<td><strong>0.005</strong></td>
<td>8.42</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>15.60</td>
<td></td>
</tr>
<tr>
<td>Dine out</td>
<td>31.53</td>
<td>11.92</td>
<td><strong>0.004</strong></td>
<td>7.50</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>15.86</td>
<td></td>
</tr>
</tbody>
</table>

TABLE 3. Results of Mann-Whitney Test on Items on Frequency of Community Activities for PM, TM and TP.

<table>
<thead>
<tr>
<th>FREQUENCY COMMUNITY ACTIVITIES</th>
<th>MEAN RANK</th>
<th>P&lt;.008</th>
<th>MEAN RANK</th>
<th>P&lt;.008</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Para Manual</td>
<td>Tetra</td>
<td></td>
<td>Tetra</td>
</tr>
<tr>
<td>Going to doctor’s office</td>
<td>39.25</td>
<td>31.43</td>
<td>0.080</td>
<td>37.65</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>33.50</td>
<td></td>
</tr>
<tr>
<td>Going to post office</td>
<td>40.31</td>
<td>28.81</td>
<td>0.025</td>
<td>39.57</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>28.53</td>
<td></td>
</tr>
<tr>
<td>Going to friend’ home</td>
<td>39.28</td>
<td>31.36</td>
<td>0.135</td>
<td>40.85</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>25.20</td>
<td></td>
</tr>
<tr>
<td>Dine out</td>
<td>7.50</td>
<td>15.86</td>
<td>0.112</td>
<td>36.26</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>37.13</td>
<td></td>
</tr>
</tbody>
</table>

TABLE 4. Results of Mann-Whitney Test on Items on Frequency of Community Activities for PP, TM and TP.

<table>
<thead>
<tr>
<th>FREQUENCY COMMUNITY ACTIVITIES</th>
<th>MEAN RANK</th>
<th>P&lt;.008</th>
<th>MEAN RANK</th>
<th>P&lt;.008</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Para Power</td>
<td>Tetra</td>
<td></td>
<td>Tetra</td>
</tr>
<tr>
<td>Going to doctor’s office</td>
<td>20.17</td>
<td>11.50</td>
<td><strong>0.005</strong></td>
<td>19.93</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>22.13</td>
<td></td>
</tr>
<tr>
<td>Going to post office</td>
<td>13.50</td>
<td>13.50</td>
<td>1.00</td>
<td>20.83</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>21.18</td>
<td></td>
</tr>
<tr>
<td>Going to friend’ home</td>
<td>11.83</td>
<td>14.00</td>
<td>0.525</td>
<td>23.69</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>18.18</td>
<td></td>
</tr>
<tr>
<td>Dine out</td>
<td>6.83</td>
<td>15.50</td>
<td>0.009</td>
<td>18.62</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>23.50</td>
<td></td>
</tr>
</tbody>
</table>
The data shows a significant difference between individuals with paraplegia who use manual wheelchairs (PM) and individuals with paraplegia who use power wheelchairs (PP) on frequency of visits to a friend’s home (p=.005) and dining out (p=.004), with a higher frequency for those using manual wheelchairs. In addition, significant differences were found between PM and individuals with tetraplegia who use power wheelchairs (TP) referring to frequency of visits to a friend’s home (p=.005), with a higher frequency for those with paraplegia who use manual wheelchairs. Therefore, individuals who use power wheelchairs visit their friends and dine out much less than individuals who use manual wheelchairs. This might be due to the lack of visitable houses and fully accessible restaurants. This is supported by Meyers and colleagues\textsuperscript{24} who demonstrated that friends or relative’s houses and restaurants were places that individuals with disabilities would like to go but are commonly unable. Mclain et al.\textsuperscript{25} indicated that the major obstacles to dining out were lack of accessible parking and restrooms. Only 60\% and 53\% of the 120 sites surveyed provided accessible restrooms and parking, respectively. In a more recent study, inaccessible restrooms were also among the most frequent barriers reported.\textsuperscript{24} Furthermore, manual wheelchairs are much smaller and lighter than power wheelchairs allowing them to be lifted by their friends and family whenever a step is faced. On the other hand, individuals who use power wheelchairs can only go to accessible houses and restaurants, as power wheelchairs are heavier and difficult to be lifted. Some power wheelchairs also require more space for maneuvering, and thus their use is restricted to environments that have wide doors and passageways as well as large areas of clear floor space. Studies have shown that the performance of individuals who use wheelchairs is often influenced by the presence of physical barriers in the environment.\textsuperscript{26} The physical environment
was also reported as a cause of decreased participation of individuals with SCI in the home, community and transportation. Ramps, wider doors, or wheelchair lifts were pointed out by individuals with SCI as equipment that would make their homes completely accessible.29

Another important finding was that significant differences were found between PP and TP (p=.005) on frequency to doctor’s office visits, with a higher frequency for those individuals with paraplegia. That is to say, individuals with tetraplegia reported going to the doctor’s office less frequently than individuals with paraplegia. Controversially, secondary complications such as prevalence and intensity of pain have been shown to be higher in individuals with tetraplegia than in individuals with paraplegia.30 A possible explanation for our findings might be that often, health care facilities are not accessible or do not have the equipment needed to serve people with severe disabilities.31,32 Bockenek et al.33 provides evidence of difficulties experienced by people with disabilities in receiving appropriate and accessible health services. Also, people may be embarrassed because their disability requires them to obtain additional assistance from the staff, requiring them to surrender some of their independence and privacy.33 Nosek and Howland34 also found that difficulties with access to primary and preventive care increased with severity of disability. Sometimes, the staff may not know how to assist a person with a disability,35 causing frustration for both the patient and the staff members. As a result, some people with disabilities only pursue medical attention for emergency or acute conditions, making primary and preventive health care services low priorities.36

In attempting to explain some of the differences found between the four groups (PM, PP, TM and TP), additional analysis were performed on age (p=.072), onset of injury (p=.109), annual income (p=.067), weight problems (p=.133), depression (p=.118), fatigue (p=.057) and
pain (p=.022). Pain was the only variable that was significantly different across groups (p=.022). Participants were able to respond to pain question on an ordinal scale which was classified as never, rarely, off and on and constantly. In order to dichotomize the variable, never and rarely were combined as well as off and on and constantly. A greater number of individuals with paraplegia who use manual wheelchairs (PM) reported more pain (off and on + constantly =39 (PM), 9 (TP), 3 (PP)) compared to individuals with tetraplegia who use power wheelchairs (TP) and individuals with paraplegia who use power wheelchairs (PP). PM is the most active group; it is the group that goes out more frequently to friend’s homes and to dine out, however it is also the one that has reported more pain. To explain this apparently controversial finding we may have to consider the interaction of pain and level of injury. We do not know if pain is limiting their daily activities yet because we have just a one point in time measurement; however their level of injury might allow them greater independence when compared to individuals with tetraplegia. Research has shown that pain, in the long run, can reduce mobility and even hamper individuals from leaving their homes.\textsuperscript{37} Experts have argued that a combination of manual and power wheelchair usage may be a solution for the problem.\textsuperscript{38} The manual wheelchair would still be used in the home and office while the power wheelchair would be used outdoors for long distance travel minimizing the effort needed to propel a manual wheelchair, reducing pain, and this could also decrease total cumulative microtraumas to soft tissue over the years.\textsuperscript{38}

In conclusion, the frequency of community participation in the daily life of individuals with SCI was identified. Individuals that use power wheelchairs visit their friends and dine out much less than individuals that use manual wheelchairs. Individuals with tetraplegia reported going to the doctor’s office less frequently than individuals with paraplegia. In addition,
individuals with paraplegia who use manual wheelchairs were shown to be the most active group and the one that has reported more pain. There are many factors, such as availability of adaptive equipment (type of mobility device), accessibility of the environment, individual’s level of injury and the presence of pain that can limit or facilitate the frequency of participation of individuals with SCI in the community. It is important not only to determine the frequency of community activities but also investigate the limiting or the facilitating factors for community participation. Awareness of these factors could lead health professionals and government authorities to advocate for social policy change in support of individuals with SCI.

1.1.5 STUDY LIMITATION

The study limitations including that the questionnaire, PARTS/M, consisted of a standardized set of questions (closed-ended questions). Therefore, it did not allow respondents to express their own personal viewpoints and in-depth analysis of respondents’ opinions was not possible to establish. Base on that, it was not possible to find the reasons why individuals who use manual wheelchairs go to a friend houses and dine out more often than individuals who use power wheelchairs. The same argument can be made for the difference found between individuals with paraplegia and tetraplegia regarding going to the doctor’s office. Another limitation was that we could not account for the quality of wheelchairs (standard and customized) in the analysis as the majority of the sample was using customized wheelchairs. In addition, controlling for difference between groups regarding level of injury and type of wheelchair, four groups were created (PM, PP, TM and TP) and as a result, sample size and power decreased. There were a small number (n=6) of individuals with paraplegia who use
power wheelchairs compared to the other groups. Furthermore, we did not control for differences in the community accessibility and health factors such as pain, which are likely important factors in determining frequency of community activities. Future studies should incorporate a larger sample size and investigate health and environmental limitations to community participation.

1.1.6 REFERENCE


APPENDIX A

Illustrates the 8 questions and answers related to frequency of leaving home.

<table>
<thead>
<tr>
<th>How often do you do the activity?</th>
<th>Never</th>
<th>Less than once a month</th>
<th>1-2 times a month</th>
<th>1-2 times a week</th>
<th>More than twice a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping for groceries</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping for clothes</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going to the pharmacy</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going to the bank</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Going to the doctor’s office</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Going to the post office</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going to a friend’s home</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

Illustrates the 3 questions and answers related to leisure activities.

<table>
<thead>
<tr>
<th>How often do you do the activity?</th>
<th>Never</th>
<th>Less than once a month</th>
<th>1-2 times a month</th>
<th>1-2 times a week</th>
<th>More than twice a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dine Out</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attend Movies</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Attend Concerts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
1.2 THE EFFECTS OF ENVIRONMENTAL BARRIERS ON DAILY ACTIVITIES OF INDIVIDUALS WITH SPINAL CORD INJURY

1.2.1 INTRODUCTION

The perception of disability has evolved in international circles within the last decade. The World Health Organization’s (WHO) International Classification of Functioning, Disability and Health\textsuperscript{1} (ICF) emphasizes what people do on a daily basis as opposed to what they have the ability to do. Thus, disability has not only been related to physical or mental limitations, but more so, has been considered dysfunction of the interaction between an individual and his environment.\textsuperscript{2} In this framework, the environment is composed of physical and social factors.

The physical factors are defined as having the availability of resources, such as, accessibility of streets, buildings and transportation.\textsuperscript{2} Richards et al.\textsuperscript{3} observed that access to the environment (home and transportation) was positively associated with satisfaction with life. The physical environment was also reported as a cause of decreased participation of individuals with SCI in the home, community and transportation.\textsuperscript{4} In another study by Rimmer et al.,\textsuperscript{5} environmental barriers including insufficient number of curb cuts, inaccessible access routes, and lack of elevators have been reported as factors limiting participation among people with disabilities. Additional factors such as limited access to accessible transportation, cost, and inaccessible exercise facilities have also been noted as barriers to participation for individuals who use a wheelchair.\textsuperscript{6-8}
Social factors are composed by attitudes of others, public priorities and availability of services. Social factors may influence the impact of impairment not only on the limitations in activities, but also on the distress experienced by the individual. Negatives attitudes, limited access to communication and/or resources, limited rights and privileges are considered to be just some of the barriers that interfere with the disabled individual’s potential to realize his/her desired roles. Pierce et al. shows that the public’s lack of understanding of the life of people with disabilities as well as attitudes of others can have a negative impact on activity performance. Persons who perceived themselves as having high levels of social support were more satisfied with their life. Perceived social support (particularly from a spouse) has been considered in several studies as a major predictor of community participation and QoL. In fact, social attitudes were reported as a limiting factor for leaving home and for using transportation.

Availability of services encompasses the individual’s ability to access assistive technology (AT) services. AT has been used by people with disabilities to facilitate the return to as many pre-injury activities as possible. People with spinal cord injury (SCI) rely on AT, especially manual and power wheelchairs to compensate for mobility needs and therefore, accomplish daily activities. Therefore, the success of community participation is affected by both the technology that a person uses in their surrounding environment as much as their physiological impairments. An appropriate matching of the individuals’ needs, their mobility device and environment has to be considered.

The wheelchair service delivery and reimbursement can determine how well the wheelchair facilitates mobility. A good match between the individual, the wheelchair (including wheelchair policy), and a supportive environment should result in a higher subjective quality
of life (QoL). The environmental factors as well as the wheelchair are considered as either facilitators or barriers to participation.\textsuperscript{2,18} Identification of physical and social barriers among individuals with SCI is the first step to reducing such barriers to facilitate community participation and improve QoL. To date, no studies have looked at the interaction of wheelchair type on the physical and social environment and its influence on community participation. Therefore, the evaluation of the effects of both the wheelchair and the environment on daily activities and community participation represent an important area of research.

The overall aim of this study was to investigate the effect of wheelchair type on perceived physical and social barriers in the home and community among individuals with SCI. The specific aims were to: 1) Determine the most common social and physical barriers that individuals with SCI rank as the most limiting for community participation; 2) Determine if differences exist between individuals who use manual and power wheelchairs regarding the frequency of social and physical barriers on community participation and 3) Determine if specific characteristics of the social and physical environment (such as stairs, curb cuts etc.) are reported as facilitators or barriers to participation and if this differs by wheelchair type.

1.2.2 METHODS

1.2.2.1 Participants

Multi-site Institutional Review Board (IRB) approval was obtained prior to initiation of the study. One hundred and six individuals with SCI who use wheelchairs for mobility provided
written informed consent. A written survey that recorded AT usage in daily activities was distributed among clients from Pittsburgh, Pennsylvania and Saint Louis, Missouri. All participants had to be discharged from rehabilitation for at least one year and live in a community setting. Pittsburgh subjects were recruited through research centers and through a specialized AT clinic that uses a client centered multi-disciplinary team approach. Saint Louis subjects were recruited from research centers and rehabilitation centers. In both locations subjects were recruited via flyer or approached by clinical study coordinators, who asked if they were interested in participating.

### 1.2.2.2 Questionnaire

The questionnaire used in this study was the Facilitators and Barriers Survey/Mobility (FABS/M). The FABS/M consist of 191 items that probe the situational specificity of activity limitations, request information on the type of assistive technology used in activities, and ask the respondents to categorize aspects of their environments as barriers or facilitators to participation. The reliability and validity of the FABS/M have been completed by Gray et al.\(^\text{19}\) but this paper shows the scores in a different manner.

For the purposes of this study, questions asked included items related to frequency of social and physical barriers encountered in the home and community, as well as questions related to the influence of the environment (such as stairs, ramps, curb cuts etc) in activities specific to the home and community. All questions and the options of answers have been provided in Appendix B and C. It is important to note that if the person did not do a specific activity, for example, was not employed or did not go to movie theater, those questions were not answered.
1.2.2.3 Data Analysis and Statistical Considerations

Data collected at both sites (Pittsburgh and Saint Louis) for participants was combined. To ensure manual and power wheelchair groups were comparable demographics were compared statistically. All analysis was completed using SPSS software (13.0 SPSS, Inc.). A student t-test was used for comparing for variables that are continuous in nature (group by age and years post injury) and chi-square was used for variables that are categorical (group by gender, level of injury, marital status and location). The only significant difference found in demographics between individuals who use manual and power wheelchairs was the level of injury. Therefore, four groups were created to control for level of injury: 1) individuals with paraplegia who use manual wheelchairs (PM), 2) individuals with paraplegia who use power wheelchairs (PP), 3) individuals with tetraplegia who use manual wheelchairs (TM), and 4) individuals with tetraplegia who use power wheelchairs (TP). One participant was removed from the analysis as he used a pushrim-activated power-assisted wheelchair. Therefore, 105 individuals were included in the analysis.

The frequency of physical and social barriers encountered in the home and community was calculated by the percentage of time that each factor was perceived as a limitation. Percentages were reported for all the participants (who marked that they were performing the tasks) as well as for the four groups (individuals with paraplegia who use manual wheelchairs (PM), individuals with paraplegia who use power wheelchairs (PP), individuals with tetraplegia who use manual wheelchairs (TM) & individuals with tetraplegia who use power wheelchairs (TP)). The differences of physical and social barriers encountered in the home and community for the four groups (PM, PP, TM and TP) were examined for each task using a chi-square test or Fishers Exact if appropriate. The significance level was set a priori at < 0.05.
Regarding the questions related to the influence of the environment (stair, curb cuts, ramps etc.) in activities within the home and community, it was felt that analyzing individual questions from the tool would have limited utility, and therefore summary scores were developed to encompass the entire set of questions asked in one content area. Table 5 illustrates an example of the question with corresponding score above each answer. Each answer of “How much” was scored as the following: Help a lot = +2, help some = +1, limit some = -1 and limit a lot = -2. Each answer of “How often” was also scored as the following: Daily= 4, Weekly= 3, Monthly= 2 and Less than monthly= 1. No influence = 0. For example, if the person checked “help a lot” and “daily”, +2 have to be multiplied by 4 and the final score is equal to +8, meaning that curb cuts help a lot daily. If the person checked “limit a lot” and “Daily”, -2 have to be multiplied by 4 and the final score is equal to -8, meaning that curb cuts limit a lot daily. Summary scores were derived and equate to positive or negative values indicating help or hinderance, respectively. Table 6 show the scoring algorithm which was created.

Table 5. Illustrates an example (with scores above and below for each answer) of the influence of the environment question in activities within the home and community.

<table>
<thead>
<tr>
<th>1. Curb Cuts</th>
<th>Yes</th>
<th>+2</th>
<th>Help a lot</th>
<th>Help some</th>
<th>Limit some</th>
<th>Limit a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No</td>
<td></td>
<td>Daily</td>
<td>Weekly</td>
<td>Monthly</td>
<td>Less than monthly</td>
</tr>
<tr>
<td></td>
<td></td>
<td>+1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>-1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>-2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 6. Scoring Explanation for the Influence of Environment on Participation in Activities.

<table>
<thead>
<tr>
<th>Assignment to “How much?”</th>
<th>Assignment to “How often?”</th>
<th>Total Influence score = “How much” X “How often”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helps a lot = +2</td>
<td>Daily = 4</td>
<td>If limit a lot daily Score = (-2) (4) = -8</td>
</tr>
<tr>
<td>Helps some = +1</td>
<td>Weekly = 3</td>
<td>If help a lot daily Score = (+2) (4) = +8</td>
</tr>
<tr>
<td>Limits some = -1</td>
<td>Monthly = 2</td>
<td></td>
</tr>
<tr>
<td>Limits a lot = -2</td>
<td>Less than monthly = 1</td>
<td></td>
</tr>
<tr>
<td>No influence = 0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

A one-way ANOVA was completed to examine differences in scores between four groups (PM, PP, TM and TP) on the set of items related to the influence of the physical environment on participation in activities within the home and community (See Appendix C). Furthermore, an independent t-test was completed to determine if there were differences between Pittsburgh and Saint Louis on the influence of the environment within activities in the home and community. The significance level is set at $p < 0.05$.

1.2.3 RESULTS

1.2.3.1 Participants

A hundred and six individuals provided informed consent; however, one was excluded as he was using a pushrim-activated power-assisted wheelchair, leaving 105 subjects for final analysis. Forty-nine individuals were from Pittsburgh and 56 were from Saint Louis. There were 84 men and 21 women with a mean age of 41 years ($\pm$ SD 11.37). Seventy six individuals were white, 23 were Black/African American, 3 were Asian/Pacific Islander and 3 classified
themselves as other (Mestizo, Hungarian and Hispanic were the specification provided). The average time post injury was 18 years ($\pm SD$ 9.87). There were 41 individuals with tetraplegia, 58 with paraplegia, 3 did not know their injury level and 3 did not respond to the question. Seventy-six subjects used manual wheelchairs, 29 used power wheelchairs. Sixty-one participants used customizable manual wheelchairs, 10 used standard manual wheelchairs, 22 used customizable power wheelchairs, 5 used standard power wheelchairs and 7 were not able to classify their type of wheelchair. Customizable manual wheelchairs were classified by a weight less than 14 kg (30lb) and have an adjustable axle position. Manual wheelchairs that do not have these features were classified as standard wheelchairs.\textsuperscript{10} Customizable power wheelchairs were defined as ones with programmable controls that had at least one of the features: 1) capable of accommodating advanced seating systems such as tilt-in-space or standing, 2) a suspension system, or 3) a high torque motor and stronger frame. A standard power wheelchair was defined as one with only programmable control.\textsuperscript{10}

1.2.3.2 Demographics

The only significant difference found in demographics between individuals who use manual and power wheelchairs was the level of injury ($p= 0.00$). Out of 58 individuals with paraplegia, eighty-nine percent ($n=52$) used manual wheelchairs and only 11% ($n=6$) used power wheelchairs. Out of 41 individuals with tetraplegia, 50% ($n=21$) used manual wheelchairs and 50% ($n=20$) used power wheelchairs. Six participants were not possible to classified, as information on type of wheelchair or level of injury was not provided. No
difference was found in demographics between manual and power wheelchair users from Pittsburgh and Saint Louis.

1.2.3.3 Perceived Physical and Social barriers in the home and community

➢ All Participants

Percentages of physical and social barriers encountered in the home and community were reported for all the participants, who marked that they were performing the tasks. Sample size changes as depending on questions. The data showed that the kitchen (28%; N=105) was considered the most limiting place in the residence. Accessibility of shelves and freezers (54%; N=85) was the most common physical barrier limiting participation in the grocery store. Waiting rooms and exam rooms (16%; N=105) was the most limiting physical barrier in the doctor’s office. In addition, tables too close together (59%; N=98) was the most common physical barrier limiting participation in restaurants followed by entrance (55%) and height of counters, tables and booths (48%). In the movie theaters, stadium seating (45%; N=84) was pointed out as the most common physical barrier limiting participation. Width of aisles (64%; N=98) was the most common physical barrier limiting participation in clothing stores followed by height of clothing racks (46%). Lack of paved paths (68%; N=98) was the most limiting factor to participation in the parks (see Table 7-16). Tables 7 to 16 illustrate the relative percentages of social and physical barriers within the home and community for all participants.
Four Groups (PM, PP, TM & TP)

The data revealed significant differences between the four groups (PM, PP, TM and TP) regarding the accessibility of place of employment (Table 8; \( p=0.026 \)). A greater number of individuals with TP (33%) reported that lack of personal assistance (PAS) as a perceived social barrier that limits their participation in their place of employment when compared to individuals with PM, PP and TM (0%). In addition, a greater number of individuals with TM (86%) and PM (41%) reported that the place of employment does not limit them (Table 8; \( p=0.048 \)) compared to PP (0%) and TP (22%). Therefore, individuals that use manual wheelchairs have less limitation in the place of employment when compared to those that use power wheelchairs.

