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

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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.

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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.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.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. 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." 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.^{4, 5} Therefore; the function of people with disabilities is affect by technology and the physical environment as much as by their physiological impairments. ^{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 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.

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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. 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. ⁴ Evidence suggests that compared to the general population, people with SCI might experience a slightly lower QoL. ⁵ Research has documented that life satisfaction is greater for those who are involved in productive activities such as work, education, and recreation. 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.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.⁸ Having an appropriate wheelchair can significantly influence how a person with a disability perceives life.⁹ Greater satisfaction with a wheelchair should result in enhanced use of that technology and contribute to a better subjective quality of life.¹⁰

A study published by Hunt and colleagues¹¹ 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. 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. 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 ¹³, either propelling them independently or with assistance. Manual wheelchair propulsion potentially benefits the wheelchair user's cardiovascular fitness ¹⁴ and upper extremity muscle strength. 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. ^{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. 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).²¹ The PARTS/M is composed of 13 major life activities ranging from grooming to going to the doctor's office.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. 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 *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 .05/6 or .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 (+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. Sixtyone 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. 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.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).

FREQUENCY					
COMMUNITY ACTIVITIES	Para Manual	Para Power	Tetra Manual	Tetra Power	P <.05
Shopping for groceries	55.94	34.83	40.81	46.60	.07
Shopping for clothes	54.11	29.33	43.81	52.03	.09
Going to pharmacy	52.44	44.00	42.02	51.50	.47
Going to bank	55.39	31.42	45.69	43.90	.08
Going to doctor's office	51.71	79.08	41.14	46.13	.00
Going to post office	57.38	41.50	41.57	42.20	.03
Going to friend' home	58.67	25.00	48.64	36.38	.00
Going to movie	52.29	39.83	44.17	53.23	.45
Going to concert	47.88	47.25	51.55	49.95	.86
Dine out	54.10	19.25	43.76	55.13	.01

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

FREQUENCY COMMUNITY	MEAN RANK			MEAN RANK		
ACTIVITIES	Para	Para	P<.008	Para	Tetra	P<.008
	Manual	Power		Power	Manual	
Going to doctor's office	27.81	44.17	.011	21.75	11.79	.001
Going to post office	30.51	20.75	.149	14.25	13.93	.921
Going to friend' home	31.55	11.75	.005	8.42	15.60	.042
Dine out	31.53	11.92	.004	7.50	15.86	.012

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

FREQUENCY COMMUNITY	MEAN RANK			MEAN RANK		
ACTIVITIES	Para	Tetra	P<.008	Para	Tetra	P<.008
	Manual	Manual		Manual	Power	
Going to doctor's office	39.25	31.43	.080	37.65	33.50	.366
Going to post office	40.31	28.81	.025	39.57	28.53	.031
Going to friend' home	39.28	31.36	.135	40.85	25.20	.004
Dine out	7.50	15.86	.112	36.26	37.13	.868

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

FREQUENCY COMMUNITY	MEAN RANK			MEAN RANK		
ACTIVITIES	Para	Tetra	P<.008	Tetra	Tetra	P<.008
	Power	Power		Manual	Power	
Going to doctor's office	20.17	11.50	.005	19.93	22.13	.393
Going to post office	13.50	13.50	1.00	20.83	21.18	.918
Going to friend' home	11.83	14.00	.525	23.69	18.18	.127
Dine out	6.83	15.50	.009	18.62	23.50	.164

1.1.4 DISCUSSION

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) reffering 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 colleagues²⁴ 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.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.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. ²⁶ The physical environment was also reported as a cause of decreased participation of individuals with SCI in the home, community and transportation.²⁷⁻²⁸ 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.³⁷ Experts have argued that a combination of manual and power wheelchair usage may be a solution for the problem.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. 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.

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APPENDIX A

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

How often do you do the activity?	Never	Less than once a month	1-2 times a month	1-2 times a week	More than twice a week
Shopping for groceries	X				
Shopping for clothes		X			
Going to the pharmacy			X		
Going to the bank				X	
Going to the doctor's office					X
Going to the post office	X				
Going to a friend's home		X			

Illustrates the 3 questions and answers related to leisure activities.