Significant differences was found between the four groups (PM, PP, TM and TP) regarding the accessibility of grocery store (Table 9; \( p=0.027 \)), with higher perceived limitations of those using power wheelchairs. A greater number of individuals with PP (60%) and TP (25%) indicated that lack of personal assistance as a perceived social barrier that limits their participation in the grocery store when compared to individuals with PM (11%) and TM (6%). Tables 7 to 16 illustrate the relative percentages of social and physical barriers within the home and community by the four groups (PM, PP, TM and TP).
Table 7. Illustrates the percentages of social and physical barriers in the residence.

<table>
<thead>
<tr>
<th>What about your residence limits you?</th>
<th>% of participants (n=105)</th>
<th>Four Groups (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
<td>15</td>
<td>19</td>
</tr>
<tr>
<td>Bathroom</td>
<td>23</td>
<td>12</td>
</tr>
<tr>
<td>Kitchen</td>
<td>28</td>
<td>23</td>
</tr>
<tr>
<td>Lack Personal finances</td>
<td>26</td>
<td>23</td>
</tr>
<tr>
<td>Lack Personal assistance</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>Parking</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Lack Special equipment</td>
<td>17</td>
<td>19</td>
</tr>
<tr>
<td>Not limited</td>
<td>37</td>
<td>39</td>
</tr>
</tbody>
</table>

Table 8. Illustrate the percentages of social and physical barriers in the place of employment. Out of 105 participants, only 40 were employed, but of those two were unable to be classified into one of the four groups. Fifty percent (n=53) were not employed and 11% (n=12) did not respond to the question. Two participants were not able to be classified into the four groups (either the level of injury was missing or the type of wheelchair).

<table>
<thead>
<tr>
<th>What about your place of employment limits you?</th>
<th>% of participants (n=38)</th>
<th>Four Groups (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Workstation</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Bathroom</td>
<td>15</td>
<td>23</td>
</tr>
<tr>
<td>Parking</td>
<td>17</td>
<td>13</td>
</tr>
<tr>
<td>Lack of child care</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Lack of personal assistance</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Lack of special equipment</td>
<td>12</td>
<td>14</td>
</tr>
<tr>
<td>Not limited</td>
<td>45</td>
<td>41</td>
</tr>
</tbody>
</table>

* p-value <0.05

Table 9. Illustrates the percentages of social and physical barriers in the grocery store. Out of 105 participants, 85 shop for grocery. Fourteen percent (n=15) do not shop for grocery and 5% (n=5) did not respond to the question. Four participants were not able to be classified into the four groups (either the level of injury was missing or the type of wheelchair).

<table>
<thead>
<tr>
<th>What about your grocery store limits you?</th>
<th>% of participants (n=85)</th>
<th>Four Groups (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Accessibility shelves and freezers</td>
<td>54</td>
<td>58</td>
</tr>
<tr>
<td>Lack of scooter/wheelchair at the store</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lack of personal finances</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Parking</td>
<td>26</td>
<td>27</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Lack of personal assistance*</td>
<td>15</td>
<td>11</td>
</tr>
<tr>
<td>Lack of child care</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Table 10. Illustrates the percentages of social and physical barriers in the doctor's office.

<table>
<thead>
<tr>
<th>What about your doctor's office limits you?</th>
<th>% of participants (n=105)</th>
<th>Para Manual (N=52)</th>
<th>Para Power (N=6)</th>
<th>Tetra Manual (N=20)</th>
<th>Tetra Power (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
<td>13</td>
<td>6</td>
<td>16</td>
<td>14</td>
<td>25</td>
</tr>
<tr>
<td>Lack of personal assistance</td>
<td>5</td>
<td>8</td>
<td>0</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Lack of insurance</td>
<td>4</td>
<td>6</td>
<td>0</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Lack of child care</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lack of personal finances</td>
<td>4</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Waiting rooms &amp; exam rooms</td>
<td>18</td>
<td>19</td>
<td>16</td>
<td>5</td>
<td>20</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>5</td>
<td>6</td>
<td>0</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Parking</td>
<td>13</td>
<td>12</td>
<td>16</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Lack of special equipment</td>
<td>13</td>
<td>12</td>
<td>0</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Not limited</td>
<td>48</td>
<td>50</td>
<td>0</td>
<td>57</td>
<td>45</td>
</tr>
</tbody>
</table>

*p-value <0.05

Table 11. Illustrate the percentages of social and physical barriers in the religious institution.

Out of 105 participants, 60 go to a religious institution. Thirty three percent (n=35) do not go to religious institution and 9% (n=10) did not respond to the question. Four participants were not able to be classified into the four groups (either the level of injury was missing or the type of wheelchair).

<table>
<thead>
<tr>
<th>What about your religious institution limits you?</th>
<th>% of participants (n=60)</th>
<th>Para Manual (N=29)</th>
<th>Para Power (N=5)</th>
<th>Tetra Manual (N=8)</th>
<th>Tetra Power (N=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
<td>17</td>
<td>17</td>
<td>20</td>
<td>13</td>
<td>21</td>
</tr>
<tr>
<td>Seating</td>
<td>15</td>
<td>24</td>
<td>0</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>Lack of personal finances</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Parking</td>
<td>15</td>
<td>21</td>
<td>20</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>Lack of child care</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>8</td>
<td>14</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Lack of personal assistance</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lack of special equipment</td>
<td>8</td>
<td>14</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Not limited</td>
<td>35</td>
<td>38</td>
<td>0</td>
<td>50</td>
<td>21</td>
</tr>
</tbody>
</table>

Table 12. Illustrates the percentages of social and physical barriers in restaurants.

Out of 105 participants, 98 go to restaurants. Four percent (n=4) do not go to restaurants and 3% (n=3) did not respond to the question. Five participants were not able to be classified into the four groups (either the level of injury was missing or the type of wheelchair).

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
<td>55</td>
<td>40</td>
<td>33</td>
<td>48</td>
<td>58</td>
</tr>
<tr>
<td>Lack of personal finances</td>
<td>15</td>
<td>17</td>
<td>33</td>
<td>14</td>
<td>11</td>
</tr>
<tr>
<td>Tables too close together</td>
<td>59</td>
<td>59</td>
<td>33</td>
<td>57</td>
<td>74</td>
</tr>
<tr>
<td>Parking</td>
<td>39</td>
<td>42</td>
<td>33</td>
<td>33</td>
<td>42</td>
</tr>
<tr>
<td>Lack of child care</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>8</td>
<td>8</td>
<td>0</td>
<td>10</td>
<td>11</td>
</tr>
</tbody>
</table>
Height of counters, tables and booths | 48 | 50 | 0 | 48 | 58
Lack of personal assistance | 8 | 8 | 0 | 0 | 16
Lack of special equipment | 6 | 8 | 0 | 0 | 5
Not limited | 9 | 6 | 0 | 10 | 16

Table 13. Illustrates the percentages of social and physical barriers in movie theaters. Out of 105 participants, 84 go to movie theaters. Sixteen percent (n=17) do not go to movie theaters and 4% (n=4) did not respond to the question. Four participants were not able to be classified into the four groups (either the level of injury was missing or the type of wheelchair).

<table>
<thead>
<tr>
<th>What about movie theaters limits you?</th>
<th>% of participants (N=84)</th>
<th>Para Manual (N=41)</th>
<th>Para Power (N=4)</th>
<th>Tetra Manual (N=17)</th>
<th>Tetra Power (N=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
<td>18</td>
<td>17</td>
<td>0</td>
<td>28</td>
<td>17</td>
</tr>
<tr>
<td>Stadium seating</td>
<td>45</td>
<td>49</td>
<td>25</td>
<td>39</td>
<td>50</td>
</tr>
<tr>
<td>Lack of personal finances</td>
<td>13</td>
<td>10</td>
<td>25</td>
<td>17</td>
<td>11</td>
</tr>
<tr>
<td>Parking</td>
<td>19</td>
<td>17</td>
<td>0</td>
<td>11</td>
<td>28</td>
</tr>
<tr>
<td>Lack of child care</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>11</td>
<td>7</td>
<td>25</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Lack of personal assistance</td>
<td>5</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Lack of special equipment</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Not limited</td>
<td>29</td>
<td>24</td>
<td>0</td>
<td>33</td>
<td>39</td>
</tr>
</tbody>
</table>

Table 14. Illustrate the percentages of social and physical barriers in shopping malls. Out of 105 participants, 100 go to shopping malls. Three percent (n=3) do not go to shopping malls and 2% (n=2) did not respond to the question. Five participants were not able to be classified into the four groups (either the level of injury was missing or the type of wheelchair).

<table>
<thead>
<tr>
<th>What about shopping malls limits you?</th>
<th>% of participants (N=100)</th>
<th>Para Manual (N=49)</th>
<th>Para Power (N=6)</th>
<th>Tetra Manual (N=20)</th>
<th>Tetra Power (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
<td>17</td>
<td>18</td>
<td>17</td>
<td>24</td>
<td>10</td>
</tr>
<tr>
<td>Lack of personal finances</td>
<td>14</td>
<td>12</td>
<td>33</td>
<td>19</td>
<td>10</td>
</tr>
<tr>
<td>Parking</td>
<td>26</td>
<td>33</td>
<td>17</td>
<td>14</td>
<td>25</td>
</tr>
<tr>
<td>Lack of child care</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>8</td>
<td>6</td>
<td>0</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td>Lack of personal assistance</td>
<td>10</td>
<td>12</td>
<td>0</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Lack of special equipment</td>
<td>5</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Not limited</td>
<td>42</td>
<td>37</td>
<td>0</td>
<td>52</td>
<td>50</td>
</tr>
</tbody>
</table>

Table 15. Illustrate the percentages of social and physical barriers in clothing stores. Out of 105 participants, 98 go to clothing stores. Four percent (n=4) do not go to clothing stores and 4 % (n=4) did not respond the question. Five participants were not able to be classified into the four groups (either the level of injury was missing or the type of wheelchair).

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
<td>21</td>
<td>20</td>
<td>16</td>
<td>21</td>
<td>25</td>
</tr>
<tr>
<td>Lack of personal finances</td>
<td>16</td>
<td>20</td>
<td>33</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Width of aisles</td>
<td>64</td>
<td>67</td>
<td>33</td>
<td>58</td>
<td>70</td>
</tr>
<tr>
<td>Parking</td>
<td>21</td>
<td>20</td>
<td>0</td>
<td>21</td>
<td>25</td>
</tr>
<tr>
<td>Height of clothing racks</td>
<td>46</td>
<td>55</td>
<td>16</td>
<td>42</td>
<td>35</td>
</tr>
<tr>
<td>Lack of child care</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>10</td>
<td>10</td>
<td>0</td>
<td>5</td>
<td>10</td>
</tr>
</tbody>
</table>
Lack of personal assistance 10 0 11 10
Lack of special equipment 5 6 5 5
Not limited 16 12 21 25

Table 16. Illustrates the percentages of social and physical barriers in parks. Out of 105 participants, 98 go to parks. Three percent (n=3) do not go to parks and 4 % (n=4) did not respond to the question. Six participants were not able to be classified into the four groups (either the level of injury was missing or the type of wheelchair).

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of paved paths</td>
<td>68</td>
<td>74</td>
<td>33</td>
<td>58</td>
<td>68</td>
</tr>
<tr>
<td>Picnic areas</td>
<td>26</td>
<td>27</td>
<td>16</td>
<td>26</td>
<td>32</td>
</tr>
<tr>
<td>Lack of personal finances</td>
<td>13</td>
<td>10</td>
<td>33</td>
<td>21</td>
<td>11</td>
</tr>
<tr>
<td>Parking</td>
<td>24</td>
<td>29</td>
<td>0</td>
<td>26</td>
<td>26</td>
</tr>
<tr>
<td>Lack of child care</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>12</td>
<td>8</td>
<td>16</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td>Lack of personal assistance</td>
<td>7</td>
<td>8</td>
<td>0</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Lack of special equipment</td>
<td>7</td>
<td>8</td>
<td>16</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Not limited</td>
<td>15</td>
<td>14</td>
<td>0</td>
<td>21</td>
<td>16</td>
</tr>
</tbody>
</table>

1.2.3.4 Perceived influence of the physical environment on participation in activities within the home and community

➢ All Participants

The influence of the physical environment on participation was a score derived from 8 home and 10 community questions. Summary scores were derived and equate to positive or negative values indicating help or hinderance, respectively. The data revealed that doors (62%) have the most positive influence on participation in activities at home, followed by ramps (59%) and room temperatures (45%). On the other hand, stairs (38%) had the most negative influence (See Table 17). In activities within the community, curb cuts (84%) and ramps (84%) had the most positive influence, followed by paved surfaces (79%), flat terrain (76%) and elevator (75%). In contrast, winter weather (85%) had the most negative influence, followed by rain (73%), crowds (60%) and gravel surfaces (57%) (See Table 18). A significant difference was found between Pittsburgh and Saint Louis regarding elevators (p=.013) and flat terrain (p=.007). Individuals from Pittsburgh reported that elevators (score = 5) and flat terrain (score=6) have higher influence on their
community participation when compared to individuals from Saint Louis (elevator score = 3 and flat terrain score = 4).

- **Four Groups (PM, PP, TM & TP)**

  No significant difference was found between the four groups regarding the influence of the physical environment on participation in activities within the home and community.

Table 17. Percentages of influence of the physical environment on participation in activities within the home.

<table>
<thead>
<tr>
<th>IN YOUR HOME, HOW MUCH AND HOW OFTEN, DO THE FOLLOWING INFLUENCE YOUR PARTICIPATION IN ACTIVITIES?</th>
<th>% OF PARTICIPANTS (N=105)</th>
<th>MEAN (SD) (RANGE = -8 TO 8*)</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stairs</td>
<td>38</td>
<td>-4.30 (4.01)</td>
<td>-2.0 (1.41)</td>
<td>-5.50 (3.20)</td>
</tr>
<tr>
<td>Ramps</td>
<td>59</td>
<td>5.73 (4.89)</td>
<td>8.00 (.00)</td>
<td>6.61 (3.40)</td>
</tr>
<tr>
<td>Doors</td>
<td>62</td>
<td>3.71 (5.52)</td>
<td>8.00 (.00)</td>
<td>5.06 (5.54)</td>
</tr>
<tr>
<td>Carpets</td>
<td>33</td>
<td>-2.6 (4.97)</td>
<td>8.00 (.00)</td>
<td>-2.85 (5.01)</td>
</tr>
<tr>
<td>Hardwood</td>
<td>33</td>
<td>6.71 (3.26)</td>
<td>8.00 (.00)</td>
<td>7.86 (.378)</td>
</tr>
<tr>
<td>Handrails</td>
<td>16</td>
<td>5.67 (2.39)</td>
<td>8.00 (.00)</td>
<td>8.00 (.00)</td>
</tr>
<tr>
<td>Adapted Computer</td>
<td>19</td>
<td>8.00 (.00)</td>
<td>00 (00)</td>
<td>8.00 (.00)</td>
</tr>
<tr>
<td>Room Temperatures</td>
<td>45</td>
<td>4.41 (4.63)</td>
<td>8.00 (.00)</td>
<td>6.27 (2.57)</td>
</tr>
</tbody>
</table>

*If limit a lot daily Score = -8  
*If help a lot daily Score = +8
Table 18. Illustrate the percentages of influence of the physical environment on participation in activities within the community.

<table>
<thead>
<tr>
<th>IN YOUR COMMUNITY, HOW MUCH AND HOW OFTEN, DO THE FOLLOWING INFLUENCE YOUR PARTICIPATION IN ACTIVITIES?</th>
<th>% OF PARTICIPANTS (N=105)</th>
<th>MEAN (SD) (RANGE = -8 TO 8*)</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Curb cuts</td>
<td>84</td>
<td>5.42 (4.11)</td>
<td>7.00 (1.15)</td>
<td>3.50 (5.76)</td>
</tr>
<tr>
<td>Ramps</td>
<td>84</td>
<td>5.26 (4.23)</td>
<td>8.00 (.00)</td>
<td>4.78 (4.74)</td>
</tr>
<tr>
<td>Elevators</td>
<td>75</td>
<td>6.25 (3.37)</td>
<td>7.00 (1.73)</td>
<td>4.82 (4.34)</td>
</tr>
<tr>
<td>Flat terrain</td>
<td>76</td>
<td>6.82 (2.87)</td>
<td>8.00 (.00)</td>
<td>6.86 (3.03)</td>
</tr>
<tr>
<td>Gravel surfaces</td>
<td>57</td>
<td>-2.88 (4.21)</td>
<td>-2.50 (1.2)</td>
<td>-2.10 (2.37)</td>
</tr>
<tr>
<td>Paved surfaces</td>
<td>79</td>
<td>6.67 (3.56)</td>
<td>8.00 (.00)</td>
<td>7.00 (2.39)</td>
</tr>
<tr>
<td>Summer weather (heat and humidity)</td>
<td>74</td>
<td>-68 (5.78)</td>
<td>1.25 (8.05)</td>
<td>2.53 (5.28)</td>
</tr>
<tr>
<td>Winter weather (ice and snow)</td>
<td>85</td>
<td>-3.26 (4.69)</td>
<td>-3.33 (1.75)</td>
<td>-4.82 (2.45)</td>
</tr>
<tr>
<td>Rain</td>
<td>73</td>
<td>-1.68 (3.98)</td>
<td>-3.00 (2.64)</td>
<td>-3.20 (1.85)</td>
</tr>
<tr>
<td>Crowds</td>
<td>60</td>
<td>-2.44 (3.47)</td>
<td>-1.50 (.70)</td>
<td>-2.06 (1.98)</td>
</tr>
</tbody>
</table>

*If limit a lot daily Score = -8
*If help a lot daily Score = +8

1.2.4 DISCUSSION

The data shows significant difference between the four groups (individuals with paraplegia who use manual wheelchairs (PM), individuals with paraplegia who use power wheelchairs (PP), individuals with tetraplegia who use manual wheelchairs (TM) and individuals with tetraplegia who use power wheelchairs (TP)) regarding the perceived accessibility of place of employment (Table 8; p=0.026). A greater number of individuals with TP (33%) reported lack
of personal assistance as a perceived social barrier that limits their participation in their place of employment when compared to those with PM, PP and TM (0%). Individuals with tetraplegia who use power wheelchairs already have, in general, a higher level of injury causing them to have a greater need for assistance in their activities of daily living. This might be a reason why we have found a statistical difference between groups regarding personal assistance in their work environment. Even though they have the required education, experience and expertise to perform their job, they may be unable to perform nonessential job functions (e.g., reach materials on a high shelf, go to the restroom, open doors) without assistance. Personal assistance is commonly used to compensate upper extremity functions\textsuperscript{20} allowing people with severe physical or health impairments to participate more fully in community settings and activities, including employment.\textsuperscript{21} The American with Disability Act (Title I) states that it is a Federal civil right to require employers to assist qualified individuals with disabilities to overcome barriers in their work environment that may result in functional limitations.\textsuperscript{22} For many people with disabilities, personal assistance has been proven to be critical for workplace functioning \textsuperscript{23} and can make a critical difference in adjustment to SCI and the ability to live independently.\textsuperscript{20}

Our study also showed that a greater number of individuals with TM (86%) and PM (41%) reported that the place of employment does not limit them (Table 8; p=0.048) compared to PP (0%) and TP (22%). That is to say, individuals that use manual wheelchairs have less limitation in the place of employment when compared to those that use power wheelchairs. In addition, significant differences were found between the four groups (PM, PP, TM and TP) regarding the accessibility of grocery store (Table 9; p=.027), with higher perceived limitations of those using power wheelchairs. A greater number of individuals with PP (60%) and TP (25%)
indicated lack of personal assistance as a perceived social barrier that limits their participation in the grocery store when compared to individuals with PM (11%) and TM (6%). Therefore, individuals who use power wheelchairs ask for personal assistance more frequently in the grocery stores when compared to individuals that use manual wheelchairs. An important factor to be considered is that it is common for a person with tetraplegia, particularly one who is several years post injury, to move from a manual wheelchair to a powered mobility device. Reasons for this transition include weight gain, upper extremity injuries and pain from overuse and overall decreased physical capacity. This could also be applied to individuals with paraplegia that have shifted from a manual to a power wheelchair. Therefore, individuals who use power wheelchairs, regardless of their injury level, might be generally more limited in upper extremity strength and function than persons who use manual ones and as a result, they have to ask more frequently for personal assistance in the grocery stores.

Another possible explanation for our results might be that most public environments are not yet adequate for power wheelchairs. This is due to their size, as they require more space for maneuvering, and are restricted to environments that have wide doors and passageways as well as large areas of clear floor space. Consequently, individuals that use power wheelchairs in their place of employment or in grocery stores would be restricted to environments with appropriate clearance and as a result, they would need to request for assistance to perform specific tasks where they are not able to reach.

Progress made over the years to advance technology and improve access to buildings may have not been sufficient. Although the majority of businesses and grocery stores are considered accessible overall, in fact, they are not truly accessible if small tasks or subtasks are examined. Interestingly, our study showed that accessibility of shelves and freezers was the most common
physical barrier limiting participation in the grocery store. A seat elevator may help individuals with limited reaching abilities access objects in higher surfaces within their home, work, school and community, thus improving their independence and decreasing their dependence on other.

In our study, out of 8 individuals who use power wheelchairs who have reported that accessibility of shelves and freezers limit their participation in the grocery stores; just one had a seat elevator in his chair. Even though, seat elevators could increase someone’s function and participation in meaningful activities, they are not seen as medically necessary and have been constantly denied by insurance companies. We have also found that waiting rooms and exam rooms were the most limiting physical barrier in the doctor’s office. A significant amount of people with disabilities are experiencing difficulty accessing adequate and appropriate primary healthcare services. Tables too close together and width of aisles were the most common physical barriers limiting participation in restaurants and clothing stores respectively. This difficulty in negotiating aisles between tables and table knee clearance were reported by McClain and colleagues as common physical barriers in restaurants. Richards et al. reported that environmental access increases the likelihood that a person with SCI will engage in a variety of meaningful activities. Individuals with disabilities should be involved as part of the team for improving accessibility and recommending additional modifications as they are an excellent resource based on their life experience and daily difficulties. Thus, all tasks that an individual with a disability could perform should be taken into consideration when planning for accessible environments. Universal design may be a solution for accessibility issues because it integrates the needs of individuals with a disability with the basic concept of the design. Universal design makes a place for people with disabilities alongside everyone else. It acknowledges disability, aging and other differences as a part of everyday life.
In recent years architectural standards and laws have focused on making environments more accessible to individuals with disabilities. Also, wheelchairs have had an enormous leap in technology making them lighter, faster, more comfortable and easier to maneuver. In spite of this, we have found in our study several accessibility issues that must be improved. To do this we must also take into consideration other factors as the presence of co-morbidities, psychological condition, and presence of family support and economical status of these individuals. All these factors interact and have an impact in participation in community life and must be targeted in future studies.

1.2.5 STUDY LIMITATION

One of the study limitations is that the questionnaire, FABS/M, is a structured survey, which subjects could completed with no pre-established time constraints. The average time to complete the survey was approximately 1 to 1 ½. Therefore, subjects may become tired during the completion of the survey, affecting their response. In addition, the questionnaire consisted of a standardized set of questions (closed-ended questions), that does not allow respondents to express their own personal viewpoints and in-depth analysis of respondents’ opinions was not possible to establish. Because of these limitations, we were not able to establish further details (for example, if the person checked kitchen we did not know where exactly in the kitchen he or she experience a barrier to participation) of the physical and social barriers that individuals with SCI encounter in their home and community. Also, we could not account for the quality of the wheelchairs (standard and customized) in the analysis as the majority of the sample was using customized wheelchairs. In addition, in order to control the difference between groups
regarding level of injury and type of wheelchair, four groups were created (PM, PP, TM and TP) and as a result, sample size and power decreased. There were a small number (n=6) of individuals with paraplegia who use power wheelchairs compared to the other groups. Future studies should incorporate a larger sample size and investigate in more detail the physical and social environmental limitations to community participation.

1.2.6 REFERENCE


18. Gray DB, Hendershot GE. The ICIDH-2: developments for a new era of outcomes 

19. Hollingsworth HH, Gray DB, Morgan KA: Participation and Environment 
    Measurement System: PARTS and FABS. Annual Conference, American Public Health 

20. Verbrugge LM, Rennert C, Madans JH. The great efficacy of personal and equipment 

21. Strobel W, McDonough JT. Workplace personal assistance service and assistive 

22. Smith A. Americans with Disabilities Act: ADA Compliance Guide. Tampa, Florida: 
    Thompson Publishing Group, 1999.

23. Nosek MA, Howland CA. Breast Personal assistance services: a review of the literature 


29. Schmeler, MR, Kelleher A, Cooper RA, Cooper R. Show me the money. Advance for Directors in Rehabil. 2003;31-33.


APPENDIX B

Illustrates 10 questions related to the frequency of social and physical barriers on community participation

1. What about your residence limits you? (Check all that apply.)

<table>
<thead>
<tr>
<th>Not Limited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

2. What about your place of employment limits you? (Check all that apply.)

<table>
<thead>
<tr>
<th>Not Limited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

3. What about your grocery store limits you? (Check all that apply.)

<table>
<thead>
<tr>
<th>Not Limited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
3. What about **restaurants** limits you?  (Check all that apply.)

<table>
<thead>
<tr>
<th>Not Limited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
</tr>
<tr>
<td>Lack of personal assistance</td>
</tr>
<tr>
<td>Tables too close together</td>
</tr>
<tr>
<td>Lack of special equipment</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

4. What about **movie theaters** limits you?  (Check all that apply.)

<table>
<thead>
<tr>
<th>Not Limited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
</tr>
<tr>
<td>Lack of personal finances</td>
</tr>
<tr>
<td>Lack of child care</td>
</tr>
<tr>
<td>Lack of transportation</td>
</tr>
<tr>
<td>Lack of special equipment</td>
</tr>
</tbody>
</table>

5. What about **shopping malls** limits you?  (Check all that apply.)

<table>
<thead>
<tr>
<th>Not Limited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
</tr>
<tr>
<td>Lack of personal assistance</td>
</tr>
<tr>
<td>Lack of transportation</td>
</tr>
<tr>
<td>Lack of special equipment</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

6. What about **clothing stores** limits you?  (Check all that apply.)

<table>
<thead>
<tr>
<th>Not Limited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrance</td>
</tr>
<tr>
<td>Lack of transportation</td>
</tr>
<tr>
<td>Lack of personal assistance</td>
</tr>
<tr>
<td>Height of clothing racks</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
7. What about public parks limits you? (Check all that apply.)

- Lack of paved paths
- Picnic areas
- Parking
- Lack of personal finances
- Lack of child care
- Lack of special equipment

What equipment would be helpful?

______________________________
APPENDIX C

Illustrates 8 questions related to the physical environment influence participation in activities within the home; 10 questions related to the physical environment influence participation in activities within the community.

The following items relate to your HOME environment and to devices that may influence how you move around and carry out activities. Please mark the choice that is closest to your experience.

In your **home**, do the following influence your participation in activities?

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Stairs</td>
<td>□ Yes</td>
<td>□ No</td>
<td>□ Help a lot</td>
<td>□ Help some</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>□ Daily</td>
<td>□ Weekly</td>
</tr>
</tbody>
</table>

| 2. Ramps | □ Yes | □ No | □ Help a lot | □ Help some | □ Limit some | □ Limit a lot |
|   |   |   | □ Daily | □ Weekly | □ Monthly | □ Less than monthly |

| 3. Doors | □ Yes | □ No | □ Help a lot | □ Help some | □ Limit some | □ Limit a lot |
|   |   |   | □ Daily | □ Weekly | □ Monthly | □ Less than monthly |

| 4. Carpets | □ Yes | □ No | □ Help a lot | □ Help some | □ Limit some | □ Limit a lot |
|   |   |   | □ Daily | □ Weekly | □ Monthly | □ Less than monthly |
The following items relate to your COMMUNITY environment and to devices that may influence how you move around and carry out activities. Please mark the choice that is closest to your experience.

In your community, do the following influence your participation in activities?

<table>
<thead>
<tr>
<th>Item</th>
<th>Choice</th>
<th>How much?</th>
<th>How often?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Curb cuts</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td>2. Ramps</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td>3. Elevators</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td>4. Flat terrain</td>
<td>Yes</td>
<td>Helps a lot</td>
<td>Daily</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>5. Gravel surfaces</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Daily</td>
<td>Weekly</td>
</tr>
<tr>
<td>6. Paved surfaces</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Daily</td>
<td>Weekly</td>
</tr>
<tr>
<td>7. Summer weather (heat and humidity)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Daily</td>
<td>Weekly</td>
</tr>
<tr>
<td>8. Winter weather (ice and snow)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Daily</td>
<td>Weekly</td>
</tr>
<tr>
<td>9. Rain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Daily</td>
<td>Weekly</td>
</tr>
<tr>
<td>10. Crowds</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Daily</td>
<td>Weekly</td>
</tr>
</tbody>
</table>
1.3 THE INFLUENCE OF A WHEELCHAIR SERVICE DELIVERY ON COMMUNITY PARTICIPATION PERCEPTIONS OF INDIVIDUALS WITH SPINAL CORD INJURY

1.3.1 INTRODUCTION

There is an estimated 247,000 persons living with spinal cord injury (SCI) in the United States. The annual incidence is approximately 11,000 new cases.\(^1\) Approximately 57% of these individuals have cervical lesions (tetraplegia) and 43% have lesions below the first thoracic level (paraplegia).\(^2\) SCI most commonly affects young, in working-age adults, 80% of whom are men.\(^1,2\) The average age of injury has been gradually increasing, and for persons injured since 2000, it is reported to be 38.0 years.\(^1\) Evidence suggests that compared to the general population, people with SCI might experience a lower QoL.\(^3\) Research has documented that life satisfaction is greater for individuals who are involved in productive activities such as work, education, and recreation.\(^4\)

The ability of people with SCI to successfully participate in their community and regain independence depends much on access to appropriate and adequate wheelchairs.\(^5\) An appropriate wheelchair can significantly influence how a person with a disability perceives life.\(^6\) It has been proposed that greater satisfaction with a wheelchair should result in enhanced use of that technology and make possible a better subjective quality of life.\(^7\) On the other hand, a poorly wheelchair fitting may be perceived as negatively impacting a person’s life as it does not enable him/her to perform key daily activities.\(^8,9\) Thus, the wheelchair can be a limiting factor or facilitator for participation dependent upon how well it matches the person’s needs and environment.\(^10,11\)

The process of wheelchair service delivery has been shown to play an essential role in the wheelchair outcomes.\textsuperscript{11,12} The successful use of wheelchair is dependent on a full range of services from evaluation to delivery follow-up, including a comprehensive evaluation of the user, his daily activities and his environment.\textsuperscript{11} An interdisciplinary approach to evaluation and prescription of wheelchairs, where consumers participate in the process, is an important component to the success of the assistive technology (AT) outcome.\textsuperscript{13} Evidence supports that individuals who attend specialized seating clinics improve skin management knowledge, awareness, and potentially reduce the incidence of pressure ulcers.\textsuperscript{14} Research into consumer dissatisfaction suggests that device abandonment could be reduced if consumers were actively involved from the start to the end of the wheelchair service delivery process.\textsuperscript{15} Verza et al.\textsuperscript{13} showed a reduction in AT device abandonment from 37\% to 9\% after using an interdisciplinary client centered approach assessment. Lack of fit between the person, environment and AT was the primary reason identified for nonuse.\textsuperscript{16} Hence, the wheelchair process delivery outcome should be a result of the team, client and family effort and will impact on client’s independence and participation in the community.

Although several studies have described the importance of AT service delivery\textsuperscript{11,12,13}, no studies to date have related service delivery to community participation. What is not known is how wheelchairs and the process of service delivery affect overall participation. Current research in wheelchair outcomes is essential to generate evidence that today’s practices are producing the expected and desired outcomes. The overall aim of this study was to investigate if the acquisition of new wheelchairs delivered by specialized AT clinics will change the frequency of participating in activities within the community of individuals with SCI and reduce the number of perceived limitations to participation. It was hypothesized that participation as measured by the
Participation Survey/Mobility (PARTS/M), would change with receipt of a wheelchair that was prescribed by a specialized AT clinic. Specifically, wheelchair users who receive new equipment from specialized AT clinic will show: 1) an increase in frequency of participation in community activities; 2) satisfaction in or with participation will improve and 3) perception of the number and types of limitations to participation will decrease when compared to those who have not received new equipment from a non-specialized AT clinic.

1.3.2 METHODS

1.3.2.1 Experimental Design

A longitudinal, quasi experimental design was used for this study, with the subjects serving as their own controls. There were four groups of participants: 1) Participants who received new wheelchairs from the Center of Assistive Technology (specialized AT clinic) at the University of Pittsburgh (NWPitt), 2) Participants who received new wheelchair from rehabilitations hospitals (non-specialized AT clinic) at Washington University at Saint Louis (NWSL), 3) Participants from Pittsburgh who acts as a control who were using their wheelchairs for more than 1 year and had no intention of changing wheelchair for 2 years (CTPitt) and 4) Participants from Saint Louis who acts as a control who were using their wheelchair for more than 1 year and had no intention of changing wheelchair for two years (CTSL).

Participants who received new wheelchairs (new wheelchair group) were assessed at 5 time points: 1) prior to receiving the new wheelchair, 2) at the time they received their new
wheelchair, 3) four months after they had used their new wheelchair, and 4) one and 5) two years after receiving their new wheelchair. The four month interval was selected to assess the influence of AT on participation after adequate time had passed to adjust their participation to the use of the new equipment. The one and two year assessments were used to assess the long-term influence of technology change on participation and wheelchair use. The control group was assessed at 3 time points, receiving assessments once a year for three consecutive years during visits of the study sites for their annual physical.

1.3.2.2 Human Subjects

Multi-site Institutional Review Board (IRB) approval was obtained prior to initiation of the study. One hundred and six individuals with SCI who use wheelchairs for mobility provided written informed consent. Out of 106, 49 individuals completed the 2 years measurement. A written survey that recorded AT usage in daily activities was distributed among clients from two locales, Pittsburgh, Pennsylvania and Saint Louis, Missouri. The new wheelchair group was composed of people with SCI who were referred to the Center of Assistive Technology (specialized AT clinic) at the University of Pittsburgh (Pitt) or rehabilitations hospitals (non-specialized AT clinic) at Washington University at Saint Louis (SL) for a new wheelchair or seating system. The new wheelchair group inclusion criteria include individuals with SCI who have been discharged from rehabilitation for at least one year and were living in the community. The exclusion criteria were newly injured people with SCI. The reason for excluding newly injured individuals was that in the first year after injury medical complications often require frequent attention interfering with participation in community
activities. Participation changes during the first year could confound any effects new technology may have on participation making comparative analysis of participation with new and old equipment difficult. The control group was individuals with SCI who made annual visits at Pitt and SL. In order to be included in the control group individuals must have SCI, their current wheelchair and seating system had to be greater than one year old and they must have stated that they did not plan to get a new wheelchair for two years. In both locations subjects were recruited via flyer or approached by clinical study coordinators, who ask if they were interested in participating.

1.3.2.3 Questionnaire

The questionnaire used in this study was the Participation Survey/Mobility (PARTS/M). The PARTS/M was specifically designed to define participation in a similar manner as the International Classification of Function and Disability (ICIDH-2). The PARTS/M is composed of 13 major life activities. For this study only 5 content areas were analyzed: 1) Leaving the home: which included going into the community such as shopping, visiting a doctor or getting into a vehicle; 2) Transportation: involved accessing and using different forms of transportation; 3) Active recreation: included sports or camping; 4) Leisure activities: included dining out, attending movies or concerts; and 5) Socializing: included visiting friends or family at home, at the homes of others, or at social events. These specific definitions were written prior to each item in the questionnaire. Subjects were asked five questions within each content area related to their perceived frequency of participating in community activity; satisfaction in participation and perception for the number and types of limitations to participation (see Appendix
Subject’s responses to the questions on frequency, satisfaction and functional limitations are also listed in the Appendix D, E, F and G. According to the PARTS/M subject responses regarding functional limitations were divided into two categories: 1) Participation limitations - defined as health-related factors that interfere with the ability to do activities (e.g. wheelchair, physical impairment, wheelchair seating, pain, fatigue and illness), and 2) Access limitations - defined as non health-related issues that interfere with the opportunity to participate in activities (e.g. wheelchair, physical environment, wheelchair seating, lack of assistance, lack of equipment, social attitudes, self-concept and family attitudes). These specific definitions were also written into the first page of the questionnaire. Per the PARTS/M the wheelchair and wheelchair seating were cited as part of participation limitation because they are used to compensate for health conditions (i.e. inability to walk). For example, manual wheelchairs for most individuals limit distance traveled, whereas, power wheelchairs that do not go through gravel and sand limit participation in those environments. The reliability and validity of the PARTS/M have been completed by Gray et al. However, this analysis utilizes a subset of questions and a modified scoring system.

1.3.2.4 Data Analysis and Statistical Considerations

Data collected at the sites (Pitt and SL) for participants was combined to produce a score of the outcomes of interest (frequency of community participation (FCP), satisfaction to community participation (SCP) and perceived functional limitations to participation (FLP). A total score, ranged from 0 to 20, for frequency of community participation was created from the following questions: frequency of leaving home, frequency of using transportation,
frequency of active recreation, frequency of socializing, and frequency of eight leisure activities (dine out, attend movies, attend concerts, play cards, play board games, watch sports, read, hobby). Since there were 8 items measuring leisure activity but only one item measuring the other types of participation, leisure activities would be weighted more heavily than other types of community participation if the total score was created by simply averaging all 12 items. To avoid this unequal weighting, the average of the 8 leisure activity items was computed first. Next the following scores were averaged to produce the total score (See Appendix D). A total score for satisfaction of community participation was computed from 5 questions: satisfaction leaving home, satisfaction using transportation, satisfaction in leisure activities, satisfaction in active recreation and satisfaction in socializing (See Appendix E). Also, a total score was created for functional limitation to participation based on 5 questions: participation limitations leaving home, participation limitations to use transportation, participation limitations in leisure activities, participation limitations in active recreation and participation limitations in socializing (See Appendix F and G).

Initial comparisons on demographic characteristics (age, years post injury, gender, type of wheelchair and level of injury) between new wheelchair and control group was completed. A student t-test was used for comparing the intervention to control group for variables that were continuous in nature (group by age and years post injury) and chi-square was used for variables that were categorical (group by gender, type of wheelchair and level of injury). Similar baseline comparisons were made between the two sites (Pitt and SL) to detect any significant differences. Loss to follow-up may also result in differences between groups, new wheelchair group and controls and between the two sites (Pitt and SL). Therefore, comparisons were made to determine whether those lost are similar to those who remained were similar using a student
t-test for variables that are continuous in nature (age and years post injury) and chi-square for variables that are categorical (gender, type of wheelchair and level of injury). As more than 20% of participants dropped out of the study, replacement of missing values were not performed (Muro, 2005).

Repeated measure ANOVA was used to determine the effects of the type of wheelchair on outcome of interest (frequency of community participation, satisfaction of community participation and functional limitation to participation) being considered the dependent variable and independent factors of type of wheelchair service delivery. Repeated measure ANOVA provided: 1) main effect of time tests where there is a difference between initial, 1 and 2 years for the entire sample (new + control together) and 2) Interaction tests whether change over time is greater for new than for control. Similarly, a repeated measure ANOVA was also used to compare outcome within the different clinical settings. Repeated measure ANOVA provided: 1) main effect of time tests where there is a difference between initial, 1 and 2 years for the entire sample (Pitt + SL together) and 2) Interaction tests whether change over time is greater for Pitt than for SL. As we were interested in long term changing two times points in the new wheelchair group (at the time they received their new wheelchair and four months after they had used their new wheelchair) were not analyzed. In addition, as these two times points were not part of the control group measurements they were not taken into consideration when comparison were performed between new wheelchair and control group. The significance level was set at p < 0.05.
1.3.3 RESULTS

1.3.3.1 Participants who withdrew and completed the study

Out of 106, 49 individuals completed the 2 years survey (see figure 1). It is important to highlight that the study is still in progress and 8 participants still remained. Six individuals from Pitt (4 belong to the new wheelchair group and 1 to the control group) and 2 from SL (one belong to the new wheelchair and the other to the control group). Out of the 49 who completed the study, 26 individuals were from Pitt and 23 from SL. There were 37 men and 12 women with a mean age of 41 years (+ STDV 11.86). The majority of participants (n=71) were white, 22 were Black/African American, 2 were Asian/Pacific Islander and 4 checked the option other (Hispanic/Latino Origin were the specification provided). The average time post injury was 18 years (+ STDV 9.31). There were 18 individuals with tetraplegia, 27 with paraplegia, 2 did not know their injury level and 2 did not respond to the question. Thirty-four subjects used manual wheelchairs and 15 used power wheelchairs. Seventeen participants belonged to the new wheelchair group and 32 to the control group.
Figure 1. Illustrates a flowchart for participation in the study.

Enrollment
N = 106

PITTSBURGH
N = 50

New Wheelchair Group = 32
Control Group = 18
Total Completed = 50

New Wheelchair Group = 20
Control Group = 15
Total Completed = 35
% Completed = 70%
Total Lost to follow-up = 15
(New Wheelchair group = 12 & Control group = 3)
Attrition Rate = 30%

SAINT LOUIS
N = 56

New Wheelchair Group = 23
Control Group = 33
Total Completed = 56

New Wheelchair Group = 9
Control Group = 22
Total Completed = 31
% Completed = 55%
Total Lost to follow-up = 25
(New Wheelchair group = 14 & Control group = 11)
Attrition Rate = 45%

Baseline

1 Year Follow-Up

New Wheelchair Group = 12
Control Group = 14
Total Completed = 26
% Completed = 52%
Analyzed = 26
Excluded from analysis = 18
Attrition Rate = 48%
Pending completion (n = 6)
1 Control & 5 new wheelchair group

2 Year Follow-Up

New Wheelchair Group = 5
Control Group = 18
Total Completed = 23
% Completed = 41%
Analyzed = 23
Excluded from analysis = 31
Attrition Rate = 59%
Pending completion (n = 2)
1 Control & 1 new wheelchair group
1.3.3.2 Participants who withdrew and completed the study

Only 46% (n=49) out of 106 participants completed the 2 year follow-up. Reasons for drop out include: 10% (n=11) were unable to contact, 29% (n=31) did not complete the follow-up survey, 5% (n=5) deceased and 2% (n=2) moved. No significant difference was found between participants who completed the study and those who withdrew from the study on demographics (gender (p=.45), age (p=.76), years post injury (p=.66) and type of mobility (p=.65). Regarding the outcome variables (frequency, satisfaction and limitation to participation) the only variable that was different between those who completed the study and those who withdrew was regarding the frequency of community activities (p=.030). The frequency of community activities was higher for those who remained in the study (remained=11.09 & withdrew = 9.32).

1.3.3.3 Study Location

At baseline, no significant difference was found between the four groups (new wheelchair group from Pittsburgh (NWPitt) (N=12), control group from Pittsburgh (CTPitt) (N=14), new wheelchair group from Saint Louis (NWSL) (N=5) and control group from Saint Louis (CTSL) (N=18)) regarding age (p=.40), years post injury (p=.92), gender (p=.29), level of injury (p=.12) and type of wheelchair (p=.13). In addition, no significant difference was found between the four groups on the variables of interest, frequency of community participation (p=.13), satisfaction of community participation (p=.122) and functional limitation to participation (p=.49).

No significance difference was found between new wheelchair group and control group regarding age (p=.099), years post injury (p=.572), gender (p=.909), level of injury (p=.309) and type of wheelchair (p=.604). In addition, no significance difference was found between Pitt
and SL regarding age (p=.830), years post injury (p=.334), gender (p=.807), level of injury (p=1.0) and type of wheelchair (p=.066)

1.3.3.4 Frequency of Community Participation (FCP)

When compared to those who have not received new equipment from a non-specialized AT clinic, it was hypothesized that users who receive new equipment from specialized AT clinic will show that frequency of participating in community activities will increase over time. No significant difference was found between groups on the frequency of community participation (see Table 19 and figure 2). When controlling for baseline, the main effect for time (baseline, 1 year, 2 years) was significant ($F(2) = 4.14$, $p=.019$). However, the main effect for group location (NWPITT, NWSL, CTPITT, CTSL) was not significant ($F(3) = .309$, $p=.819$). After completing a post-hoc analysis, no significant difference was found between samples times.

Figure 2. Illustrates Frequency of Community Participation (FCP) scores by the four groups over time.
Table 19. Illustrates the scores of perception of frequency of community participation (FCP), satisfaction of community participation (SCP) and functional limitations (Participation and Access limitations) of community participation by the four groups over time.