How often do you do the activity?	Never	Less than once a month	1-2 times a month	1-2 times a week	More than twice a week
Dine Out			X		
Attend Movies				X	
Attend Concerts					X

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 Health¹ (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.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.² Richards et al. 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. ⁴ In another study by Rimmer et al., 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. ⁶⁻⁸

Social factors are composed by attitudes of others, public priorities and availability of services. ^{2,9} Social factors may influence the impact of impairment not only on the limitations in activities, but also on the distress experienced by the individual. ¹⁰ 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. ¹¹ Pierce et al. ¹² 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. ¹³ In fact, social attitudes were reported as a limiting factor for leaving home and for using transportation. ⁴

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.¹⁵ 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.^{2,15}

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.^{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.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.

In your community, do	the following	influence you	ır participatior	n in activities?	
1. Curb Cuts		+2 □Help a lot	+1 □Help some	-1 □Limit some	-2 □Limit a lot
0	How often?	□ <i>Daily</i> 4	□Weekly 3	☐ <i>Monthly</i> 2	☐Less than monthly 1

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

Assign the following scores to "How much?"	Assign the following scores to "How often?"	Total Influence score = "How much" X "How often"		
Helps a lot = +2 Helps some = +1 Limits some = -1 Limits a lot = -2 No influence = 0	Daily = 4 Weekly = 3 Monthly = 2 Less than monthly = 1	If limit a lot daily Score = (-2) (4) = -8	If help a lot daily Score = $(+2)$ (4) = $+8$	

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 (± 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 (±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. 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. 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=.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.**

	% of	Four Groups (%)				
What about your residence	participants	Para	Para	Tetra	Tetra	
limits you?	(n=105)	Manual	Power	Manual	Power	
		N=52	N=6	N=20	N=20	
Entrance	15	19	17	5	20	
Bathroom	23	12	0	14	20	
Kitchen	28	23	67	33	30	
Lack Personal finances	26	23	50	24	30	
Lack Personal assistance	11	10	33	9	15	
Parking	9	8	0	19	5	
Lack Special equipment	17	19	50	5	15	
Not limited	37	39	0	38	40	

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).

	% of		Four G	roups (%)	
What about your place of employment limits you?	participants (n=38)	Para Manual (N=22)	Para Power (N=1)	Tetra Manual (N=6)	Tetra Power (N=9)
Entrance	2	5	0	0	0
Workstation	7	9	0	0	11
Bathroom	15	23	0	0	11
Parking	17	13	0	17	33
Lack of child care	2	0	0	0	11
Lack of transportation	2	5	0	0	0
Lack of personal assistance	7	0	0	0	33 *
Lack of special equipment	12	14	0	0	22
Not limited	45	41	0	86 *	22

^{*} 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).

		Four Groups (%)						
	% of	Para	Para	Tetra	Tetra			
What about your grocery	participants	Manual	Power	Manual	Power			
store limits you?	(n=85)	(N=45)	(N=5)	(N=15)	(N=16)			
Entrance	6	7	20	0	6			
Accessibility shelves and	54	58	60	56	31			
freezers								
Lack of scooter/wheelchair at	0	0	0	0	0			
the store								
Lack of personal finances	11	11	20	13	6			
Parking	26	27	0	25	31			
Lack of transportation	7	7	0	6	13			
Lack of personal assistance*	15	11	60	6	25			
Lack of child care	0	0	0	0	0			

Lack of special equipment	5	7	0	0	6
Not limited	27	24	0	38	31
*n-value <0.05					

Table 10. Illustrates the percentages of social and physical barriers in the **doctor's office**.

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

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).

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

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). **Four Groups (%)**

		Four Groups (%)				
What about restaurants	% of	Para	Para	Tetra	Tetra	
limits you?	participants	Manual	Power	Manual	Power	
	(n=98)	(N=48)	(N=6)	(N=20)	(N=19)	
Entrance	55	40	33	48	58	
Lack of personal finances	15	17	33	14	11	
Tables too close together	59	59	33	57	74	
Parking	39	42	33	33	42	
Lack of child care	0	0	0	0	0	
Lack of transportation	8	8	0	10	11	

Height of counters, tables	48	50	0	48	58
and booths					
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).

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

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).

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

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).