<table>
<thead>
<tr>
<th>Community Participation variables</th>
<th>Location</th>
<th>Time Mean (STDV)</th>
<th>Within subjects effects</th>
<th>Between subjects effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Baseline</td>
<td>1 year</td>
<td>2 years</td>
</tr>
<tr>
<td>FCP (Score range = 0 – 20)</td>
<td>NWPITT</td>
<td>11.4 (4.05)</td>
<td>11.4 (3.72)</td>
<td>10.5 (4.33)</td>
</tr>
<tr>
<td></td>
<td>NWSL</td>
<td>12.5 (2.93)</td>
<td>13.2 (4.13)</td>
<td>11.3 (3.55)</td>
</tr>
<tr>
<td></td>
<td>CTPITT</td>
<td>11.9 (2.75)</td>
<td>11.4 (3.02)</td>
<td>10.6 (1.79)</td>
</tr>
<tr>
<td></td>
<td>CTSL</td>
<td>9.62 (2.65)</td>
<td>10.3 (3.32)</td>
<td>9.92 (2.53)</td>
</tr>
<tr>
<td>SCP (sore range = 0 - 15)</td>
<td>NWPITT</td>
<td>7.08 (5.36)</td>
<td>7.16 (4.23)</td>
<td>6.00 (4.63)</td>
</tr>
<tr>
<td></td>
<td>NWSL</td>
<td>9.00 (3.60)</td>
<td>9.80 (1.92)</td>
<td>9.20 (2.58)</td>
</tr>
<tr>
<td></td>
<td>CTPITT</td>
<td>9.28 (4.00)</td>
<td>8.92 (4.74)</td>
<td>8.00 (4.09)</td>
</tr>
<tr>
<td></td>
<td>CTSL</td>
<td>5.66 (4.13)</td>
<td>6.55 (4.42)</td>
<td>6.44 (4.30)</td>
</tr>
<tr>
<td>Participation Limitations (sore range = 0 - 28)</td>
<td>NWPITT</td>
<td>7.41 (4.50)</td>
<td>8.41 (7.90)</td>
<td>12.50 (9.69)</td>
</tr>
<tr>
<td></td>
<td>NWSL</td>
<td>6.20 (3.83)</td>
<td>9.40 (1.94)</td>
<td>8.40 (3.36)</td>
</tr>
<tr>
<td></td>
<td>CTPITT</td>
<td>7.50 (4.27)</td>
<td>9.14 (7.19)</td>
<td>10.14 (6.57)</td>
</tr>
<tr>
<td></td>
<td>CTSL</td>
<td>9.83 (7.71)</td>
<td>10 (6.66)</td>
<td>12.44 (7.07)</td>
</tr>
<tr>
<td>Access Limitations (sore range = 0 – 46)</td>
<td>NWPITT</td>
<td>8.16 (5.50)</td>
<td>8.58 (6.03)</td>
<td>11.1 (8.65)</td>
</tr>
<tr>
<td></td>
<td>NWSL</td>
<td>10.4 (6.06)</td>
<td>9.60 (3.20)</td>
<td>7.20 (3.89)</td>
</tr>
<tr>
<td></td>
<td>CTPITT</td>
<td>8.64 (4.68)</td>
<td>8.21 (4.61)</td>
<td>8.71 (5.31)</td>
</tr>
<tr>
<td></td>
<td>CTSL</td>
<td>11.0 (8.69)</td>
<td>11.1 (6.25)</td>
<td>10.5 (6.98)</td>
</tr>
</tbody>
</table>

NWPITT = Individuals from Pitt who purchased new wheelchairs in the specialized AT clinic.
NWSL = Individuals from SL who purchased new wheelchairs in a non-specialized AT clinic.
CTPITT= Individuals from Pitt who have been used wheelchairs for more than 1 year and were not planning to change wheelchair in two years.
CTSL= Individuals from SL who have been used wheelchairs for more than 1 year and were not planning to change wheelchair in two years.
FCP= Frequency of Community Participation
SCP= Satisfaction in Community Participation

1.3.3.5 Satisfaction in Community Participation (SCP)

When compared to those who have not received new equipment from a non-specialized AT clinic, it was hypothesized that users who receive new equipment from specialized AT clinic will show that satisfaction in participation will improve over time. Unfortunately, no significant difference was found between groups on satisfaction of community participation (see Table 19 and figure 3). When controlling for baseline, the main effect for time (baseline, 1 year, 2 years) was significant ($F(2) = 3.98$, $p=.022$). However, the main effect for group location (NWPITT, NWSL, CTPITT, CTSL) was not significant ($F(3) = .774$, $p=.515$). After completing a post-hoc analysis, no significant difference was found between sample times.

Figure 3. Illustrate Satisfaction of Community Participation (SCP) scores by the four groups over time.
When compared to those who have not received new equipment from a non-specialized AT clinic, it was hypothesized that users who receive new equipment from specialized AT clinic will show that the number and types of limitations to participation will decrease. The data showed no significant difference between individuals who received new wheelchairs as well as different sites (Pitt and SL) regarding functional limitations (see Table 1 and Graph 3). Participation limitations: when controlling for baseline, the main effect for time (baseline, 1 year, 2 years) was
significant \( (F(2) = 4.59, \ p=.013) \). However, the main effect for group location (NWPITT, NWSL, CTPITT, CTSL) was not significant \( (F(3) = .169, \ p=.917) \). After completing a post-hoc analysis, no significant difference was found between times. *Access limitations:* when controlling for baseline, the main effect for time (baseline, 1 year, 2 years) was significant \( (F(2) = 6.26, \ p=.003) \). However, the main effect for group location (NWPITT, NWSL, CTPITT, CTSL) was not significant \( (F(3) = .656, \ p=.584) \) (see Table 19 and figure 4 and 5).

Figure 4. Illustrate functional limitations (participation limitations) scores by the four groups over time.

**Participation Limitations**

![Graph](image-url)
Figure 5. Illustrate functional limitations (access limitations) scores by the four groups over time.
1.3.4 DISCUSSION

The data showed no significant difference among individuals who received new wheelchairs delivered by specialized AT clinic (NWPitt) and those who attended a non-specialized AT clinic (NWSL) on the frequency, satisfaction and number of perceived limitations to participation over time (baseline, 1 and 2 years). Similarly, no difference was found between new wheelchair groups (NWPitt & NWSL) and control groups (CTPitt & CTSL) on the variables of interest (frequency, satisfaction and number of perceived limitations to participation) over time. Our hypothesis that participation as measured by the Participation Survey/Mobility (PARTS/M), would change with receipt of a wheelchair that was prescribed by a specialized AT clinic was not supported by the data.

People with SCI rely on manual and power wheelchairs to compensate for mobility needs to accomplish daily activities. The wheelchair is one of the most important of rehabilitation interventions. However, individuals who use wheelchairs face many participation barriers. To address these problems, efforts have been made to improve the wheelchair delivery process. The process of wheelchair service delivery has been shown to play an essential role in wheelchair related outcomes. However, identification of the impact of service delivery on community participation can be difficult as it involves physical barriers which cannot be mitigated by the service delivery system. In addition, our sample was composed of individuals with an average age of injury of 18 years (+ 9.31), leading us to think that the majority of participants could already have proper wheelchairs, maybe they have been attending that specialized AT clinic for years, and no drastic changes were required to their new wheelchair system. Therefore, participants may have experienced changes in their personal mobility level
(e.g. the wheelchair was easier to propel, maneuver or was more comfortable to use) but those changes may not have had an impact on the frequency of activities, satisfaction and functional limitations to community participation. Reason for that might be that participants had no benefit to gain in participation (changes in participation could have occurred earlier in their injury) as they have an established routine or perhaps the questionnaire was not sensitive to capture those nuances.

Another possible explanation for our findings might be that individuals who attended a non-specialized wheelchair clinic may have received services from therapists or suppliers who might have had good training and experience with wheelchair prescription and, as a result, the participants received good quality wheelchairs and seating system, which may have impacted in their community activities.

All the five community items (leaving home, transportation, leisure activities, active recreation and socializing) in the questionnaire were scored together. Therefore, we were not able to detect exactly in which item participants had changes in their frequency of community participation, satisfaction of community participation and functional limitation to participation scores. Furthermore, we did not account for differences in community accessibility for each city tested or if recommendations related to transportation or environmental modifications made by the AT clinic were strictly followed by the participants. The wheelchair and seating system can limit or facilitate participation depending on how well the seating and wheelchair match the person’s needs and environment. Therefore, an individual can have state of the art technology but if the environment is not supportive, he or she will not be able to use that technology effectively and consequently their community activities performance may be affected. Access to environments has been considered in several studies as a major predictor of
community participation and QoL.\textsuperscript{20, 25, 26} Therefore, received benefit of the wheelchair is only as effective as the extent to which it meets the needs of the individual and allows him or her to better function in their daily environments.

Finally, our small sample size may have impacted our ability to detect differences that may have existed between the two service deliver methods tested. Results from a power calculation showed that we could have found differences with total of 64 participants, or 16 participants per group. The large number of dropouts might also have affected our results. The reasons why we had many dropouts may be related to the length of the questionnaire (participants did not want to fill it out the survey because was too long) and also due to the lack of communication between investigators and supplier regarding the delivery of the new wheelchairs (there was a large number of subjects n=27 who dropout during the new wheelchair assessment). Investigators were communicated after several weeks that the wheelchair was delivered; therefore the new wheelchair measurement could not be taken. Future studies should incorporate a larger sample size and investigate environmental and transportation recommendations of the clinics. Relationship between supplier and investigators should be strait down. Community items should be analyzed separately and interaction between the user, activity, wheelchair and the environment \textsuperscript{27} should be taken into consideration. A thorough documentation of the wheelchair service delivery process performed by each clinic, professional and client level of wheelchair knowledge should be also investigated, as this would affect the decision making process. Studying a larger number of individuals with a broader range of physical impairment or with newer injury may provide greater insight into the benefit of a specialized seating clinic in a wheelchair service delivery and community
participation. Such studies could be used to advocate for social policy change in support of the provision of AT.
1.3.5 REFERENCE


APPENDIX D

Illustrates the 5 questions related to the frequency of participating in major life activities:

1. How frequently do you leave your home?
   - Never
   - I choose not to do this
   - I am unable to do this
     (Go to question 3 on next page.)
     - Once or twice a month
     - Once or twice a week
     - Once or twice a day
     - 3 or more times a day

2. How **frequently** do you use transportation?

3. For the following leisure activities, please indicate **how often** you do them

<table>
<thead>
<tr>
<th>Leisure Activities</th>
<th>How often do you do the activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dine out</td>
<td>• Never</td>
</tr>
<tr>
<td></td>
<td>• Less than once a month</td>
</tr>
<tr>
<td></td>
<td>• 1-2 times a month</td>
</tr>
<tr>
<td></td>
<td>• 1-2 times a week</td>
</tr>
<tr>
<td></td>
<td>• More than twice a week</td>
</tr>
<tr>
<td>Attend movies</td>
<td>• Never</td>
</tr>
<tr>
<td></td>
<td>• Less than once a month</td>
</tr>
<tr>
<td></td>
<td>• 1-2 times a month</td>
</tr>
<tr>
<td></td>
<td>• 1-2 times a week</td>
</tr>
<tr>
<td></td>
<td>• More than twice a week</td>
</tr>
<tr>
<td>Activity</td>
<td>Never</td>
</tr>
<tr>
<td>------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Attend concerts</td>
<td></td>
</tr>
<tr>
<td>Play cards</td>
<td></td>
</tr>
<tr>
<td>Play board games</td>
<td></td>
</tr>
<tr>
<td>Watch sports</td>
<td></td>
</tr>
<tr>
<td>Read</td>
<td></td>
</tr>
<tr>
<td>Hobby (specify)</td>
<td></td>
</tr>
<tr>
<td>Other (specify)</td>
<td></td>
</tr>
</tbody>
</table>

4. **How often** do you participate in activity recreation?
- Never
- I choose not to do this
- I am unable to do this (Go to question 4)
- Less than once a month (Continue)
- 1-2 times a month (Continue)
- 1-2 times a week (Continue)
- More than twice a week (Continue)

5. How **frequently** do you socialize with others?
- Less than once a week
- 1 to 2 times a week
- 3 to 4 times a week
- Daily or almost daily
A total score for FCP will be created from the following questions: frequency of leaving home, frequency of using transportation, frequency of active recreation, frequency of socializing, and frequency of eight leisure activities (dine out, attend movies, attend concerts, play cards, play board games, watch sports, read, hobby). Since there are 8 items measuring leisure activity but only one item measuring the other types of participation, leisure activities would be weighted more heavily than other types of community participation if the total score was created by simply averaging all 12 items. To avoid this unequal weighting, the average of the 8 leisure activity items will be computed first. Next the following scores will be averaged to produce the total score.

<table>
<thead>
<tr>
<th>Frequency leaving home (1 questions)</th>
<th>Frequency of using transportation (1 question)</th>
<th>Frequency of leisure activities (8 questions)</th>
<th>Frequency of Active Recreation (1 question)</th>
<th>Frequency of socializing (1 question)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never = 0</td>
<td>Never = 0</td>
<td>Never = 0</td>
<td>Never = 0</td>
<td>Less than once a week=1</td>
</tr>
<tr>
<td>1-2 month = 1</td>
<td>1-2 month = 1</td>
<td>Less than once a month=1</td>
<td>Less than once a month=1</td>
<td>1-2 week = 2</td>
</tr>
<tr>
<td>1-2 week = 2</td>
<td>1-2 week = 2</td>
<td>1-2 month = 2</td>
<td>1-2 week = 2</td>
<td>3-4 week = 3</td>
</tr>
<tr>
<td>1-2 day = 3</td>
<td>1-2 day = 3</td>
<td>1-2 week = 3</td>
<td>1-2 week = 3</td>
<td>Daily or almost daily = 4</td>
</tr>
<tr>
<td>3 or more times a day = 4</td>
<td>More than twice a day = 4</td>
<td>More than twice a week = 4</td>
<td>More than twice a week = 4</td>
<td></td>
</tr>
<tr>
<td>(Score range = 0 - 4)</td>
<td>(Score range = 0 - 4)</td>
<td>(Mean score with all the 8 leisure activity questions will be computed)</td>
<td>(Score range = 0 - 4)</td>
<td>(Score range = 0 - 4)</td>
</tr>
</tbody>
</table>

**Total score range** = average score for leisure activities + score for each of the other four types items.
APPENDIX E

Illustrates the 5 questions related to satisfaction in participation:

1. How satisfied are you with your participation in leaving your home?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

2. How satisfied are you with your participation in using transportation?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

3. How satisfied are you with your participation in leisure activities?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

4. How satisfied are you with your participation in active recreational activities?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

5. How satisfied are you with your participation in social activities?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

The 5 items related to satisfaction in participation will be score as the following:

<table>
<thead>
<tr>
<th>Satisfaction leaving home (1 question)</th>
<th>Satisfaction using transportation (1 question)</th>
<th>Satisfaction in leisure activities (1 question)</th>
<th>Satisfaction Active Recreation (1 question)</th>
<th>Satisfaction socializing (1 question)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dissatisfied = 0</td>
<td>Dissatisfied = 0</td>
<td>Dissatisfied = 0</td>
<td>Dissatisfied = 0</td>
<td>Dissatisfied = 0</td>
</tr>
<tr>
<td>Somewhat satisfied = 1</td>
<td>Somewhat satisfied = 1</td>
<td>Somewhat satisfied = 1</td>
<td>Somewhat satisfied = 1</td>
<td>Somewhat satisfied = 1</td>
</tr>
<tr>
<td>Satisfied = 2</td>
<td>Satisfied = 2</td>
<td>Satisfied = 2</td>
<td>Satisfied = 2</td>
<td>Satisfied = 2</td>
</tr>
<tr>
<td>Very satisfied = 3</td>
<td>Very satisfied = 3</td>
<td>Very satisfied = 3</td>
<td>Very satisfied = 3</td>
<td>Very satisfied = 3</td>
</tr>
</tbody>
</table>

(Score range = 0 - 3)                  (Score range = 0 - 3)                  (Score range = 0 - 3)                  (Score range = 0 - 3)                  (Score range = 0 - 3)                  

Total score range = 0 - 15
APPENDIX F

Illustrates the 5 questions related perception for the number and types of limitations to participation:

1. Is your participation in leaving your home limited by … (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other_________________________
   - Not limited

2. Is your participation in using transportation limited by ... (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other_________________________
   - Not limited

3. Is your participation in leisure activities limited by ... (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other_________________________
   - Not limited

4. Is your participation in active recreational activities limited by ... (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other_________________________
   - Not limited

5. Is your participation in social activities limited by ... (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other_________________________
   - Not limited
The 5 items regarding participation limitations (PL) will be scored as the following:

<table>
<thead>
<tr>
<th>PL leaving home  (1 questions)</th>
<th>PL transportation (1 questions)</th>
<th>PL leisure activities (1 questions)</th>
<th>PL Active Recreation (1 questions)</th>
<th>PL socializing (1 questions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PL (score range =0 – 7)</td>
<td>PL (score range =0 – 7)</td>
<td>PL (score range =0 – 7)</td>
<td>PL (score range =0 – 7)</td>
<td>PL (score range =0 – 7)</td>
</tr>
</tbody>
</table>

**Total score range = 0 – 28**
APPENDIX G

Illustrates the 5 questions related perception for the number and types of access limitations (AL):

1. Is your access to leaving your home to go out into the community limited by ... (Check all that apply.)
   - Physical factors in the environment
   - Social attitudes
   - Family attitudes
   - Self-concept
   - Lack of assistance
   - Wheelchair
   - Wheelchair seating
   - Lack of special equipment

   What equipment would be helpful?

   Other (specify) ________________________________  Not limited

2. Is your access to using transportation limited by ... (Check all that apply.)
   - Physical factors in the environment
   - Social attitudes
   - Family attitudes
   - Self-concept
   - Limited finances
   - Lack of assistance
   - Wheelchair
   - Wheelchair seating

   What equipment would be helpful?

   Other (specify) ________________________________  Not limited

3. Is your access to leisure activities limited by ... (Check all that apply.)
   - Physical factors in the environment
   - Social attitudes
   - Family attitudes
   - Self-concept
   - Limited finances
   - Lack of assistance
   - Wheelchair
   - Wheelchair seating

   What equipment would be helpful?

   Other (specify) ________________________________  Not limited

4. Is your access to active recreational activities limited by ... (Check all that apply.)
   - Physical factors in the environment
   - Lack of assistance
   - Social attitudes
   - Family attitudes
   - Limited finances
   - Lack of organized accessible teams
   - Self-concept
   - Wheelchair
   - Wheelchair seating

   What equipment would be helpful?
5. Is your access to social activities limited by ... (Check all that apply.)
☐ Physical factors in the environment ☐ Social attitudes ☐ Family attitudes
☐ Self-concept ☐ Lack of assistance ☐ Limited finances
☐ Lack of companion(s) ☐ Wheelchair ☐ Wheelchair seating
☐ Lack of special equipment  ➔ What equipment would be helpful?

☐ Other (specify) _____________________________ ☐ Not limited

The 5 items regarding Access limitations (AL) will be score as the following:

<table>
<thead>
<tr>
<th>Leaving home (1 questions)</th>
<th>Transportation (1 questions)</th>
<th>Leisure activities (1 questions)</th>
<th>Active Recreation (1 questions)</th>
<th>Socializing (1 questions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>AL (score range =0 – 8)</td>
<td>AL (score range =0 – 9)</td>
<td>AL (score range =0 – 9)</td>
<td>AL (score range =0 – 10)</td>
<td>AL (score range =0 – 10)</td>
</tr>
</tbody>
</table>

Total score range = 0 – 46
THE RELATIONSHIP BETWEEN MOBILITY PATTERNS AND COMMUNITY PARTICIPATION OF INDIVIDUALS WITH SPINAL CORD INJURY

1.4.1 INTRODUCTION

The term community participation may be used to refer to returning to the mainstream of family and community life, engaging in normal roles and responsibilities, actively contributing to ones social groups and of society as a whole. A great deal of work has been done in developing tools to measure and document a person’s physiological impairment (or lack of ability to perform an activity) however, limited attempts have focused on the measurement and assessment of long-term individual participation. The measurement of participation has been considered the most meaningful outcome of rehabilitation; however, it is probably also the most challenging to measure since there are many things that contribute to a person’s level of participation. Some participation measures primarily assess behaviors (e.g. hours of physical assistance, how much time is someone with you to assist you, how many relatives do you visit), such as The Craig Handicap Assessment and Reporting Technique (CHART) while other assess perception of participation (individual’s perspective on the impact of the health condition and problems they experienced when carrying out everyday activities), such as the Impact on Participation and Autonomy Questionnaire (IPAQ), Reintegration to Normal Living (RNL) Index and the Canadian Occupational Performance Measure (COPM); one measure, Participation Survey/Mobility (PARTS/M) include both.
The CHART is probably the most widely used participation measure for individuals with spinal cord injury (SCI). However, information collected in the CHART does not include the individual’s perspective and so information about how the person performs the tasks as well as what tasks are important to them is not captured, which is a significant limitation. The PARTS/M can be used to test not only personal limitations but also the environmental factors that may restrict or facilitate participation. The PARTS/M not only provides a detailed individual’s perception to participation in major life activities (e.g. travel, parenting, leisure, work) but also evidence for social policy change of existing legislation.

Several researchers have also investigated the possibility of using electronic sensor technology to provide a more objective measure of the activity levels of manual wheelchair users. The Human Engineering Research Laboratories (HERL) has developed a data logger that attaches to manual and power wheelchairs and records movement activity. Using such technology eliminates the possibility of recall bias and misinterpretation of survey questions, which are associated with self-report measures. The data logger has been shown to be reliable and accurate and has been used to investigate the driving characteristics of wheelchair users in the community.

The overall aim of this study is to investigate if there is a correlation between mobility characteristics (distance traveled, speed, number of starts and stops and drive time) and the frequency of community activities of individuals with SCI as measured by the PARTS/M and data logger device.
1.4.2 METHODS

1.4.2.1 Participants

Thirty-two individuals were recruited in this study. The inclusion criteria included 1) having a spinal cord injury 2) using a manual wheelchair or power wheelchair as a primary source of mobility, 3) being 18 years of age or older, and 4) available to meet with study personnel to have the data logging device attached to their wheelchair. Thirteen participants did not return the data logging device and/or the questionnaire at the end of the study and the data from three additional participants was incomplete due to problems with the instrumentation; therefore, the data for a total of 16 subjects were used for analysis in this study.

1.4.2.2 Recruitment Procedures

Subjects were recruited during the 27th annual National Veterans Wheelchair Games (NVWG) held in Milwaukee, Wisconsin during June 2007. Subject recruitment was carried out by study personnel at the NVWG sponsored exposition, which takes place each year during the opening day of the games. Individuals who expressed interest in this research completed the study during that time or set up an appointment to meet later at a more convenient time.
1.4.2.3 Protocol

The VA Pittsburgh Healthcare System Institutional Review Board approved the study’s protocol before its initiation. The nature of the study was explained and written informed consent was obtained from all subjects before the start of data collection. A data logging device was instrumented on each subject’s wheelchair. In addition, the participants were asked to complete a questionnaire which is a combination of two surveys: 1) the Participation Survey/Mobility (PARTS/M) and 2) Facilitators and Barriers Survey/Mobility (FABS/M). At this time, subjects also received a packet that contained materials (i.e. a hex key, box with prepaid postage, packing wrap, and removal instructions for the instrumentation) to remove the data logging device at the end of the study period and send it back to the HERL. The data logging device was placed in a location that did not obstruct the propulsion of the wheelchair or interfere with the subjects’ functioning. Thus, the data logging device required little to no attention during the study period, so individuals were able to conduct daily activities as normal. For all subjects, the data logging device monitored their wheelchair activities for three weeks; one week during the NVWG and 2 weeks in their home environment.

1.4.2.4 Questionnaire

The questionnaire used in this study was a combination of the PARTS/M and the FABS/M. The PARTS/M is composed of 13 major life activities ranging from activities that people perform in the house to recreation and socializing. The FABS/M consist of 191 items that probe the situational specificity of activity limitations, request information on the type of assistive technology used in activities, and asks the respondents to categorize aspects of their environments as barriers or facilitators to participation. For this study, only 5 content areas
related to activity performance in the community were analyzed: 1) Leaving the home: which included going into the community such as shopping, visiting a doctor or getting into a vehicle; 2) Transportation: involved accessing and using different forms of transportation; 3) active recreation: included sports or camping; 4) Leisure activities: included dining out, attending movies or concerts; and 5) Socializing: included visiting friends or family at home, at the homes of others, or at social events. These specific definitions were written prior to each item in the questionnaire. Subjects were asked one question within each content area related to their perceived frequency of participating in community activity (see Appendix H). Subject’s responses to the questions are also listed in the Appendix 1.

1.4.2.5 Data logger

There were two types of data logging device used in this study: 1) data logger for manual wheelchairs and 2) data logger for power wheelchairs. Both of them were developed at the HERL. The data logger for manual wheelchairs attaches to the spokes of manual wheelchair (see figure 7) and the other one replace the caster of power wheelchairs (see figure 8) to record movement activity. No modifications are required to be made to the wheelchair. Movement sensing components allow the data logger to automatically begin recording when the chair is moved, and automatically stop recording, when the chair is stationary. Using onboard memory and a software program for data collection, the data logger records a time stamp every time the magnet passes a reed switch. The time stamp data are used to calculate speed, distances traveled, and the number of times in a day the individual moves using their wheelchair. 8
1.4.2.6 Reduction of Data logging Device Data

Raw data stored on the flash memory chip of the data logging device were transferred to a personal computer. The raw data files were then decompressed and analyzed using a custom
designed MATLAB\textsuperscript{3} program. The custom code computed the mobility characteristic variables of daily total distance traveled and average daily speed. The daily distance ($D_{\text{day}}$) was calculated using:

$$D_{\text{day}} = \frac{\text{(# of time stamps} \times C_{\text{wheel}})}{3}$$

where $C_{\text{wheel}}$ is the circumference of the wheelchair wheel on which the data logging device was mounted. Daily distance was measured in meters. To find the average speed ($S_{\text{day}}$) at which the wheelchair users traveled during a single day, the total daily distance ($D_{\text{day}}$) during the 24 hour period was divided by the total amount of time the wheelchair user was moving in their wheelchair during that day. The total length of time the wheelchair user was moving is defined below as the total accumulated movement time. $S_{\text{day}}$ was measured as meters/second.

The activity level variables of total accumulated drive time and number of starts/stops per thousand meters were also calculated using MATLAB code. The total accumulated movement time was calculated by summing the length of time between time stamps when the users were considered to be active (i.e. not in an idle state). Wheelchair users were considered to be idle or stopped if the amount of time between the current time stamp $t(i)$ and the next time stamp $t(i+1)$ exceeded seven seconds. The number of starts/stops per thousand meters ($N_{\text{stop/1000m}}$) was calculated using:

$$N_{\text{stop/1000m}} = \frac{N_{\text{stop/day}}}{D_{\text{day}}} \times 1000$$

where $N_{\text{stop/day}}$ is the total number of stops recorded during a single day. Averaging the number of start/stops per thousand meters was done to accommodate for differences in
mobility levels among the subject population. All data obtained after processing it through the MATLAB code were entered into Microsoft Excel for management purposes.

1.4.2.7 Data Analysis

All data were examined for normalcy. Gender, type of SCI (paraplegia or tetraplegia), type of wheelchair (manual or power) were described using frequency counts. Means and standard deviations were calculated for continuous data including age and years since diagnosis.

Data collected on the questionnaire for participants was combined to produce a score of frequency of community participation. A total score, ranged from 0 to 20, for frequency of community participation was created from the following questions: frequency of leaving home, frequency of using transportation, frequency of active recreation, frequency of socializing, and frequency of four leisure activities (dine out, attend movies, attend concerts, hobby). A subset of 4 questions of leisure activities (dine out, attend movies, attend concerts and hobby-include activities performed outside the house) were selected which we were felt to better describe community participation. Activities such as reading, playing cards, watching sports and playing board games were not included as there was a high probability that subjects were not leaving the house to perform them. Since there were four items measuring leisure activity but only one item measuring the other types of participation, leisure activities would be weighted more heavily than other types of community participation if the total score was created by simply averaging all 8 items. To avoid this unequal weighting, the average of the four leisure activity items was computed first. The remaining scores were averaged to produce the total score (See Appendix H).
Out of three weeks, the two weeks after the NVWG (when participants were at home) were averaged and used in the analyses to characterize the mobility characteristics of the subjects. Analysis of the week days and weekend average daily distance traveled, speed, number of starts and stops and daily drive minutes obtained from the data logger over the two week time period was compared to the community participation scores of the PARTS/M using a Pearson correlation. Since the number of starts and stops variable was not normally distributed the Spearman rho test was used instead. Further comparison was made between manual and power wheelchair users as they are using different mobility devices and may have different mobility patterns. An independent t-test was used to compare average daily distance, speed and drive minutes as they were normally distributed. As number of starts and stops variable was not normally distributed a Mann-whitney test was used. All statistical analyses were completed using SPSS v13.0 software. The significance level was set at $p < 0.05$. 
1.4.3 RESULTS

Data from 16 subjects collected over a two week period were used to describe the mobility patterns and activity levels of community participation of individuals who use manual wheelchairs and power wheelchairs. Out of 16 participants, 15 were men and 1 was a women with a mean age of 53 years (± 11.31). The majority of participants (n=12) were white, 3 were Black/African American and 1 was Indian/Alaska Native. The average time post injury was 21 years (± 10.11). Ten individuals had tetraplegia, 5 had paraplegia and 1 did not know their injury level. Seven subjects used manual wheelchairs and 9 used power wheelchairs. Three individuals were employed and 13 unemployed (out of 13 unemployed, 2 participants attended school). One individual uses his own non-adapted car/van, 10 individuals used their own adapted car/van and 4 individuals used only public transportation (buses and Para transit).

Considering the average of two weeks (14 days at total), data from the data logging device revealed that the 16 subjects traveled an average daily distance of 2827.75 (±1746.92) meters at a speed of 0.70 (± 0.21) meters/second. The maximum average daily distance traveled by a subject was 5855.29 meters. The average daily number of stops and starts that occurred was 156.87 (± 100.09). The subjects were also found to be driving for an average of 57.044 (± 31.04) min per day during the entire monitoring period. The average number of minutes the subjects were driving ranged from 10 to 107 min.

Considering week days, data from the data logging device revealed that the 16 subjects traveled an average daily distance of 2815.97 (±1762.93) meters at a speed of 0.69 (± 0.19) meters/second. The maximum average daily distance traveled by a subject was 6104.42 meters. The average daily number of stops and starts that occurred was 193.17 (± 155. 23). The subjects were also found to be driving for an average of 57.91 (± 32.35) min per day during the entire monitoring period. The average number of
minutes the subjects were driving ranged from 9 to 113 min (see Table 20). Results from average daily distance, speed, number of starts/stops and drive minutes during the week days (Monday trough Friday) weekend (Saturday and Sunday) are shown in table 20.

Table 20. Shows results from all participants on correlation between community participation scores and average daily distance, speed, number of stops/starts and active minutes during the week and weekend.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean ± SD (Range)</th>
<th>r (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Distance (m) week</td>
<td>2815.97 ± 1762.93 (499.62---6104.42)</td>
<td>.300 (.259)</td>
</tr>
<tr>
<td>Daily Distance (m) weekend</td>
<td>2885.91 ± 2114.63 (84.68---7127.52)</td>
<td>.038 (.888)</td>
</tr>
<tr>
<td>Daily Speed (m/s) week</td>
<td>0.69 ± 0.19 (0.33---1.08)</td>
<td>.615 (.011)</td>
</tr>
<tr>
<td>Daily Speed (m/s) weekend</td>
<td>0.72 ± 0.30 (0.06---1.30)</td>
<td>.090 (.741)</td>
</tr>
<tr>
<td>Daily Number Starts/Stops week (per 1000 meters)</td>
<td>187.17 ± 155.23 (29.29---658.06)</td>
<td>-.408 (.117)</td>
</tr>
<tr>
<td>Daily Number Starts/Stops weekend (per 1000 meters)</td>
<td>146.15 ± 118.82 (20.33---492.32)</td>
<td>.319 (.228)</td>
</tr>
<tr>
<td>Daily Drive minutes (min) week</td>
<td>57.11 ± 32.35 (9.32---113.81)</td>
<td>.270 (.312)</td>
</tr>
<tr>
<td>Daily Drive minutes (min) weekend</td>
<td>57.37 ± 34.64 (5.45---113.57)</td>
<td>.079 (.770)</td>
</tr>
</tbody>
</table>
A significant positive correlation was found \((r = .615, \ p = 0.011)\) between subject’s community participation scores and daily speed, indicating that faster subjects tend to have higher level of community participation (see table 20). The average community participation score was equal to 12.53 ± 3.25 (range from 1 to 20).

When individuals were divided by their type of mobility device (manual and power wheelchairs), a significant negative correlation \((r= -0.783, \ p = .013)\) was found between number of start and stops during week days and community participation scores, indicating that individuals who use power wheelchairs who have less number of starts and stops have higher level of community participation. Also, a significant positive correlation \((r = 0.772, \ p = .015)\) was found between daily drive minutes during week days and community participation scores, indicating that individuals who use power wheelchairs who drive their wheelchair more have higher level of community participation (see table 21). Individuals who use power wheelchairs had a community participation score of 11.63 ± 3.17 (range from 1 to 20).

In the manual wheelchair group, a significant positive correlation was found between speed during week days \((r = 0.760, \ p = .047)\) and community participation, indicating that individuals who travel at a higher speed have higher levels of community participation (see table 21). Individuals who use manual wheelchairs had community participation scores of 13.67 ± 3.20 (range form 1 to 20).

Table 21. Illustrates the correlations between mobility characteristics and community participation of manual and power wheelchair users.

<table>
<thead>
<tr>
<th>VARIABLES</th>
<th>MANUAL</th>
<th></th>
<th>POWER</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MEAN</td>
<td>SD</td>
<td>MEAN</td>
<td>SD</td>
</tr>
<tr>
<td>Daily Total Distance (m) week</td>
<td>2461.57</td>
<td>1741.60</td>
<td>.093 (.843)</td>
<td>3091.61</td>
</tr>
<tr>
<td>Daily Total Distance (m) weekend</td>
<td>2486.44</td>
<td>2299.13</td>
<td>.168 (.719)</td>
<td>3196.62</td>
</tr>
<tr>
<td>Daily Speed (m/s) week</td>
<td>0.75</td>
<td>0.19</td>
<td>.760 (.047)</td>
<td>0.65</td>
</tr>
<tr>
<td>Daily Speed (m/s) weekend</td>
<td>0.74</td>
<td>0.19</td>
<td>.698 (.081)</td>
<td>0.69</td>
</tr>
</tbody>
</table>
A comparison was also made between manual and power wheelchairs users regarding their mobility characteristics. Results showed that the only significant difference found between manual and power wheelchair users was regarding daily number of start and stops during the weekend (p = 0.030). Manual wheelchairs users had higher number of starts and stops during weekend than power wheelchair users (see table 2).

### 1.4.4 DISCUSSION

This study investigates the relationship between the mobility characteristics and level of community participation of individuals of SCI. The mobility patterns of manual and power wheelchair users were also identified. Manual wheelchair users traveled during week days an average daily distance of 2461 (± 1741) at a speed of 0.75 (± 0.19) meters/second. These results are supported by results from previous studies which also utilized a data logging device to collect data on the usage characteristics of manual wheelchair users. Tolerico et al.\(^8\) found that the average distance traveled were 2456 (± 1195) meters per day in the home environment at a speed of 0.79 (± 0.19). Souza et al.\(^16\) examined the mobility patterns of individuals with SCI that were more severely impaired (tetraplegia) and found the average daily distance traveled to be 1816 (± 1730) meters at a speed of 0.62 (± 0.18) meter/second. In addition, Fitzgerald et al.\(^17\) indicated the average daily distance of individuals with paraplegia who use manual wheelchairs to be 1671.4 ± 314.8 meters at a speed of 0.26 (± 0.05). Our study also indicated that individuals who use power wheelchairs travel an average daily distance of
3091 (± 1832) meters. This results are similar to Cooper et al.\textsuperscript{18} who found that the average distance traveled of power wheelchair users was 3432.8 (± 1741.6) meters per day at the National Veteran Wheelchair Games (NVWG) and 1667.0 (± 1414.8) meters per day in the home environment.

The data revealed that among manual wheelchair users (all of them were using ultralights wheelchairs), a significant positive correlation between speed during week days ($r=.760$, $p=.047$) and community participation, indicating that faster subjects tend to have higher levels of community participation. Being able to speed up is crucial in some daily circumstances, such as when crossing a street. If the traffic light changes and the person is still in the middle of the street, he or she might be in a dangerous situation. In addition, being able to go from one appointment to another during the day, sometimes require rapidity to arrive on time as well as fulfillment of all the required tasks. Going faster lets you go further in less time.

Examining only individuals who use power wheelchairs, a significant positive correlation ($r=.772$, $p=.015$) was found between average daily drive minutes during week days and community participation scores, indicating that individuals who drive their wheelchair longer have higher levels of community participation. Along these lines, Tolerico et al.\textsuperscript{8} found a significant correlation between employment status and drive hours per day with those who were employed being more active throughout the day. They also noted a trend towards significance between the average distance traveled ($p=0.066$) and average drive minutes ($p=0.086$) and employment status. Participation is defined as being involved in life situation, such as taking care of oneself and participates in productive occupations of work and leisure.\textsuperscript{21} Research has pointed out that mobility, the physical and social environment are seen as important predictors of community participation.\textsuperscript{5,22} Other studies have revealed that the severity of injury indirectly affects quality of life (QoL) through its influence on community participation.\textsuperscript{23,24} If the level of community participation valued by a person is not affected because of favorable conditions (e.g. appropriate environmental adaptations, social support), it is likely that subjective well-being will not be affected, regardless the severity of injury.\textsuperscript{5,25}
Therefore, individuals with more favorable conditions might be able to accomplish all their required activities throughout the day and consequently they use their power wheelchairs for a longer period of time. Furthermore, having an appropriate mobility device can significantly influence how a person with a disability perceives life.\textsuperscript{26} Power wheelchair options such as tilt-in-space and recline can increase overall function simply by increasing someone’s sitting tolerance.\textsuperscript{27} A person who can sit throughout the workday by periodically changing postures is more functional than someone who works only half-days because of poor sitting tolerance. Therefore, power wheelchair tilt-in-space and recline have helped persons with disabilities to rest comfortably in the chair during the day without having to return to bed or to transfer to a static chair.\textsuperscript{28} Power wheelchair functions impact positively on QoL \textsuperscript{29} as they allow participants to stay longer in their chairs, conserve energy, access a variety of environments and participate in more activities during the day.\textsuperscript{30}

Our study also found a significant negative correlation (r= -.783, p=.013) between number of start and stops during week days and community participation scores, indicating that individuals who use power wheelchairs who have less number of starts and stops have higher level of community participation. This may be also related to the fact of attending smaller and restricted environments. Because of that, power wheelchair users may have to stop more frequently to maneuver their wheelchair in confined spaces, for example making a sharp turns to pass through a doorway. Reduced mobility has been associated with difficulty in fulfilling daily activities, restrictions to participation in life \textsuperscript{22,23} and reduced quality of life.\textsuperscript{30}

The data logger provides a means to quantify and understand the mobility characteristics of individuals who use wheelchairs. The PARTS/M quantified the level of community participation of individuals with SCI. Relationships between mobility characteristics and community participation was identified in this study. By being aware of the mobility characteristics of a person, it may be possible for clinicians to try to facilitate the way ones propels a wheelchair through training and/or recommend a new wheelchair or modify the wheelchair set up to increase speed, drive time or reduce the number
of rests to overall enhance the community participation of individuals who use wheelchair as a primary means of mobility.

1.4.5 STUDY LIMITATION

There are several limitations to this study that need to be discussed. The sample size was small and primarily was made up of male veterans which limit the generalizability of the study. Obtaining a greater distribution of females and individuals from all age groups would provide a more comprehensive characterization of typical mobility patterns and drive levels of manual and power wheelchair users. Subjects may have over or underestimated activity during self report questionnaire. The study sample primarily collected information on individuals who use manual and power wheelchairs. Obtaining information from individuals who use different types of mobility devices, such as PAPAW or scooters would provide a more comprehensive characterization of other typical mobility patterns. The data logger device did not capture whether subjects where traveling in the home or out in the community. Hence, it would be interesting to explore differences in mobility patterns of wheelchairs users in these two environments. This study collected data only during the summer months, which due to weather conditions, is when individuals typically use their wheelchair the most. Collecting data during other times of the year would provide a more accurate estimation of mobility characteristics of wheelchair users.


10. Cooper, RA; Thorman, T; Cooper, R; Dvorznak, MJ; Fitzgerald, SG; Ammer, W; Song-Feng, G; Boninger, ML. Driving characteristics of electric-powered wheelchair users: How far, fast, and often to people drive? *Arch Phys Med Rehabil.* 2002; 83: 250-255.


27. Sprigle S. Physiologic Effects and Design Considerations of Tilt-and-Recline Wheelchairs. 


2.0 CONCLUSION

Based on our findings we can conclude that there is still room for improvement regarding wheelchair accessibility and measurement tools for assesses community participation of individuals with spinal cord injury (SCI). In our first chapter it was demonstrated that there are differences on the frequency of going to friends house, dine out and going to the doctors among individuals who different types of mobility devices. Individuals who use power wheelchairs visit their friends and dine out much less than individuals who use manual wheelchairs. Individuals with tetraplegia reported going to the doctor’s office less frequently than individuals with paraplegia. Therefore, differences on the frequency of daily activities between individuals with different injury level as well as different mobility devices was identified.

The study limitations including that the questionnaire, PARTS/M, consisted of a standardized set of questions (closed-ended questions). Therefore, it did not allow respondents to express their own personal viewpoints and in-depth analysis of respondents’ opinions was not possible to establish. Based on that, it was not possible to find the reasons why individuals who use manual wheelchairs go to a friend’s houses and dine out more often than individuals who use power wheelchairs. The same argument can be made for the difference found between individuals with paraplegia and tetraplegia regarding going to the doctor’s office. Another limitation was that we could not account for the quality of wheelchairs (standard and customized) in the analysis as the majority of the sample was using customized wheelchairs. In addition, controlling for difference between groups regarding level of injury and type of wheelchair, four groups were created (PM, PP, TM and TP) and as a result, sample
size and power decreased. There were a small number (n=6) of individuals with paraplegia who used power wheelchairs compared to the other groups. Furthermore, we did not control for differences in the community accessibility and health factors such as pain, which are likely important factors in determining frequency of community activities. Future studies should incorporate a larger sample size and investigate health and environmental limitations to community participation.

Our second chapter showed that although the majority of businesses and grocery stores are considered accessible overall (following the ADA guidelines), in fact, they are not truly accessible if small tasks or subtasks are examined. Accessibility of shelves and freezers was the most common physical barrier limiting participation in the grocery store. A significant amount of people with SCI are experiencing difficulty accessing adequate and appropriate primary healthcare services as waiting rooms and exam rooms was the most limiting physical barrier in the doctor’s office. In addition, tables too close together was the most common physical barrier limiting participation in restaurants followed by entrance and height of counters, tables and booths. In the movie theaters, stadium seating was pointed out as the most common physical barrier limiting participation. Width of aisles was the most common physical barrier limiting participation in clothing stores followed by height of clothing racks. Lack of paved paths was the most limiting factor to participation in the parks. In addition, a greater number of individuals with tetraplegia who use power wheelchairs (TP) reported that lack of personal assistance as a barrier that limits their participation in their place of employment when compared to those with paraplegia who use manual (PM), paraplegia who use power (PP) and tetraplegia who use manual (TM). A greater number of individuals with PP and TP indicated that lack of personal assistance as a barrier that limits their participation in the grocery store when compared to those with PM and TM.

Despite having a number of guidelines and standards, barriers to participation persist. Based on that, progress made over the years to improve access to buildings and employment may have not been sufficient and significant challenges related to accessibility still remained. The lack of consistency in
the methods used to measure access may be the reasons for individuals still find barriers. Most often access is determined by measuring a building’s compliance to existing regulations, focusing only on architectural artifacts, instead of the functional access experienced by the user. Annual critical surveys should be collected from individuals with disabilities to examine their functional perspective on the quality of the accessibility of commercial and employment facilities. Based on that, the ADA must be constantly updated with a more detailed guideline based on the needs of individuals with disability. Therefore, there is a need for further research to study functional access to public buildings and also develop a better measurement instruments to capture barriers to improve community participation of individuals with SCI.

In our third study it was demonstrated that no significant difference was found among individuals who received new wheelchairs delivered by specialized AT clinic and those who attended a non-specialized AT clinic on the frequency, satisfaction and number of perceived limitations to community participation. Instead of measuring the broad concept of community participation, we should understand the interaction between each daily activity performed by a person, the wheelchair and environment. Future studies should seek to further investigate the wheelchair prescription process using the Human Activity Assistive Technology Model (HAAT) model. With this in mind, and considering the potential impact of an appropriate environment on the level of satisfaction with wheelchair, investigating the extent to which individuals with SCI are receiving appropriate home or any other environmental modifications for optimal use of their wheelchair is important.