			Four (Groups (%)	
What about clothing stores	% of	Para	Para	Tetra	Tetra
limits you?	participants	Manual	Power	Manual	Power
	(N=98)	(N=49)	(N=6)	(N=18)	(N=20)
Entrance	21	20	16	21	25
Lack of personal finances	16	20	33	10	5
Width of aisles	64	67	33	58	70
Parking	21	20	0	21	25
Height of clothing racks	46	55	16	42	35
Lack of child care	0	0	0	0	0
Lack of transportation	10	10	0	5	10

Lack of personal assistance	10	10	0	11	10
Lack of special equipment	5	6	0	5	5
Not limited	16	12	0	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).

			rour v	31 Oups (/0)	
What public parks limit	% of	Para	Para	Tetra	Tetra
you?	participants	Manual	Power	Manual	Power
	(N=98)	(N=49)	(N=6)	(N=18)	(N=19)
Lack of paved paths	68	74	33	58	68
Picnic areas	26	27	16	26	32
Lack of personal finances	13	10	33	21	11
Parking	24	29	0	26	26
Lack of child care	0	0	0	0	0
Lack of transportation	12	8	16	10	15
Lack of personal assistance	7	8	0	10	5
Lack of special equipment	7	8	16	0	5
Not limited	15	14	0	21	16

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.

IN YOUR HOME, HOW MUCH AND HOW	% OF	MEAN (SD) (RANGE = -8 TO 8*)				F	P
OFTHEN, DO THE FOLLOWING INFLUENCE YOUR PARTICIPATION IN ACTIVITIES?	PARTICIPANTS (N=105)	Para Manual N=52	Para Power N=6	Tetra Manual N=20	Tetra Power N=20		_
Stairs	38	-4.30 (4.01)	-2.0 (1.41)	-5.50 (3.20)	-5.20 (3.03)	.53	.66
Ramps	59	5.73 (4.89)	8.00 (.00)	6.61 (3.40)	7.23 (1.53)	.71	.54
Doors	62	3.71 (5.52)	8.00 (.00)	5.06 (5.54)	2.75 (5.75)	.85	.47
Carpets	33	-2.6 (4.97)	8.00 (.00)	-2.85 (5.01)	-5.00 (2.00)	2.0	.13
Hardwood	33	6.71 (3.26)	8.00 (.00)	7.86 (.378)	7.25 (1.38)	.44	.72
Handrails	16	5.67 (2.39)	8.00 (.00)	8.00 (.00)	7.60 (.89)	1.6	.22
Adapted Computer	19	8.00 (.00)	00 (00)	8.00 (.00)	7.20 (1.78)	1.35	.28
Room Temperatures	45	4.41 (4.63)	8.00 (.00)	6.27 (2.57)	4.50 (6.56)	.69	.55

^{*}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.

detivities within the com	· · · · · · · · · · · · · · · · · · ·	1					1
IN YOUR COMMUNITY,	0/ OF	MEAN (SD)					
HOW MUCH AND HOW	% OF		(RANGE = -8 TO 8*)				
OFTHEN, DO THE	PARTICIPANTS	Para	Para	Tetra	Tetra	F	P
FOLLOWING	(N=105)	Manual	Power	Manual	Power		
INFLUENCE YOUR		N=52	N=6	N=20	N=20		
PARTICIPATION IN		11-32	11-0	11-20	11-20		
ACTIVITIES?							
Curb cuts	84	5.42 (4.11)	7.00 (1.15)	3.50 (5.76)	5.00 (4.15)	1.0	.36
Ramps	84	5.26 (4.23)	8.00 (.00)	4.78 (4.74)	7.06 (1.76)	1.75 ¹	.16
Elevators	75	6.25 (3.37)	7.00 (1.73)	4.82 (4.34)	5.29 (2.01)	1.01	.40
Flat terrain	76	6.82 (2.87)	8.00 (.00)	6.86 (3.03)	6.25 (2.43)	.54	.65
Gravel surfaces	57	-2.88 (4.21)	-2.50(1.2)	-2.10 (2.37)	-1.13 (3.75)	.49	.68
Paved surfaces	79	6.67 (3.56)	8.00 (.00)	7.00 (2.39)	5.87 (2.85)	.69	.55
Summer weather	74	68 (5.78)	1.25 (8.05)	2.53 (5.28)	1.00 (6.59)	1.19	.31
(heat and humidity)							
Winter weather	85	-3.26 (4.69)	-3.33 (1.75)	-4.82 (2.45)	-2.14 (5.86)	.97	.40
(ice and snow)							
Rain	73	-1.68 (3.98)	-3.00 (2.64)	-3.20 (1.85)	-2.14 (4.50)	.65	.58
Crowds	60	-2.44 (3.47)	-1.50 (.70)	-2.06 (1.98)	-2.17 (5.00)	.078	.97