Another area that was not within the scope of this investigation, yet which bears great influence on the appropriateness of mobility device prescription is the amount of consumer education/training on the use of a wheelchair that is provided to individuals with SCI. Training and consumer education regarding wheelchair use is important given the importance of wheelchair propulsion techniques and set-up on the ability to effectively use a wheelchair. Therefore, it is important to investigate the
amount of training on the proper use of a wheelchair that individuals with SCI receive. Studying a larger number of individuals with a broader range of physical impairment or with newer injury may provide greater insight into the benefit of a specialized seating clinic in a wheelchair service delivery on individual’s with SCI daily activities. Using qualitative data in addition to empirical data will provide greater insights into human-technology- activity- environment interactions.

The fourth study demonstrated that during week days, 16 subjects traveled an average daily distance of 2815.97 (±1762.93) meters at a speed of 0.69 (± 0.19) meters/second. The maximum average daily distance traveled by a subject was 6104.42 meters. The average daily number of stops and starts that occurred was 193.17 (± 155. 23). The subjects were also found to be driving for an average of 57.91 (± 32.35) min per day during the entire monitoring period. The average number of minutes the subjects were driving ranged from 9 to 113 min.

A significant negative correlation (r=-.783, p=.013) was found between number of start and stops during week days and community participation scores, indicating that individuals who use power wheelchairs who have less number of starts and stops have higher level of community participation. A significant positive correlation (r=.772, p=.015) was found between daily drive minutes during week days and community participation scores, indicating that individuals who use power wheelchairs who drive their wheelchair more have higher level of community participation. In addition, in the manual wheelchair group, a significant positive correlation was found between speed during week days (r=.760, p=.047) and community participation, indicating that individuals who travel at a higher speed have higher levels of community participation.

The data logger provides a means to quantify and understand the mobility characteristics of individuals who use wheelchairs. The PARTS/M quantified the level of community participation of individuals with SCI. Relationships between mobility characteristics and community participation was identified in this study. By being aware of the mobility characteristics of a person, it may be possible
for clinicians to try to facilitate the way one propels a wheelchair through training and/or recommend a new wheelchair or modify the wheelchair set up to increase speed, drive time or reduce the number of rests to overall enhance the community participation of individuals who use wheelchair as a primary means of mobility.

There are several limitations to this study that need to be discussed. The sample size was small and primarily was made up of male veterans which limit the generalizability of the study. Obtaining a greater distribution of females and individuals from all age groups would provide a more comprehensive characterization of typical mobility patterns and drive levels of manual and power wheelchair users. Subjects may have over or underestimated activity during self report questionnaire. The study sample primarily collected information on individuals who use manual and power wheelchairs. Obtaining information from individuals who use different types of mobility devices, such as PAPAW or scooters would provide a more comprehensive characterization of other typical mobility patterns. The data logger device did not capture whether subjects where traveling in the home or out in the community. Hence, it would be interesting to explore differences in mobility patterns of wheelchairs users in these two environments. This study collected data only during the summer months, which due to weather conditions, is when individuals typically use their wheelchair the most. Collecting data during other times of the year would provide a more accurate estimation of mobility characteristics of wheelchair users. Futures studies should seek to further investigate the wheelchair mobility patterns using the HAAT model as a framework. Using qualitative data in addition to empirical data will provide greater insights into comparison on the individual’s mobility patterns and daily activities.
APPENDIX H

Illustrates the 5 questions related to the frequency of participating in major life activities:

1. How frequently do you leave your home?
   - □ Never
   - □ I choose not to do this
   - □ I am unable to do this
     (Go to question 3 on next page.)
     - □ Once or twice a month
     - □ Once or twice a week
     - □ Once or twice a day
     - □ 3 or more times a day

2. How **frequently** do you use transportation?
   - □ Never
   - □ I choose not to do this
   - □ I am unable to do this
     (Go to question 3 on next page)
     - □ Once or twice a month
     - □ Once or twice a week
     - □ Once or twice a day
     - □ More than twice a day

3. For the following leisure activities, please indicate **how often** you do them

<table>
<thead>
<tr>
<th>Leisure Activities</th>
<th>How often do you do the activity</th>
</tr>
</thead>
</table>
| Dine out          | □ Never
   - □ Less than once a month
   - □ 1-2 times a month
   - □ 1-2 times a week
   - □ More than twice a week |
| Attend movies     | □ Never
   - □ Less than once a month
   - □ 1-2 times a month
   - □ 1-2 times a week
   - □ More than twice a week |
<table>
<thead>
<tr>
<th>Activity</th>
<th>Frequency Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attend concerts</td>
<td>Never, Less than once a month, 1-2 times a month, 1-2 times a week, More than twice a week</td>
</tr>
<tr>
<td>Hobby (specify)</td>
<td>Never, Less than once a month, 1-2 times a month, 1-2 times a week, More than twice a week</td>
</tr>
</tbody>
</table>

4. **How often** do you participate in activity recreation?
   - Never
   - I choose not to do this (Go to question 4)
   - Less than once a month (Continue)
   - 1-2 times a month (Continue)
   - 1-2 times a week (Continue)
   - More than twice a week (Continue)

5. How **frequently** do you socialize with others?
   - Less than once a week
   - 1 to 2 times a week
   - 3 to 4 times a week
   - Daily or almost daily
A total score for community participation will be created from the following questions: frequency of leaving home, frequency of using transportation, frequency of active recreation, frequency of socializing, and frequency of eight leisure activities (dine out, attend movies, attend concerts and hobby). Since there are 4 items measuring leisure activity but only one item measuring the other types of participation, leisure activities would be weighted more heavily than other types of community participation if the total score was created by simply averaging all 8 items. To avoid this unequal weighting, the average of the 4 leisure activity items will be computed first. Next the following scores will be averaged to produce the total score:

<table>
<thead>
<tr>
<th>Frequency leaving home (1 questions)</th>
<th>Frequency of using transportation (1 question)</th>
<th>Frequency of leisure activities (4 questions)</th>
<th>Frequency of Active Recreation (1 question)</th>
<th>Frequency of socializing (1 question)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never = 0</td>
<td>Never = 0</td>
<td>Never = 0</td>
<td>Never = 0</td>
<td>Less than once a week=1</td>
</tr>
<tr>
<td>1-2 month = 1</td>
<td>1-2 month = 1</td>
<td>Less than once a month=1</td>
<td>Less than once a month=1</td>
<td>1-2 week = 2</td>
</tr>
<tr>
<td>1-2 week = 2</td>
<td>1-2 week = 2</td>
<td>1-2 month = 2</td>
<td>1-2 month = 2</td>
<td>3-4 week = 3</td>
</tr>
<tr>
<td>1-2 day = 3</td>
<td>1-2 day = 3</td>
<td>1-2 week = 3</td>
<td>1-2 week = 3</td>
<td>Daily or almost daily = 4</td>
</tr>
<tr>
<td>3 or more times a day = 4</td>
<td>More than twice day = 4</td>
<td>More than twice a week = 4</td>
<td>More than twice a week = 4</td>
<td></td>
</tr>
<tr>
<td>(Score range = 0 - 4)</td>
<td>(Score range = 0 - 4)</td>
<td>(Mean score with all the 4 leisure activity questions will be computed)</td>
<td>(Score range = 0 - 4)</td>
<td>(Score range = 0 - 4)</td>
</tr>
</tbody>
</table>

**Total score range** = average score for leisure activities + score for each of the other four types items.
APPENDIX I

Core survey
YOU AND YOUR HEALTH

This interview is completely voluntary on your part. The questions will take about two hours of your time to answer. There are three sections to this interview. The first section includes questions about background information and health status; the second section involves participation in various activities; and the last section deals with the accessibility of your physical environment and support systems. Please select the answers most appropriate to you. Thank you for agreeing to participate.

1. What is your gender?  
   □ Male  □ Female

2. What is your birthdate? ___ / ___ / ___ (MM/DD/YY)

3. What is your race/ethnicity? (Check all that apply.)
   □ White  □ Asian/Pacific Islander
   □ Black/African American  □ American Indian/Alaskan Native
   □ Other (specify) __________________________

4. Are you of Spanish/Hispanic origin?  
   □ Yes  □ No

5. Are you: (Check all that apply.)
   □ Married  □ Separated
   □ Divorced  □ Never been married
   □ Widowed  □ Member of an unmarried couple

6. What is the highest grade or year of school you have completed?  
   □ Never attended school or only kindergarten
   □ Grades 1 through 8
   □ Grades 9 through 11
   □ Grade 12 or GED (high school graduate)
   □ College 1 year to 3 years
   □ College 4 years or more (college graduate)
7. Is your annual household income from all sources:
   - Less than $10,000
   - $10,000 to less than $15,000
   - $15,000 to less than $20,000
   - $20,000 to less than $25,000
   - $25,000 to less than $35,000
   - $35,000 to less than $50,000
   - $50,000 to $75,000 or
   - Over $75,000
   - Don’t know/Not sure

8. Which of the following benefits are you currently receiving? (Check all that apply.)
   - SSI (Supplemental Security Income)
   - SSDI (disability benefits from Social Security)
   - Medicare
   - Medicaid
   - Food Stamps
   - Subsidized Housing
   - Personal Care Assistance
   - Meals on Wheels
   - Other ______________________________
   - None

9. Do you have any of the following impairments? (Check all that apply.)
   - Mobility impairment (difficulty moving your legs or arms)
   - Visual impairment
   - Hearing impairment
   - Cognitive impairment (difficulty with thinking)
   - Mental health illness

10. What level is your spinal cord injury? ________

11. Are you a person with:  
    - Paraplegia
    - Quadriplegia
    - Don’t know

12. Is your injury:  
    - Complete
    - Incomplete
    - Don’t know

13. When was the onset of your spinal cord injury? __ __ / __ __ __ __ (month/year)

Do you have any of the following secondary conditions? If Yes, how often do you experience the condition?

<table>
<thead>
<tr>
<th>Condition</th>
<th>How often do you experience this condition?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Check all that apply.</td>
<td></td>
</tr>
<tr>
<td>1. Pain</td>
<td>Constantly   Off and on   Rarely</td>
</tr>
<tr>
<td>2. Osteoporosis</td>
<td>Constantly   Off and on   Rarely</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>3. Spasticity</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>4. Upper Respiratory Infection</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>5. Circulatory problems</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>6. Scoliosis</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>7. Weight problems</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>8. Skin problems</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>9. Depression</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>10. Contractures – permanent limitation of joint movement</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>11. Bladder incontinence</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>12. Bowel incontinence</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>13. Stomach problems</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>14. Urinary Tract Infection</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>15. High Blood Pressure</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>16. Phlebitis – inflammation of blood vessels</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>17. Fingernail or toenail infections</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>18. Fatigue</td>
<td>✓ Constantly  ✓ Off and on  ✓ Rarely</td>
</tr>
<tr>
<td>19. None of these</td>
<td></td>
</tr>
</tbody>
</table>

These next two questions are about your support needs and life satisfaction.

1. How often do you get the social and emotional support you need?
   - Always
   - Usually
   - Sometimes
   - Rarely
   - Never
2. In general, how satisfied are you with your life? Would you say . . .

☐ Very satisfied
☐ Satisfied
☐ Dissatisfied
☐ Very dissatisfied

The following questions are about limitations you may have in your Daily life.

1. Are you limited in the kind or amount of work you could do because of any impairment or health problem?
   ☐ Yes
   ☐ No

2. Because of any impairment or health problem, do you have any trouble learning, Remembering or concentrating?
   ☐ Yes
   ☐ No

3a. Do you use special equipment or help from others to get around?
   ☐ Yes (Continue.)
   ☐ No special equipment or help used (Go to Question 5)

   *********************************************************

3b. If you use special equipment or help from others to get around, what type do you use? (Check all that apply.)
   ☐ Other people
   ☐ Cane or walking stick
   ☐ Walker
   ☐ Crutch or crutches
   ☐ Manual wheelchair
   ☐ Motorized wheelchair
   ☐ Electric mobility scooter
   ☐ Artificial leg
   ☐ Brace
   ☐ Service Animal (i.e., guide dog or other specifically trained to assistance)
   ☐ Other (Specify) _____________________

4. Using special equipment or help, what is the farthest distance that you can go?
   ☐ Across a small room
   ☐ About the length of a typical house
   ☐ About one or two city blocks
   ☐ About one mile
   ☐ More than one mile
5. What is the farthest distance you can walk by yourself, without any special equipment or help from others?
   - [ ] Unable to walk
   - [ ] Across a small room
   - [ ] About the length of a typical house
   - [ ] About one or two city blocks
   - [ ] About one mile
   - [ ] More than one mile

6. Are you LIMITED in any way in any activities because of any impairment or health problem?
   - [ ] Yes
   - [ ] No (Go to question 9.)

7. What is the MAJOR impairment or health problem that limits your activities?
   - [ ] Arthritis/rheumatism
   - [ ] Back or neck problem
   - [ ] Fractures, bone/joint injury
   - [ ] Walking problem
   - [ ] Lung/breathing problem
   - [ ] Hearing problem
   - [ ] Eye/vision problem
   - [ ] Heart problem
   - [ ] Stroke problem
   - [ ] Hypertension/high blood pressure
   - [ ] Diabetes
   - [ ] Cancer
   - [ ] Depression/anxiety/emotional problem
   - [ ] Other impairment/problem □ Not applicable

8. For HOW LONG have your activities been limited because of your major impairment or health problem?
   - [ ] Days ▶ How many days? _____
   - [ ] Weeks ▶ How many weeks? _____
   - [ ] Months ▶ How many months? _____
   - [ ] Years ▶ How many years? _____
   - [ ] Not applicable

9. Because of any impairment or health problem, do you need the help of other persons with your PERSONAL CARE needs, such as eating, bathing, dressing, or getting around the house?
   - [ ] Yes
   - [ ] No
   - [ ] Not applicable

10. Because of any impairment or health problem, do you need the help of other persons in handling your ROUTINE needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?
    - [ ] Yes
    - [ ] No
    - [ ] Not applicable
11. During the past 30 days, for about how many days did PAIN make it hard for you to do your usual activities, such as self-care, work, or recreation?

11a. ☐ Number of days: _______  ☐ None

12. During the past 30 days, for about how many days have you felt SAD, BLUE, or DEPRESSED?

12a. ☐ Number of days: _______  ☐ None

13. During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS?

13a. ☐ Number of days: _______  ☐ None

14. During the past 30 days, for about how many days have you felt you did NOT get ENOUGH REST or SLEEP?

14a. ☐ Number of days: _______  ☐ None

15. During the past 30 days, for about how many days have you felt VERY HEALTHY AND FULL OF ENERGY?

15a. ☐ Number of days: _______  ☐ None
The first part of the survey is completed. The next section asks about participation in major life activities. This part consists of 13 different areas of major life activities, and the questions are similar in each area. Please answer the questions using the framework of a typical day in the past 4 weeks. A typical day is neither your worst day nor your best day but represents most of your days during the past 4 weeks.

The following definitions may help you answer these survey questions:

**Choice** means having the opportunity to select freely from a number of available options concerning when, where, how, how often, and with whom you participate in an activity.

**Help from another person** refers to either paid help (such as a paid attendant) or unpaid help (such as from a family member or friend).

**Access limitations** may be anything that keeps you from participating in activities (such as people’s attitudes, your self-concept, physical factors in the environment, or lack of special equipment).

**Adaptations** are changes made to rooms or buildings, such as lowered shelves or widened doors, or the use of special devices, such as a raised toilet, hand-held shower, grab bars, a ramp, or a modified cutting board to secure food. Adaptations could also include choosing to purchase such things as a portable phone instead of a stationary phone, a long-handled shoehorn instead of a short one, or a refrigerator with a freezer on the side or bottom instead of on the top.

**Accommodations** are ways of changing your environment to make activities easier to do. Some examples are placing items within reach, arranging furniture so that you can move around more easily, scheduling preparation time for activities, or calling ahead to check on accessibility.

**Special equipment** is equipment made especially for people with disabilities, including, but Not Limited to, a wheelchair, scooter, walker, cane, crutches, orthotic or prosthetic device, reacher, communication board, sliding board, adapted vehicle, lift, or an accessible Parking permit. Also included would be a catheter for bladder management.
1. How **frequently** do you groom?
   - ☐ 2 or 3 times a week  ☐ Once a day  ☐ 2 - 3 times a day  ☐ More than 3 times a day

2. How much **time** do you require for grooming on a typical day?
   - ☐ Less than 10 minutes  ☐ 10 to 20 minutes  ☐ More than 20 minutes

3. Is your participation in grooming **limited** by …
   (Check all that apply.)
   - ☐ Illness  ☐ A physical impairment  ☐ Pain  ☐ Fatigue  ☐ Wheelchair
   - ☐ Wheelchair seating  ☐ Other __________________________  ☐ Not limited

4. When grooming, how much **choice** do you have compared to others without disabilities? (Choice includes how often, when, where and how you groom.)
   - ☐ A lot of choice  ☐ Some choice  ☐ Little choice  ☐ No choice

5. How **satisfied** are you with your participation in grooming?
   - ☐ Very satisfied  ☐ Satisfied  ☐ Somewhat satisfied  ☐ Dissatisfied

6. How much **help from another person** do you require for grooming?
   - ☐ None  ☐ Just a little  ☐ A moderate amount  ☐ A great deal

7. If you use assistance, who helps you with grooming? (Check all that apply.)
   - ☐ No one  ☐ Family/Significant Other  ☐ Friends  ☐ People I hire

8. How often do you use **accommodations, adaptations, or special equipment** to groom?
   - ☐ Never  ☐ A little of the time  ☐ Some of the time  ☐ Most of the time  ☐ All of the time

9. If you use **accommodations, adaptations, or special equipment** to groom, what do you use? (Check all that apply.)
   - ☐ N/A  ☐ Dressing table  ☐ Orthotic/prosthetic device
   - ☐ Electric shaver  ☐ Shower chair  ☐ Electric toothbrush  ☐ Special grooming device
   - ☐ Grab bars  ☐ Specialized bathroom equipment  ☐ Lift  ☐ Special seat/chair
   - ☐ Long-handled equipment  ☐ Lowered shelves/counters  ☐ Wheelchair - manual  ☐ Wheelchair - power
   - ☐ Wheelchair seating  ☐ Other __________________________
MEAL PREPARATION and CLEAN-UP: The following questions involve meal preparation and cleaning after the meal is finished.

1. In a typical day, how much time do you spend on meal preparation and cleanup?
   - None
   - I choose not to do this
   - I am unable to do this
   - Under 1 hour

2. Is your participation in meal preparation limited by ... (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other_________________________
   - Not limited

3. For meal preparation and clean-up, how much choice do you have compared to others without disabilities?
   (Choice includes when, what, where and with whom you prepare meals.)
   - A lot of choice
   - Some choice
   - Little choice
   - No choice

4. How satisfied are you with your participation in meal preparation and clean-up?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

5. How much help from another person do you need to prepare/clean up?
   (Check all that apply.)
   - None
   - Just a little
   - A moderate amount
   - A great deal

   If you use assistance, who helps you to prepare and clean up?
   (Check all that apply.)
   - No one
   - Family/Significant Other
   - Friends
   - People I hire

6. How often do you use accommodations, adaptations, or special equipment to prepare and clean up?
   - Never
   - A little of the time
   - Some of the time
   - Most of the time
   - All of the time

7. If you use accommodations, adaptations, or special equipment for meal preparation, what do you use? (Check all that apply.)
   (N/A
   - Cane
   - Adaptive cooking utensils
   - Lap board/TV tray
   - Specialized wheelchair
   - Lowered shelves/counters
   - Orthotic/prosthetic device
   - Wheelchair - manual
   - Wheelchair seating
   - Scooter
   - Special seat/chair
   - Specialized kitchen equipment
   - Universal cuff
   - Reacher/grab stick/grabber
   - Walker
   - Wheelchair – power
   - Other ____________________
BLADDER CARE: The next questions involve emptying your bladder, which includes getting to a bathroom, adjusting clothing, using accommodations, or using special equipment.

1. How much time do you require for bladder care on a typical day?
   - Less than 30 minutes
   - 30 to 60 minutes
   - More than 60 minutes

2. Is your participation in performing and managing bladder care limited by …
   (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other
   - Not limited

3. For management of bladder care, how much choice do you have compared to others without disabilities? (Choice includes when, where and how care takes place.)
   - A lot of choice
   - Some choice
   - Little choice
   - No choice

4. How satisfied are you with your participation in bladder care?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

5. Do problems associated with bladder care affect your participation in Daily activities, such as attending a movie, going shopping, or working?
   - No, not at all
   - Once in a while
   - Sometimes
   - Most of the time

6. How much help from another person do you require for bladder care?
   - None
   - Just a little
   - A moderate amount
   - A great deal

7. If you use assistance, who helps you with bladder care? (Check all that apply.)
   - No one
   - Family/Significant Other
   - Friends
   - People I hire

8. How often do you use accommodations, adaptations, or special equipment for bladder care?
   - Never
   - A little of the time
   - Some of the time
   - Most of the time
   - All of the time

9. If you use accommodations, adaptations, or special equipment for bladder care, what do you use? (Check all that apply.)
   - N/A
   - Absorbency pads/undergarments
   - Grab bars
   - Accessible bathroom
   - Medication
   - Urinal/bedpan/potty chair
   - Orthotic/prosthetic device
   - Catheter
   - Raised toilet
   - Leg bag/overnight bags/bed bags
   - Shower chair
   - Wheelchair - manual
   - Wheelchair - power
   - Wheelchair seating
   - Other ____________________
MOVING AROUND INSIDE YOUR HOME: The following questions are about moving around inside your home. This includes getting out of bed, getting out of a chair, going from room to room or getting to another floor, such as the basement.

1. How many waking hours each day do you spend in the following rooms of your home?

<table>
<thead>
<tr>
<th>Room</th>
<th>Less than 1</th>
<th>1 to 4</th>
<th>More than 4</th>
<th>Not applicable to my home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living room</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dining room</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kitchen</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathroom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bedroom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Is your participation in moving around your home limited by …
(Choose all that apply.)

- Illness
- A physical impairment
- Pain
- Fatigue
- Wheelchair sitting
- Wheelchair
- Other
- Not limited

3. When moving around your home, how much choice do you have compared to others without disabilities? (Choice includes when, where and how you move around).

- A lot of choice
- Some choice
- Little choice
- No choice

4. How satisfied are you with your participation in moving around your home?

- Very satisfied
- Satisfied
- Somewhat satisfied
- Dissatisfied

5. Do problems associated with moving around your home affect your participation in Daily activities, such as doing laundry, cooking, or making home repairs?