^{*}If limit 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

^{*}If help a lot daily Score = +8

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 functions²⁰ allowing people with severe physical or health impairments to participate more fully in community settings and activities, including employment. 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.²² For many people with disabilities, personal assistance has been proven to be critical for workplace functioning 23 and can make a critical difference in adjustment to SCI and the ability to live independently.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, ²⁴ upper extremity injuries and pain from overuse ^{25,26} and overall decreased physical capacity.²⁷ 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. ²⁸ 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 ²⁹ 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.³⁰ 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 collegues³¹ as common physical barriers in restaurants. Richards et al.³ 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. 17

In recent years architectural standards ¹² and laws have focused on making environments more accessible to individuals with disabilities. ²² 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.

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APPENDIX B

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

Not Limited	your residence limits you? (Check all that apply.) □Entrance □Bathroom □Kitchen □Lack of personal finances □P □ Lack of special equipment → What equipment would be helpful? □ What equipment would be helpful?	arking	□Lack of personal assistance
2. What abou Not Limited	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?	ı	
3. What about Not Limited	t your grocery store limits you? (Check all that apply.) □Entrance □Lack of personal finances □Parking □Lack of child car □Accessibility of shelves and freezers □Lack of transportation □Lack of scooter/wheelchair at the store □Lack of personal assistance □ Lack of special equipment → What equipment would be helpful?	e	

t restaurants limits you? (Ch	eck all that apply.)	
☐Tables too close together	☐Height of counters, tables, and booths	ing of transportation
nt movie theaters limits you? (Check all that apply.)	
□Lack of child care □Lack □Lack of transportation	a of personal assistance	□Parking —
at shopping malls limits you? ((Check all that apply.)	
☐ Lack of personal assistance	□Lack of child care □Lack of transportat	ion
at clothing stores limits you?	(Check all that apply.)	
	□Lack of child care □Height of clothing racks	□Parking □Width of aisles
	□ Entrance □ Lack of personal assistance □ Tables too close together □ Lack of special equipment □ Lack of special equipment □ Lack of child care □ Lack of transportation □ Lack of special equipment □ Lack of personal assistance □ Lack of special equipment □ Lack of personal assistance □ Lack of personal assistance □ Lack of personal assistance	Lack of personal assistance Lack of child care Lack of special equipment Height of counters, tables, and booths What equipment would be helpful?

7. What about	at public parks limits you? (Check all that apply.)
Not Limited	□ Lack of paved paths □ Picnic areas □ Parking □ Lack of personal finances □ Lack of transportation □ 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 <u>home</u>, do the following <u>influence your participation in activities</u>?

1.	Stairs No V	☐Yes How much? How often?		□Help some □Weekly	□Limit some □Monthly	
2.	Ramps No	☐Yes How much? How often?		□Help some □Weekly	□Limit some □Monthly	
3.	Doors No	□Yes How much? How often?		□Help some □Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly
4.	Carpets No	☐Yes How much? How often?	4	□Help some □Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly

5. Hardwood	$\square Yes$				
floors	How much?	□Heln a lot	□Heln some	□ Limit some	$\Box U$ imit a lot
	How often?	-	□Weekly	□ Monthly	Less than monthly
1	now orten.	— Дану	— weekiy	шиопшу	Less than monthly
V					
6. Handrails	$\square Yes$				
$\square No$	How much?	□Help a lot	□Help some	\Box Limit some	\Box Limit a lot
•	How often?	$\square Daily$	\square Weekly	$\square Monthly$	□Less than monthly
			•		
7. Adapted	$\Box Yes$				
computer	How much?	□ Helps a lot	□Helps some	□Limits some	□Limits a lot
$\square No$	How often?	•	\square Weekly	$\square Monthly$	\Box Less than monthly
•		•	·	•	·
8. Room	$\square Yes$				
temperatures	How much?	•	□Help some	\Box Limit some	\Box Limit a lot
$\square No$	How often?	$\square Daily$	$\square Weekly$	$\square Monthly$	$\square Less than monthly$
•					
The following items ro you move around and	•				that may influence how
In your community, do	•				si to your experience.
1. Curb cuts	□Yes				
		h? □Heln a	lot □Help so	me 💷 imit so	me 🖫 Limit a lot
		\mathbf{n} ? $\mathbf{\Box}$ $Daily$	□Weekly	☐Monthly	
•	HOW Offer	— Dany	= Weekiy	<u> </u>	Ecss than monthly
2. Ramps	$\Box Yes$				
$\square N_O$		h? []Haln a	lot □Help so	me L imit so	me 🖫 Limit a lot
1	How often		Weekly	Monthly ⊒	
▼	110W UITE	ш. шрину	— weekty	— woniniy	L ess man monny
3. Elevators	$\Box Yes$				
		h9 □ <i>II</i>	104		ma Dimit a lot
			lot Help so		
	How often	$\mathbf{n?}$ $\square Daily$	□Weekly	□Monthly	□Less than monthly
1 Elet termin					
4. Flat terrain	□Yes	. b.9 □111 -1	104 🗆 11 - 1	am a 🗇 Lii-ta	ama DI imita a lat
		n≀ ⊔Heips a n? □Daily	tot ⊔ Helps so □Weekly		ome Limits a lot Uless than monthly
NH2					

5. Gravel surfaces	$\square Yes$			
$\square No$	How much? □ <i>Help a lot</i>	□ Help some ∣	□ Limit some ∣	⊒ Limit a lot
↓	How often? □ <i>Daily</i>	□Weekly	$\square Monthly$	□Less than monthly
6. Paved surfaces	□Yes			
$\square No$	How much? □ <i>Help a lot</i>	□Help some	\Box Limit some	\Box Limit a lot
Ψ	How often? □ <i>Daily</i>	□Weekly	□ Monthly	□Less than monthly
7.Summer weather	$\square Yes$			
(heat and humidity)	How much? □ <i>Helps a lot</i>	□Helps some	□Limits some	r \square Limits a lot
$\square No$	How often? □ <i>Daily</i>	\square Weekly \square M	Aonthly □Les.	s than monthly
•				
8. Winter weather	$\square Yes$			
(ice and snow)	How much? □ <i>Helps a lot</i>	□Helps some	□Limits some	e □ Limits a lot
$\square No$	How often? □ <i>Daily</i>	\square Weekly	$\square Monthly$	\Box Less than monthly
•		(Durir	ng the season)	
9. Rain	$\square Yes$			
$\square No$	How much? □ <i>Helps a lot</i>	□Helps some	□ Limits some	e □ Limits a lot
•	How often? □ <i>Daily</i>	\square Weekly	$\square Monthly$	\Box Less than monthly
10. Crowds	$\Box Yes$			
$\square N_O$	How much? □ <i>Help a lot</i>	□Help some	□ Limit some	□Limit a lot
↓	How often? □ <i>Daily</i>	□Weekly	$\square Monthly$	□Less than monthly

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. Approximately 57% of these individuals have cervical lesions (tetraplegia) and 43% have lesions below the first thoracic level (paraplegia). SCI most commonly affects young, in working-age adults, 80% of whom are men. The average age of injury has been gradually increasing, and for persons injured since 2000, it is reported to be 38.0 years. Evidence suggests that compared to the general population, people with SCI might experience a lower QoL. Research has documented that life satisfaction is greater for individuals who are involved in productive activities such as work, education, and recreation.

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. 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. 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. 13 Evidence supports that individuals who attend specialized seating clinics improve skin management knowledge, awareness, and potentially reduce the incidence of pressure ulcers. 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. 15 Verza et al. 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. 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 ^{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 consecutives 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. ¹⁷ 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

D, E, F and G). 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. ¹⁸ 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).