- No, not at all
- Once in a while
- Sometimes
- Most of the time

6. How much help from another person do you need to move around your home?

- None
- Just a little
- A moderate amount
- A great deal

7. If you use assistance, who helps you move around your home?
(Choose all that apply.)

- No one
- Family/Significant Other
- Friends
- People I hire
MOVING AROUND INSIDE YOUR HOME (continued)

8. How often do you use accommodations, adaptations, or special equipment to move around your home?
   - Never
   - A little of the time
   - Some of the time
   - Most of the time
   - All of the time

9. If you use accommodations, adaptations, or special equipment to move around your home, what do you use? (Check all that apply.)
   - N/A
   - Lift
   - Wheelchair - manual
   - Wheelchair seating
   - Other _________________
   - Walker
   - Orthotic/prosthetic device
   - Wheelchair - power
   - Widened doors
   - Cane
   - Scooter
   - Crutches
   - Special seat or chair
   - Grab bars
   - Ramp
   - Hand rails
LEAVING YOUR HOME: The following questions are about leaving your home to go into the community (such as to go shopping or to the doctor). This includes getting into a vehicle.

1. How frequently do you leave your home?
   - Never
   - I choose not to do this
   - I am unable to do this
   (Go to question 3 on next page.)
   - Once or twice a month (Continue)
   - Once or twice a week (Continue)
   - Once or twice a day (Continue)
   - 3 or more times a day (Continue)

2. For the following activities you do outside your home, please indicate how often you do each activity and how long it takes you to prepare to do them.

<table>
<thead>
<tr>
<th>Community Activities</th>
<th>How often do you do the activity?</th>
<th>(Please answer corresponding follow-up question)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping for groceries</td>
<td>❑ Never</td>
<td>❑ I choose not to do this activity</td>
</tr>
<tr>
<td></td>
<td>❑ Less than once a month</td>
<td>❑ Preparation time</td>
</tr>
<tr>
<td></td>
<td>❑ 1-2 times a month</td>
<td>❑ Under 10 minutes</td>
</tr>
<tr>
<td></td>
<td>❑ 1-2 times a week</td>
<td>❑ 10-20 minutes</td>
</tr>
<tr>
<td></td>
<td>❑ More than twice a week</td>
<td>❑ More than 20 minutes</td>
</tr>
<tr>
<td>Shopping for clothes</td>
<td>❑ Never</td>
<td>❑ I choose not to do this activity</td>
</tr>
<tr>
<td></td>
<td>❑ Less than once a month</td>
<td>❑ Preparation time</td>
</tr>
<tr>
<td></td>
<td>❑ 1-2 times a month</td>
<td>❑ Under 10 minutes</td>
</tr>
<tr>
<td></td>
<td>❑ 1-2 times a week</td>
<td>❑ 10-20 minutes</td>
</tr>
<tr>
<td></td>
<td>❑ More than twice a week</td>
<td>❑ More than 20 minutes</td>
</tr>
<tr>
<td>Going to the pharmacy</td>
<td>❑ Never</td>
<td>❑ I choose not to do this activity</td>
</tr>
<tr>
<td></td>
<td>❑ Less than once a month</td>
<td>❑ Preparation time</td>
</tr>
<tr>
<td></td>
<td>❑ 1-2 times a month</td>
<td>❑ Under 10 minutes</td>
</tr>
<tr>
<td></td>
<td>❑ 1-2 times a week</td>
<td>❑ 10-20 minutes</td>
</tr>
<tr>
<td></td>
<td>❑ More than twice a week</td>
<td>❑ More than 20 minutes</td>
</tr>
<tr>
<td>Going to the bank</td>
<td>❑ Never</td>
<td>❑ I choose not to do this activity</td>
</tr>
<tr>
<td></td>
<td>❑ Less than once a month</td>
<td>❑ Preparation time</td>
</tr>
<tr>
<td></td>
<td>❑ 1-2 times a month</td>
<td>❑ Under 10 minutes</td>
</tr>
<tr>
<td></td>
<td>❑ 1-2 times a week</td>
<td>❑ 10-20 minutes</td>
</tr>
<tr>
<td></td>
<td>❑ More than twice a week</td>
<td>❑ More than 20 minutes</td>
</tr>
</tbody>
</table>
LEAVING YOUR HOME (continued)

<table>
<thead>
<tr>
<th>Community Activities</th>
<th>How often do you do the activity?</th>
<th>(Please answer corresponding follow-up question)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Going to the doctor’s office</td>
<td>❏ Never ➔</td>
<td>❏ I choose not to do this activity ❏ I am unable to do this activity</td>
</tr>
<tr>
<td></td>
<td>❏ Less than once a month ❏ 1-2 times a month ❏ 1-2 times a week ❏ More than twice a week ➔</td>
<td>Preparation time ❏ Under 10 minutes ❏ 10-20 minutes ❏ More than 20 minutes</td>
</tr>
<tr>
<td>Going to the post office</td>
<td>❏ Never ➔</td>
<td>❏ I choose not to do this activity ❏ I am unable to do this activity</td>
</tr>
<tr>
<td></td>
<td>❏ Less than once a month ❏ 1-2 times a month ❏ 1-2 times a week ❏ More than twice a week ➔</td>
<td>Preparation time ❏ Under 10 minutes ❏ 10-20 minutes ❏ More than 20 minutes</td>
</tr>
<tr>
<td>Going to the friend’s home</td>
<td>❏ Never ➔</td>
<td>❏ I choose not to do this activity ❏ I am unable to do this activity</td>
</tr>
<tr>
<td></td>
<td>❏ Less than once a month ❏ 1-2 times a month ❏ 1-2 times a week ❏ More than twice a week ➔</td>
<td>Preparation time ❏ Under 10 minutes ❏ 10-20 minutes ❏ More than 20 minutes</td>
</tr>
<tr>
<td>Other (specify)</td>
<td>❏ Never ➔</td>
<td>❏ I choose not to do this activity ❏ I am unable to do this activity</td>
</tr>
<tr>
<td></td>
<td>❏ Less than once a month ❏ 1-2 times a month ❏ 1-2 times a week ❏ More than twice a week ➔</td>
<td>Preparation time ❏ Under 10 minutes ❏ 10-20 minutes ❏ More than 20 minutes</td>
</tr>
</tbody>
</table>

3. Is your access to leaving your home to go out into the community limited by ... (Check all that apply.)

- Physical factors in the environment
- Social attitudes
- Family attitudes
- Self-concept
- Lack of assistance
- Wheelchair
- Wheelchair seating
- Lack of special equipment ➔ What equipment would be helpful?

- Other (specify) ____________________________
- Not limited
4. Is your participation in leaving your home limited by … (Check all that apply.)
- Illness
- A physical impairment
- Pain
- Fatigue
- Wheelchair
- Wheelchair seating
- Other___________________________
- Not limited

5. To leave your home, how much choice do you have compared to others
   without disabilities? (Choice includes how often, when, and how you leave
   and where you go.)
- A lot of choice
- Some choice
- Little choice
- No choice

6. How satisfied are you with your participation in leaving your home?
- Very satisfied
- Satisfied
- Somewhat satisfied
- Dissatisfied

7. How important is it for you to leave your home?
- Very important
- Somewhat important
- Somewhat unimportant
- Not important

8. How much time do you need to prepare to go to a place that is ...
   a. Unfamiliar?
   - Less than 10 minutes
   - 10 to 30 minutes
   - More than 30 minutes
   b. Familiar?
   - Less than 10 minutes
   - 10 to 30 minutes
   - More than 30 minutes

9. How much help from another person do you need to leave your home?
- None
- Just a little
- A moderate amount
- A great deal

10. If you use assistance, who helps you with leaving your home? (Check all that apply.)
   - No one
   - Family/Significant Other
   - Friends
   - People I hire

11. How often do you use accommodations, adaptations, or special equipment to leave your home?
   - Never
   - A little of the time
   - Some of the time
   - Most of the time
   - All of the time

12. If you use accommodations, adaptations, or special equipment to leave your home, what do you use? (Check all that apply.)
   - N/A
   - Walker
   - Wheelchair seating
   - Wheelchair - manual
   - Wheelchair - power
   - Pedal for car
   - Widened doors
   - Ramp
   - Scooter
   - Grab bars
   - Vehicle (not adapted)
   - Other___________________________
TRANSPORTATION: The following questions involve accessing and using different forms of transportation.

1. How frequently do you use transportation?

   - Never
   - I choose not to do this
   - I am unable to do this
   (Go to question 3 on next page)
   - Once or twice a month
   - Once or twice a week
   - Once or twice a day
   - More than twice a day

2. Which of the following types of transportation do you use and how do they influence your participation in activities?

<table>
<thead>
<tr>
<th>Please check all forms of transportation that you use</th>
<th>Overall, how does this type of transportation influence your Participation in activities?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own car/van (not adapted)</td>
<td>Helps a lot</td>
</tr>
<tr>
<td>Own adapted car/van</td>
<td>Helps a lot</td>
</tr>
<tr>
<td>Buses</td>
<td>Helps a lot</td>
</tr>
<tr>
<td>Taxis</td>
<td>Helps a lot</td>
</tr>
<tr>
<td>Airlines</td>
<td>Helps a lot</td>
</tr>
<tr>
<td>Light rail / subway</td>
<td>Helps a lot</td>
</tr>
<tr>
<td>Special services:</td>
<td>Helps a lot</td>
</tr>
<tr>
<td>------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Paratransit</td>
<td></td>
</tr>
<tr>
<td>(such as Call-A-Ride)</td>
<td></td>
</tr>
<tr>
<td>Adapted taxi</td>
<td></td>
</tr>
<tr>
<td>Adapted rental car/van</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>_______________</td>
<td></td>
</tr>
</tbody>
</table>

**TRANSPORTATION (continued)**

3. Is your access to using transportation limited by ...  
   (Check all that apply.)
   - Physical factors in the environment
   - Social attitudes
   - Family attitudes
   - Self-concept
   - Lack of assistance
   - Limited finances
   - Wheelchair
   - Wheelchair seating
   - Lack of special equipment ➔ What equipment would be helpful?
   - Other (specify) ________________________________
   - Not limited

4. Is your participation in using transportation limited by ...  
   (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other ________________________________
   - Not limited

5. How much choice do you have about using transportation, compared to others without disabilities?  
   (Choice includes when, where, how and with whom you use transportation.)
   - A lot of choice
   - Some choice
   - Little choice
   - No choice

6. How satisfied are you with your participation in using transportation?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

7. How important is it for you to use transportation?
   - Very important
   - Somewhat important
   - Somewhat unimportant
   - Not important

8. How much help from another person do you need when using transportation?
   - None
   - Just a little
   - A moderate amount
   - A great deal

9. If you use assistance, who helps you to use transportation?  
   (Check all that apply.)
   - No one
   - Family/Significant Other
   - Friends
   - People I hire

10. How often do you use accommodations, adaptations, or special equipment when using transportation?
    - Never
    - A little of the time
    - Some of the time
    - Most of the time
    - All of the time
11. If you use accommodations, adaptations, or special equipment when using transportation, what do you use? (Check all that apply.)

☐ N/A
☐ Accessible parking permit ☐ Lift
☐ Adapted vehicle ☐ Ramp
☐ Cane ☐ Scooter
☐ Crutches ☐ Walker
☐ Door opener ☐ Orthotic/prosthetic device
☐ Wheelchair - manual ☐ Wheelchair - power
☐ Wheelchair seating ☐ Other __________________

TAKING VACATIONS: The next questions are about taking vacations away from home.

1. How often do you take a vacation?
   ☐ Never ☐ I choose not to do this ☐ I am unable to do this
   ☐ Less than once a year
   ☐ Once or twice a year
   ☐ More than twice a year

2. Is your access to vacations limited by ... (Check all that apply.)
   ☐ Physical factors in the environment ☐ Social attitudes ☐ Family attitudes
   ☐ Self-concept ☐ Limited finances ☐ Lack of assistance
   ☐ Wheelchair ☐ Wheelchair seating
   ☐ Lack of special equipment ☐ What equipment would be helpful?
   ________________________________
   ☐ Other (specify) ____________________________
   ☐ Not limited

3. Is your participation in taking a vacation limited by ... (Check all that apply.)
   ☐ Illness ☐ A physical impairment ☐ Pain ☐ Fatigue ☐ Wheelchair
   ☐ Wheelchair seating ☐ Other______________________________ ☐ Not limited

4. When taking a vacation, how much choice do you have compared to others without disabilities? (Choice includes how, where, when and how often you take a vacation.)
   ☐ A lot of choice ☐ Some choice ☐ Little choice ☐ No choice

5. How satisfied are you with your participation in taking a vacation?
   ☐ Very satisfied ☐ Satisfied ☐ Somewhat satisfied ☐ Dissatisfied

6. How important is it for you to take a vacation?
   ☐ Very important ☐ Somewhat important ☐ Somewhat unimportant ☐ Not important

7. If you haven’t taken a vacation in the last year, would you like to? ☐ Yes ☐ No

   IF YOU TAKE VACATIONS:

8. How much time do you need to prepare for a vacation? (This might include
arranging airline seating or accessible lodging.)

- Under 1 hour
- 1 to 3 hours
- More than 3 hours

TAKING A VACATION (continued)

9. How much help from another person do you need to take a vacation?
   - None
   - Just a little
   - A moderate amount
   - A great deal

10. If you use assistance, who helps you with taking a vacation?
   (Check all that apply.)
   - No one
   - Family/Significant Other
   - Friends
   - People I hire

11. How often do you use accommodations, adaptations, or special equipment for a vacation?
   - Never
   - A little of the time
   - Some of the time
   - Most of the time
   - All of the time

12. If you use accommodations, adaptations, or special equipment to take a vacation, what do you use? (Check all that apply.)

   - N/A
   - Accessible parking permit
   - Ramp
   - Adapted vehicle
   - Scooter
   - Cane
   - Special chair
   - Crutches
   - Walker
   - Lift
   - Orthotic/Prosthetic device
   - Wheelchair - manual
   - Wheelchair - power
   - Wheelchair seating
   - Vehicle
   - Other ______________________

150
WORKING INSIDE YOUR HOME: The following questions refer to working inside your home.

1. How **frequently** do you participate in housework or home maintenance activities?
   - Never
   - I choose not to do this
   - I am unable to do this
   - 1 to 2 times a week
   - 3 to 4 times a week
   - 5 or more times a week

2. Is your participation in housework or home maintenance **limited** by …
   (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other ______________________
   - Not limited

3. To participate in housework or home maintenance activities, how much **choice** do you have compared to others without disabilities? (Choice includes how often, when, how and by whom these activities are completed.)
   - A lot of choice
   - Some choice
   - Little choice
   - No choice

4. How **satisfied** are you with your participation in housework or home maintenance?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

5. How **important** is it for you to participate in housework or home maintenance?
   - Very important
   - Somewhat important
   - Somewhat unimportant
   - Not important

**IF YOU PARTICIPATE IN HOUSEWORK OR HOME MAINTENANCE ACTIVITIES:**

6. How much **help from another person** do you require?
   - None
   - Just a little
   - A moderate amount
   - A great deal

7. If you use assistance, **who helps you** with housework or home maintenance?
   (Check all that apply.)
   - No one
   - Family/Significant Other
   - Friends
   - People I hire

8. How often do you use **accommodations, adaptations, or special equipment** for housework or home maintenance activities?
   - Never
   - A little of the time
   - Some of the time
   - Most of the time
   - All of the time

9. If you use **accommodations, adaptations, or special equipment** for housework or home maintenance activities, what do you use? (Check all that apply.)
   - N/A
   - Cane
   - Scooter
   - Walker
   - Computer
   - Stair glide
   - Wheelchair - power
   - Crutches
   - Special seat/chair
- Wheelchair - manual
- Lowered shelves/counters
- Reacher/grab stick/grabber
- Orthotic/prosthetic device
- Urinal/bedpan/potty chair
- Wheelchair seating
- Other __________________
LEISURE ACTIVITIES: The following questions are about leisure activities, such as spectator sports, playing cards and going to movies.

1. For the following leisure activities, please indicate **how often** you do them and **how long** it takes you to prepare to do them.

<table>
<thead>
<tr>
<th>Leisure Activities</th>
<th>How often do you do the activity</th>
<th>Preparation time (in minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dine out</td>
<td>Never</td>
<td>Under 10, 10-20, More than 20</td>
</tr>
<tr>
<td>Attend movies</td>
<td>Never</td>
<td>Under 10, 10-20, More than 20</td>
</tr>
<tr>
<td>Attend concerts</td>
<td>Never</td>
<td>Under 10, 10-20, More than 20</td>
</tr>
<tr>
<td>Play cards</td>
<td>Never</td>
<td>Under 10, 10-20, More than 20</td>
</tr>
<tr>
<td>Play board games</td>
<td>Never</td>
<td>Under 10, 10-20, More than 20</td>
</tr>
<tr>
<td>Watch sports</td>
<td>Never</td>
<td>Under 10, 10-20, More than 20</td>
</tr>
<tr>
<td>Read</td>
<td>Never</td>
<td>Under 10, 10-20, More than 20</td>
</tr>
<tr>
<td>Hobby (specify)</td>
<td>Never</td>
<td>Under 10, 10-20, More than 20</td>
</tr>
<tr>
<td>Other (specify)</td>
<td>Never</td>
<td>Under 10, 10-20, More than 20</td>
</tr>
</tbody>
</table>

2. Is your **access** to leisure activities limited by ...
   (Check all that apply.)
   - Physical factors in the environment
   - Social attitudes
   - Family attitudes
Self-concept
Limited finances
Lack of assistance
Wheelchair
Wheelchair seating
Lack of special equipment ➔ What equipment would be helpful?

Other (specify) _______________________
Not limited

3. Is your participation in leisure activities limited by ... (Check all that apply.)
- Illness
- A physical impairment
- Pain
- Fatigue
- Wheelchair
- Wheelchair seating
- Other _____________________________
- Not limited

4. To participate in leisure activities, how much choice do you have compared to others without disabilities? (Choice includes how, where, when, how often, and with whom you participate in leisure activities.)
- A lot of choice
- Some choice
- Little choice
- No choice

5. How satisfied are you with your participation in leisure activities?
- Very satisfied
- Satisfied
- Somewhat satisfied
- Dissatisfied

6. How important is it for you to participate in leisure activities?
- Very important
- Somewhat important
- Somewhat unimportant
- Not important

IF YOU PARTICIPATE IN LEISURE ACTIVITIES:

7. How much help from another person do you need to participate?
- None
- Just a little
- A moderate amount
- A great deal

8. If you use assistance, who helps you with leisure activities? (Check all that apply.)
- No one
- Family/Significant Other
- Friends
- People I hire

9. How often do you use accommodations, adaptations, or special equipment to do leisure activities?
- Never
- A little of the time
- Some of the time
- Most of the time
- All of the time

10. If you use accommodations, adaptations, or special equipment to do leisure activities, what do you use? (Check all that apply.)
- N/A
- Card holder
- Scooter
- Computer (adaptive)
- Remote control
- Computer (regular)
- Wheelchair - manual
ACTIVE RECREATION: The following questions are about active recreational activities, such as a team sport or camping.

1. **How often** do you participate in this type of activity?
   - □ Never
   - □ I choose not to do this
   - □ I am unable to do this
   (Go to question 4)
   - □ Less than once a month (Continue)
   - □ 1-2 times a month (Continue)
   - □ 1-2 times a week (Continue)
   - □ More than twice a week (Continue)

2. If you participate in active recreation, what is **one activity that you participate in the most**?

   ________________________________________________

3. **How long** does it take you to prepare to do this activity?
   - □ Under 10 minutes
   - □ 10-20 minutes
   - □ More than 20 minutes

4. Is your **access** to active recreational activities limited by ...
   (Check all that apply.)
   - □ Physical factors in the environment
   - □ Lack of assistance
   - □ Social attitudes
   - □ Family attitudes
   - □ Limited finances
   - □ Lack of organized accessible teams
   - □ Self-concept
   - □ Wheelchair
   - □ Wheelchair seating
   - □ Lack of special equipment
   ➔ What equipment would be helpful?

   ________________________________________________
   - □ Other (specify) ________________________________
   - □ Not limited

5. Is your **participation** in active recreational activities limited by ...
   (Check all that apply.)
   - □ Illness
   - □ A physical impairment
   - □ Pain
   - □ Fatigue
   - □ Wheelchair
   - □ Wheelchair seating
   - □ Other ________________________________
   - □ Not limited

6. To participate in active recreational activities, how much **choice** do you have compared to others without disabilities? (Choice includes how, where, when, how often, and with whom you participate in activities.)
7. How **satisfied** are you with your participation in active recreational activities?
   - [ ] Very satisfied
   - [ ] Satisfied
   - [ ] Somewhat satisfied
   - [ ] Dissatisfied

8. How **important** is it for you to participate in active recreational activities?
   - [ ] Very important
   - [ ] Somewhat important
   - [ ] Somewhat unimportant
   - [ ] Not important

**IF YOU PARTICIPATE IN ACTIVE RECREATIONAL ACTIVITIES:**

9. How much **help from another person** do you need to participate?
   - [ ] None
   - [ ] Just a little
   - [ ] A moderate amount
   - [ ] A great deal

10. If you use assistance, **who helps you** with active recreational activities?
    (Check all that apply.)
    - [ ] No one
    - [ ] Family/Significant Other
    - [ ] Friends
    - [ ] People I hire

11. How often do you use **accommodations, adaptations, or special equipment** for active recreational activities?
    - [ ] Never
    - [ ] A little of the time
    - [ ] Some of the time
    - [ ] Most of the time
    - [ ] All of the time

12. If you use **accommodations, adaptations, or special equipment** to do active recreational activities, what do you use? (Check all that apply.)
    - [ ] N/A
    - [ ] Scooter
    - [ ] Wheelchair seating
    - [ ] Wheelchair - power
    - [ ] Wheelchair - manual
    - [ ] Other _____________________
SOCIALIZING: The next questions are about socializing with people. This includes visiting with friends or family at home, at the homes of others, or at social events.

1. How frequently do you socialize with others?
   - Less than once a week
   - 1 to 2 times a week
   - 3 to 4 times a week
   - Daily or almost daily

2. Is your access to social activities limited by ... (Check all that apply.)
   - Physical factors in the environment
   - Social attitudes
   - Family attitudes
   - Self-concept
   - Lack of assistance
   - Limited finances
   - Lack of companion(s)
   - Wheelchair
   - Wheelchair seating
   - Lack of special equipment
   - What equipment would be helpful?

   - Other (specify) _______________________________________
   - Not limited

3. Is your participation in social activities limited by ... (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other _____________________________
   - Not limited

4. When socializing, how much choice do you have compared to others without disabilities? (Choice includes how often, when, how and with whom you socialize.)
   - A lot of choice
   - Some choice
   - Little choice
   - No choice

5. How satisfied are you with your participation in social activities?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

6. How important is it for you to participate in social activities?
   - Very important
   - Somewhat important
   - Somewhat unimportant
   - Not important

7. How much help from another person do you need to socialize?
   - None
   - Just a little
   - A moderate amount
   - A great deal

8. If you use assistance, who helps you with socializing? (Check all that apply.)
   - No one
   - Family/Significant Other
   - Friends
   - People I hire

9. How often do you use accommodations, adaptations, or special equipment to socialize? (Check all that apply.)
   - Never
   - A little of the time
   - Some of the time
   - Most of the time
   - All of the time

10. If you use accommodations, adaptations, or special equipment to socialize, what do you use? (Check all that apply.)
    - N/A
    - Accessible parking permit
    - Orthotic/prosthetic device
    - Adapted vehicle
    - Scooter
    - Adapted telephone
    - Walker
<table>
<thead>
<tr>
<th>Cane/crutches</th>
<th>Wheelchair seating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computer</td>
<td>Wheelchair – manual</td>
</tr>
<tr>
<td>Hearing aid</td>
<td>Wheelchair - power</td>
</tr>
<tr>
<td>Lift</td>
<td>Other ______________</td>
</tr>
</tbody>
</table>
RELIGIOUS ACTIVITIES: The following questions are about participation in religious activities. This topic includes attending Weekly religious services or classes or singing in a choir.

1. How much time do you spend on participation in religious activities?
   - None
   - I choose not to do this
   - I am unable to do this
   - 1 to 5 hours a week
   - More than 5 hours a week

2. Is your access to religious activities limited by ... (Check all that apply.)
   - Physical factors in the environment
   - Social attitudes
   - Family attitudes
   - Self-concept
   - Lack of assistance
   - Wheelchair
   - Wheelchair seating
   - Lack of special equipment
   - What equipment would be helpful?
   - Other (specify)____________________
   - Not limited

3. Is your participation in religious activities limited by ... (Check all that apply.)
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair seating
   - Other____________________________
   - Not limited

4. How much choice do you have about participating in religious activities compared to others without disabilities? (Choice includes when, where, how and with whom.)
   - A lot of choice
   - Some choice
   - Little choice
   - No choice

5. How satisfied are you with your participation in religious activities?
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied

6. How important is it for you to participate in religious activities?
   - Very important
   - Somewhat important
   - Somewhat unimportant
   - Not important

**IF YOU PARTICIPATE IN RELIGIOUS ACTIVITIES:**

7. How much help from another person do you require?
   - None
   - Just a little
   - A moderate amount
   - A great deal

8. If you use assistance, who helps you participate in religious activities? (Check all that apply.)
   - No one
   - Family/Significant Other
   - Friends
   - People I hire

9. How often do you use accommodations, adaptations, or special equipment to participate in religious activities?
   - Never
   - A little of the time
   - Some of the time
   - Most of the time
   - All of the time

159
10. If you use **accommodations, adaptations, or special equipment** to participate in religious activities, what do you use? *(Check all that apply.)*

   - N/A
   - Elevator
   - Scooter
   - Grab bars
   - Vehicle (not adapted)
   - Handrails
   - Walker
   - Level threshold
   - Wheelchair seating
   - Lift
   - Wheelchair - manual
   - Pedal for car
   - Wheelchair - power
   - Ramp
   - Widened
   - Other _________________________

**EMPLOYMENT:** The next questions are about part-time or full-time work.

1. Are you currently employed?  
   - Yes  
   - No

2. Is your **access** to employment limited by ... *(Check all that apply.)*
   - Physical factors in the environment
   - Social attitudes
   - Family attitudes
   - Self-concept
   - Lack of assistance
   - Wheelchair
   - Wheelchair seating
   - Lack of special equipment  ➔ What equipment would be helpful?

   - Other (specify) ____________________________
   - Not limited

3. Is your **participation** in employment limited by ... *(Check all that apply.)*
   - Illness
   - A physical impairment
   - Pain
   - Fatigue
   - Wheelchair
   - Wheelchair seating
   - Other ____________________________
   - Not limited

4. How much **choice** do you have about employment compared to others without disabilities? *(Choice includes when, where, how much and how you work.)*
   - A lot of choice
   - Some choice
   - Little choice
   - No choice

5. How **satisfied** are you with your participation in work?  
   - Very satisfied
   - Satisfied
   - Somewhat satisfied
   - Dissatisfied
6. How **important** is it for you to work?
   - Very important
   - Somewhat important
   - Somewhat unimportant
   - Not important

IF YOU ARE EMPLOYED:

7. a. What type of work do you do? ________________________________

   b. In a typical week, how many hours do you work?
   - Less than 10
   - 11 to 30
   - 31 to 40
   - More than 40

8. How much help from another person do you require to participate in work?
   - None
   - Just a little
   - A moderate amount
   - A great deal

9. If you use assistance, **who helps you** with participating in work?
   (Check all that apply.)
   - No one
   - Family/Significant Other
   - Friends
   - People I hire

10. How often do you use accommodations, adaptations or special equipment to participate in work?
    - Never
    - A little of the time
    - Some of the time
    - Most of the time
    - All of the time

11. If you use accommodations, adaptations, or special equipment to participate in work, what do you use? (Check all that apply.)

   - N/A
   - Accessible parking permit
   - Lift
   - Adaptive computer equipment
   - Orthotic/Prosthetic device
   - Adapted vehicle
   - Scooter
   - Cane
   - Walker
   - Computer
   - Wheelchair seating
   - Crutches
   - Wheelchair – power
   - Hearing aid
   - Wheelchair – manual
   - Other ________________________________
The last section of the survey relates to your environment and includes sections about:

- The accessibility of buildings within your home and community environments
- Mobility devices you use
- Health benefits
- Social support
- The services and attitudes of people

You will note that the questions ask how the accessibility of your environment influences your participation. By participation we mean not only what you do, but how independently you do it, how much choice you have, and how satisfied you are. In this section, accessibility refers to your ability to go into and move around inside the various places listed. Accessibility can involve doorway size, the weight of doors, the direction a door opens or how fast it closes; convenient location of ramps, if applicable; availability of elevators or escalators; the size of restrooms; the location of furniture in a room, etc. All these things can affect accessibility.

The first group of questions relates to the accessibility of buildings.

1. How does the accessibility of your residence influence your participation in Daily activities?

   - Helps a lot
   - Helps some
   - Has no effect
   - Limits some
   - Limits a lot

   What about your residence limits you? (Check all that apply.)

   - Entrance
   - Bathroom
   - Kitchen
   - Lack of personal finances
   - Parking
   - Lack of personal assistance
   - Lack of special equipment
   - Other__________________________

   What equipment would be helpful?

   ________________________________

   - Other__________________________

2. How does the accessibility of your place of employment influence your participation in working?

   - Helps a lot
   - Helps some
   - Has no effect
   - Limits some
   - Limits a lot
   - Not employed

   What about your place of employment limits you? (Check all that apply.)

   - Entrance
   - Workstation
   - Bathroom
   - Parking
   - Lack of child care
   - Lack of personal assistance
   - Lack of transportation
   - Lack of special equipment
   - What equipment would be helpful?

   ________________________________

   - Other__________________________
3. How does the accessibility of your grocery store influence your participation in shopping?

- Helps a lot
- Helps some
- Has no effect
- Limits some
- Limits a lot
- Do not shop for groceries

What about your grocery store limits you? (Check all that apply.)

- Entrance
- Lack of personal finances
- Parking
- Lack of child care
- Accessibility of shelves and freezers
- Lack of scooter/wheelchair at the store
- Lack of special equipment

What equipment would be helpful?

Other_____________________

4. How does the accessibility of your doctor’s office influence your participation in health care?

- Helps a lot
- Helps some
- Has no effect
- Limits some
- Limits a lot
- Do not go to a doctor

What about your doctor’s office limits you? (Check all that apply.)

- Entrance
- Lack of personal finances
- Parking
- Lack of child care
- Lack of transportation
- Waiting rooms and exam rooms
- Lack of special equipment

What equipment would be helpful?

Other_____________________

5. How does the accessibility of your religious institution or place of worship influence your participation in religious activities?

- Helps a lot
- Helps some
- Has no effect
- Limits some
- Limits a lot
- Do not go to a religious institution or a place of worship

What about your religious institution limits you? (Check all that apply.)

- Entrance
- Seating
- Lack of personal finances
- Parking
- Lack of child care
- Lack of transportation
- Lack of special equipment

What equipment would be helpful?

Other_____________________

163
6. How does the accessibility of **restaurants** influence your participation in dining out?

- [ ] Helps a lot
- [ ] Helps some
- [ ] Has no effect
- [ ] Limits some
- [ ] Limits a lot
- [ ] Do not go to restaurants

What about **restaurants** limits you? (Check all that apply.)

<table>
<thead>
<tr>
<th>Not Limited</th>
</tr>
</thead>
</table>
| [ ] Entrance
| [ ] Lack of personal assistance
| [ ] Lack of child care
| [ ] Tables too close together
| [ ] Height of counters, tables, and booths
| [ ] Lack of special equipment | What equipment would be helpful? |

[ ] Other _______________________

7. How does the accessibility of **movie theaters** influence your participation in going to movies?

- [ ] Helps a lot
- [ ] Helps some
- [ ] Has no effect
- [ ] Limits some
- [ ] Limits a lot
- [ ] Do not go to movie theaters

What about **movie theaters** limits you? (Check all that apply.)

<table>
<thead>
<tr>
<th>Not Limited</th>
</tr>
</thead>
</table>
| [ ] Entrance
| [ ] Stadium seating
| [ ] Lack of personal assistance
| [ ] Lack of child care
| [ ] Lack of transportation
| [ ] Lack of special equipment | What equipment would be helpful? |

[ ] Other _______________________

8. How does the accessibility of **shopping malls** influence your participation in shopping?

- [ ] Helps a lot
- [ ] Helps some
- [ ] Has no effect
- [ ] Limits some
- [ ] Limits a lot
- [ ] Do not go to shopping malls

What about **shopping malls** limits you? (Check all that apply.)

<table>
<thead>
<tr>
<th>Not Limited</th>
</tr>
</thead>
</table>
| [ ] Entrance
| [ ] Lack of personal assistance
| [ ] Lack of child care
| [ ] Lack of transportation
| [ ] Lack of special equipment | What equipment would be helpful? |

[ ] Other _______________________

9. How does the accessibility of **clothing stores** influence your participation in shopping for clothes?
16. How does the accessibility of public parks and recreation areas influence your participation in outdoor activities, such as picnicking?

- Helps a lot
- Helps some
- Has no effect
- Limits some
- Limits a lot

What about public parks limits you? (Check all that apply.)

<table>
<thead>
<tr>
<th>Limited</th>
<th>Entrance</th>
<th>Lack of personal finances</th>
<th>Parking</th>
<th>Lack of transportation</th>
<th>Lack of child care</th>
<th>Height of clothing racks</th>
<th>Lack of personal assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>

Other________________________________________

11. How accessible are the following types of transportation?

(Please check all the following that you use, then mark the response that is closest to your own experience regarding accessibility of each.)

<table>
<thead>
<tr>
<th>Transportation</th>
<th>Not accessible</th>
<th>Somewhat accessible</th>
<th>Very accessible</th>
<th>Don’t know</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your own car/van (not adapted)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your own adapted car/van</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Buses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taxis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Airlines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

165
The following items relate to your HOME environment and to devices that may influence how you move around and carry out activities. Please mark the choice that is closest to your experience.

In your home, do the following influence your participation in activities?

<table>
<thead>
<tr>
<th>NO.</th>
<th>Item</th>
<th>Yes/No</th>
<th>How much?</th>
<th>How often?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Stairs</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Help some</td>
<td>Weekly</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Limit some</td>
<td>Monthly</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Limit a lot</td>
<td>Less than monthly</td>
</tr>
<tr>
<td>2.</td>
<td>Ramps</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Help some</td>
<td>Weekly</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Limit some</td>
<td>Monthly</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Limit a lot</td>
<td>Less than monthly</td>
</tr>
<tr>
<td>3.</td>
<td>Doors</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Help some</td>
<td>Weekly</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Limit some</td>
<td>Monthly</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Limit a lot</td>
<td>Less than monthly</td>
</tr>
<tr>
<td>4.</td>
<td>Carpets</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Help some</td>
<td>Weekly</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Limit some</td>
<td>Monthly</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Limit a lot</td>
<td>Less than monthly</td>
</tr>
</tbody>
</table>
The following items relate to your COMMUNITY environment and to devices that may influence how you move around and carry out activities. Please mark the choice that is closest to your experience.

In your community, do the following influence your participation in activities?

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes/No</th>
<th>How Much?</th>
<th>How Often?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Curb cuts</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td>Ramps</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td>Elevators</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td>Flat terrain</td>
<td>Yes</td>
<td>Helps a lot</td>
<td>Daily</td>
</tr>
<tr>
<td>Gravel surfaces</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
<tr>
<td>Paved surfaces</td>
<td>Yes</td>
<td>Help a lot</td>
<td>Daily</td>
</tr>
</tbody>
</table>
| 7. Summer weather (heat and humidity) | Yes  
|   | No  
| How much? | Helps a lot  
|   | Helps some  
|   | Limits some  
|   | Limits a lot  
| How often? | Daily  
|   | Weekly  
|   | Monthly  
|   | Less than monthly  
| 8. Winter weather (ice and snow) | Yes  
|   | No  
| How much? | Helps a lot  
|   | Helps some  
|   | Limits some  
|   | Limits a lot  
| How often? | Daily  
|   | Weekly  
|   | Monthly  
|   | Less than monthly  
|   | (During the season)  
| 9. Rain | Yes  
|   | No  
| How much? | Helps a lot  
|   | Helps some  
|   | Limits some  
|   | Limits a lot  
| How often? | Daily  
|   | Weekly  
|   | Monthly  
|   | Less than monthly  
| 10. Crowds | Yes  
|   | No  
| How much? | Helps a lot  
|   | Helps some  
|   | Limits some  
|   | Limits a lot  
| How often? | Daily  
|   | Weekly  
|   | Monthly  
|   | Less than monthly  

168
The following items relate to your WORK or SCHOOL environment.
Do you work?  ✔Yes  ❌No  Do you attend school?  ✔Yes  ❌No

If you have answered “No” to both questions, please skip to next page.
If you work AND attend school, please answer the following questions based on where you spend the most time:  ✔Work  ❌School
Please mark the choice that is closest to your experience.
At work or school, do the following influence your participation in activities?

<p>| | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ramps</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>How much?</td>
<td>Help a lot</td>
<td>Help some</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Elevators</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>How much?</td>
<td>Help a lot</td>
<td>Help some</td>
<td>Limit some</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Floor surfaces</td>
<td></td>
<td></td>
<td>Yes</td>
<td>How much?</td>
<td>Help a lot</td>
<td>Help some</td>
<td>Limit some</td>
<td>Limit a lot</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Distances between rooms</td>
<td></td>
<td>Yes</td>
<td>How much?</td>
<td>Help a lot</td>
<td>Help some</td>
<td>Limit some</td>
<td>Limit a lot</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Daily</td>
<td>Weekly</td>
<td>Monthly</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Daily</td>
<td>Weekly</td>
<td>Monthly</td>
</tr>
<tr>
<td>5. Work or school cafeteria</td>
<td>Yes</td>
<td>How much?</td>
<td>Helps a lot</td>
<td>Helps some</td>
<td>Limits some</td>
<td>Limits a lot</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Daily</td>
<td>Weekly</td>
<td>Monthly</td>
</tr>
</tbody>
</table>
**Mobility Devices**

*Please answer the following questions for the mobility devices you use. Mobility devices could include a manual wheelchair, a power wheelchair, or a scooter.*

Do you use a mobility device?  
[ ] Yes (Continue below.)  
[ ] No (Go to Health Benefits on next page.)

1. **Name of mobility device: MANUAL WHEELCHAIR**  
   **MAKE:** __________________  
   **YEAR PURCHASED:** _______

   a. How often do you use this device at home, at work or school, and in your community?  
   b. How does it influence your participation in *Daily* activities?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th><em>Often</em></th>
<th><em>Always</em></th>
<th><em>Helps a lot</em></th>
<th><em>Helps some</em></th>
<th><em>Limits some</em></th>
<th><em>Limits a lot</em></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td><strong>Work/School</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

2. **Name of mobility device: POWER WHEELCHAIR**  
   **MAKE:** __________________  
   **YEAR PURCHASED:** _______

   a. How often do you use this device at home, at work or school, and in your community?  
   b. How does it influence your participation in *Daily* activities?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th><em>Often</em></th>
<th><em>Always</em></th>
<th><em>Helps a lot</em></th>
<th><em>Helps some</em></th>
<th><em>Limits some</em></th>
<th><em>Limits a lot</em></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td><strong>Work/School</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Name of mobility device: **SCOOTER**  
**MAKE:** __________________  
**YEAR PURCHASED:** _______

a. How often do you use this device at home, at work or school, and in your community?  

b. How does it influence your participation in *Daily* activities?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th><em>Often</em></th>
<th><em>Always</em></th>
<th><em>Helps a lot</em></th>
<th><em>Helps some</em></th>
<th><em>Limits some</em></th>
<th><em>Limits a lot</em></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td><strong>Work/School</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
Health Benefits

The following questions are about your health benefits. Health benefits may include:
private insurance - such as Blue Cross/Blue Shield or AetN/A
government insurance - Medicaid/Medicare or Veterans Administration Benefits

What health insurance or benefits do you have?

- I have NO insurance or benefits (Go to next page.)

1. Name of benefit or insurance_________________________________
   a. Is this benefit
      - A private plan    - A public (government) plan    - Don’t know
   b. Who pays for this benefit? (Check all that apply.)
      - Self    - Employer    - Government    - Other_____________________
   c. How many years have you had this benefit?
      - 1 year or less     - 2 to 5     - 6 to 10    - More than 10
   d. To what extent does this benefit influence your access to health care?
      - Helps a lot    - Helps some    - Has no effect    - Limits some    - Limits a lot

2. Name of benefit or insurance_________________________________
   a. Is this benefit
      - A private plan    - A public (government) plan    - Don’t know
   b. Who pays for this benefit? (Check all that apply.)
      - Self    - Employer    - Government    - Other_____________________
   c. How many years have you had this benefit?
      - 1 year or less     - 2 to 5     - 6 to 10    - More than 10
   d. To what extent does this benefit influence your access to health care?
      - Helps a lot    - Helps some    - Has no effect    - Limits some    - Limits a lot
Agencies and Organizations

The following questions are about other types of benefits, as well as agencies and organizations that may provide assistance to you.

1. Do you receive any of the following? (Check all that apply.)

<table>
<thead>
<tr>
<th>Benefit</th>
<th>To what extent does this benefit influence your participation in daily activities?</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ No SSI (Supplemental Security Income)</td>
<td>Helps a lot Helps some No effect Limits some Limits a lot</td>
</tr>
<tr>
<td>☐ SSDI (Social Security Disability Insurance)</td>
<td>Helps a lot Helps some No effect Limits some Limits a lot</td>
</tr>
<tr>
<td>☐ Worker’s Compensation</td>
<td>Helps a lot Helps some No effect Limits some Limits a lot</td>
</tr>
</tbody>
</table>

2. The Department of Vocational Rehabilitation helps people find and maintain jobs. Do you use Vocational Rehabilitation services?

☐ Yes - How do these services influence your access to work?

☐ No Help a lot ☐ Help some ☐ No effect ☐ Limit some ☐ Limit a lot

Services and Attitudes

The next questions deal with personal support and the services of people. Please mark how both the services and the attitudes of these people influence your participation in activities.

1. How often do you go to a doctor’s office?

☐ Never ☐ Rarely ☐ Once or twice a year ☐ Once or twice a month ☐ More than twice a week

How does the care you receive influence your participation in Daily activities?

☐ Helps a lot ☐ Helps some ☐ No effect ☐ Limits some ☐ Limits a lot

How do the attitudes of doctors influence your use of health care services?

☐ Helps a lot ☐ Helps some ☐ No effect ☐ Limits some ☐ Limits a lot
2. How often do you see a therapist? (For this question, therapists include occupational therapists, physical therapists, recreational therapists, and speech therapists.)

- Never
- Rarely
- Once or twice a year
- Once or twice a month
- Once or twice a week
- More than twice a week
- How does the therapy you receive influence your participation in Daily Activities?
  - Helps a lot
  - Helps some
  - No effect
  - Limits some
  - Limits a lot
- How do the attitudes of therapists influence your use of therapy services?
  - Help a lot
  - Help some
  - No effect
  - Limit some
  - Limit a lot

3. How often do you use the services of paid personal attendants?

- Never
- Rarely
- Once or twice a year
- Once or twice a month
- Once or twice a week
- More than twice a week
- How does the personal assistance you receive influence your participation in Daily activities?
  - Helps a lot
  - Helps some
  - No effect
  - Limits some
  - Limits a lot
- How do the attitudes of personal attendants influence your use of Personal attendant services?
  - Help a lot
  - Help some
  - No effect
  - Limit some
  - Limit a lot

4. How often do you ask for help from family members?

5. How often do you ask for help from friends?

- Never
- Rarely
- Once or twice a year
- Once or twice a month
- Once or twice a week
- More than twice a week
- How does their help influence your participation in Daily activities?
  - Helps a lot
  - Helps some
  - No effect
  - Limits some
  - Limits a lot
- How do their attitudes influence your participation in Daily activities?
  - Help a lot
  - Help some
  - No effect
  - Limit some
  - Limit a lot

6. How often do you ask for help from peers?
7. How often do you ask for help from store clerks?

- Never
- Rarely
- Once or twice a year
- Once or twice a month
- Once or twice a week
- More than twice a week

How does their help influence your participation in Daily activities?
- Helps a lot
- Helps some
- No effect
- Limits some
- Limits a lot

How do their attitudes influence your participation in Daily activities?
- Help a lot
- Help some
- No effect
- Limit some
- Limit a lot

8. How often do you ask for help from strangers?

- Never
- Rarely
- Once or twice a year
- Once or twice a month
- Once or twice a week
- More than twice a week

How does their assistance influence your participation in Daily activities?
- Helps a lot
- Helps some
- No effect
- Limits some
- Limits a lot

How do their attitudes influence your participation in Daily activities?
- Help a lot
- Help some
- No effect
- Limit some
- Limit a lot

9. How often do you use a special equipment repair service?

- Never
- Rarely
- Once or twice a year
- Once or twice a month
- Once or twice a week
- More than twice a week

How does their services influence your participation in Daily activities?
- Helps a lot
- Helps some
- No effect
- Limits some
- Limits a lot

How do their attitudes of equipment repair personnel influence your participation in Daily activities?
- Help a lot
- Help some
- No effect
- Limit some
- Limit a lot

Who assisted in completing this survey? (Check all that apply.)

- Participant
- Paid personal attendant
- Family member
- Interviewer
- Friend
- Other ______________________