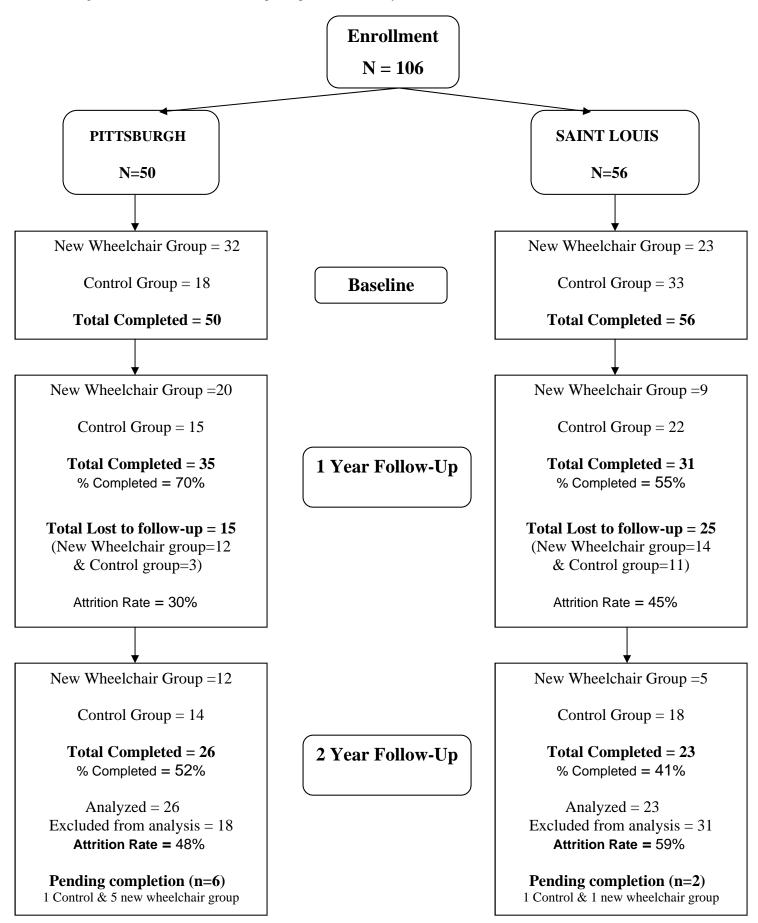
Repeated measure ANOVA was used to determine the effects of the type of wheelchair on outcome of interest (frequency of community participation, satisfaction of community participation and functional limitation to participation) being considered the dependent variable and independent factors of type 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.



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 completed 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.

Frequency of Community Participation

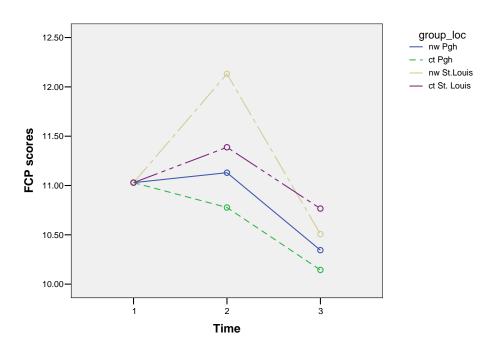


Table 19. Illustrates the scores of perception of frequency of community participation (FCP), satisfaction of community participation (SCP) and functional limitations (Participation and Access limitations) of community participation by the four groups over time.

Community Participation	Location	Time Mean (STDV)			Within subjects effects	Between subjects effects
variables		Baseline	1 year	2 years		
	NWPITT	11.4 (4.05)	11.4 (3.72)	10.5 (4.33)		
FCP	NWSL	12.5 (2.93)	13.2 (.4.13)	11.3 (3.55)	F(2) = 4.14 p = .019	F(3) = .309
(Score range = $0 - 20$)	CTPITT	11.9 (2.75)	11.4 (3.02)	10.6 (1.79)		p=819
	CTSL	9.62 (2.65)	10.3 (3.32)	9.92 (2.53)		
	NWPITT	7.08 (5.36)	7.16 (4.23)	6.00 (4.63)		
SCP	NWSL	9.00 (3.60)	9.80 (1.92)	9.20 (2.58)	F(2) = 3.98 p = .022	F(3) = .774
(sore range = $0 - 15$)	CTPITT	9.28 (4.00)	8.92 (4.74)	8.00 (4.09)		p=.515
	CTSL	5.66 (4.13)	6.55 (4.42)	6.44 (4.30)		
	NWPITT	7.41 (4.50)	8.41 (7.90)	12.50 (9.69)		
Participation Limitations	NWSL	6.20 (3.83)	9.40 (1.94)	8.40 (3.36)	F(2) = 4.59 p = .013	F(3) = .169
(sore range = $0 - 28$)	CTPITT	7.50 (4.27)	9.14 (7.19)	10.14 (6.57)		p=.917
	CTSL	9.83 (7.71)	10 (6.66)	12.44 (7.07)		
	NWPITT	8.16 (5.50)	8.58 (6.03)	11.1 (8.65)		
Access	NWSL	10.4 (6.06)	9.60 (3.20)	7.20 (3.89)	F(2) = .023 p=.977	F(3) = .513
Limitations	CTPITT	8.64 (4.68)	8.21 (4.61)	8.71 (5.31)		p=.676
(sore range = $0-46$)	CTSL	11.0 (8.69)	11.1 (6.25)	10.5 (6.98)		

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

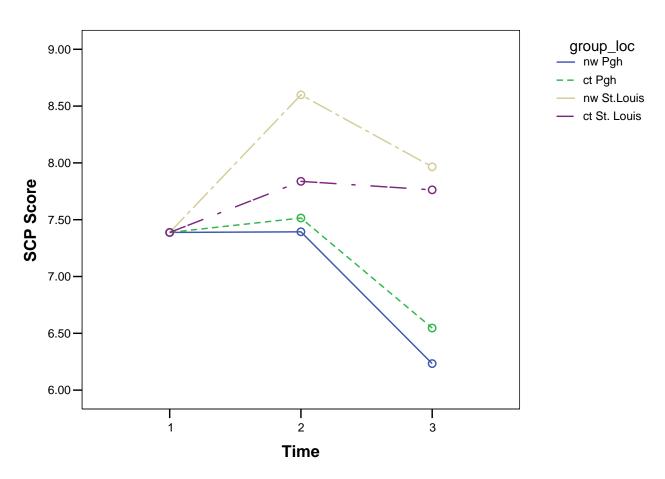
SCP= Satisfaction in Community Participation

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.

Satisfaction in Participation on Community Activities



1.3.3.6 Functional Limitations

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. <u>Access limitations:</u> 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

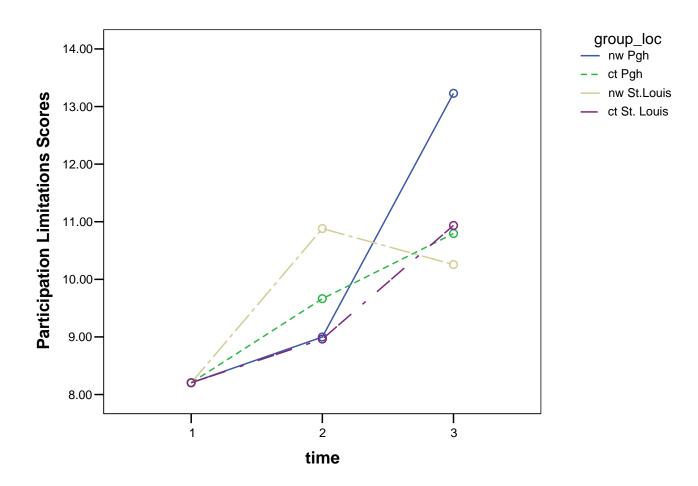
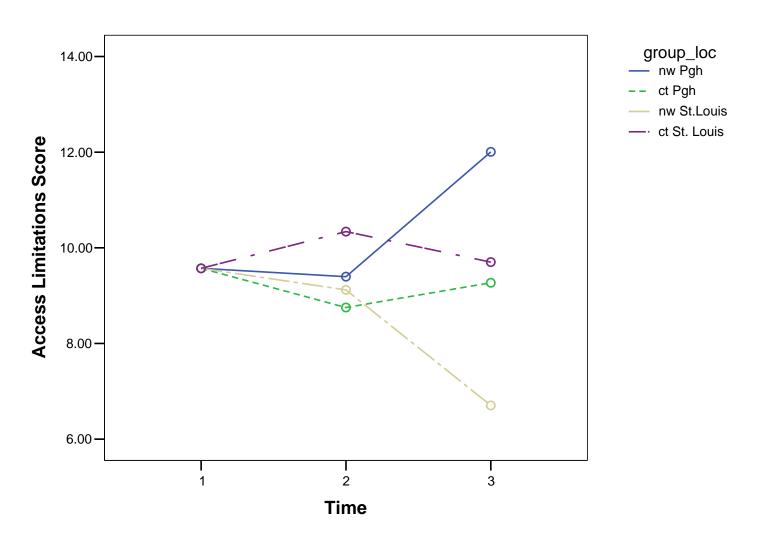


Figure 5. Illustrate functional limitations (access limitations) scores by the four groups over time.

Access Limitations



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. ¹⁹ The wheelchair is one of the most important of rehabilitation interventions. However, individuals who use wheelchairs face many participation barriers. ²⁰⁻²⁴ 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 ^{9,11} 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. ^{10, 11} 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.^{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 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

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APPENDIX D

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

1.	How frequ	ently do you le	eave your home?		
	□Never	→	☐ I choose not	to do this	☐ I am unable to do this
			(Go to	question 3 o	n next page.)
	☐ Onc	e or twice a m	onth		
	Onc	ce or twice a w	eek		
	☐ Onc	ce or twice a da	ay		
	□ 3 or	more times a	day		
2.			use transportation		
	□Never	$\rightarrow \Box I choos$	se not to do this	☐ I am una	able to do this
			uestion 3 on next	page)	
	Once o	er twice a mont	$^{\circ}h$		
	Once o	or twice a week	•		
		or twice a day			
	☐ More to	han twice a da	y		

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

Leisure Activities	How often do you do the activity			
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		

Attend concerts	u	\square Less than once a month				
	Never	\Box 1-2 times a month				
	Ψ	□1-2 times a week				
		☐More than twice a week				
Play cards		☐Less than once a month				
	Never	□1-2 times a month				
	•	□1-2 times a week				
		☐More than twice a week				
Play board games		☐Less than once a month				
	Never	□1-2 times a month				
	Ψ	□1-2 times a week				
		☐More than twice a week				
Watch sports		☐Less than once a month				
1	Never	□1-2 times a month				
	4	□1-2 times a week				
		☐ More than twice a week				
Read		☐ Less than once a month				
	Never	$\Box 1$ -2 times a month				
	Ψ	$\Box 1$ -2 times a week				
		\square More than twice a week				
Hobby (specify)		☐ Less than once a month				
libery (specify)	Never	$\Box 1$ -2 times a month				
	•	$\Box 1$ -2 times a week				
		\square More than twice a week				
Other (specify)		☐ Less than once a month				
(specify)	Never	$\Box 1$ -2 times a month				
	Ψ	$\Box 1$ -2 times a week				
		☐ More than twice a week				
		amore man inter a neck				
4 How often do you	ı narticinate	e in activity recreation?				
□Never		If choose not to do this I am unable to do this				
-IVEVE		Go to question 4)				
□ Less than i		th (Continue)				
□1-2 times a						
	,					
	$\Box 1$ -2 times a week (Continue) \Box More than twice a week (Continue)					
■ More man	ivice a we	ek (Commue)				
5. How frequently	, do vou so	cialize with others?				
Less than onc	•	\Box 1 to 2 times a week				
□ 3 to 4 times a						
🛥 5 to 4 times a	week	lacktriangle 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.

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

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

APPENDIX E

	•	participation in leaving your Somewhat satisfied	
	•	participation in using tran	•
	•	participation in leisure as Somewhat satisfied	
	•	participation in active red Somewhat satisfied	

Illustrates the 5 questions related to satisfaction in participation:

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

5. How satisfied are you with your participation in social activities?

□ Very satisfied □ Satisfied

Satisfaction leaving home (1 questions)	Satisfaction using transportation (1 question)	Satisfaction in leisure activities (1 question)	Satisfaction Active Recreation (1 question)	Satisfaction socializing (1 question)	
Dissatisfied = 0 Somewhat satisfied = 1 Satisfied = 2 Very satisfied = 3	Dissatisfied = 0 Somewhat satisfied = 1 Satisfied = 2 Very satisfied = 3	Dissatisfied = 0 Somewhat satisfied = 1 Satisfied = 2 Very satisfied = 3	Dissatisfied = 0 Somewhat satisfied = 1 Satisfied = 2 Very satisfied = 3	Dissatisfied = 0 Somewhat satisfied = 1 Satisfied = 2 Very satisfied = 3	
(Score range = 0 - 3)					
Total score range = 0 - 15					

☐ Somewhat satisfied

 \square Dissatisfied

APPENDIX F

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

 Is your participation in leaving your home limited by (Checular limited by	☐ Wheelchair
2. Is your participation in using transportation limited by (Ch. ☐ Illness ☐ A physical impairment ☐ Pain ☐ Fatigut Wheelchair seating ☐ Other	e 🛭 Wheelchair 📮
3. Is your participation in leisure activities limited by (<i>Check</i> ☐ <i>Illness</i> ☐ <i>A physical impairment</i> ☐ <i>Pain</i> ☐ <i>Fatigue</i> ☐ <i>Wheelchair seating</i> ☐ <i>Other</i>	☐ Wheelchair
4. Is your participation in active recreational activities limited by (<i>Check all that apply</i> .)	
☐ Illness ☐ A physical impairment ☐ Pain ☐ Fatigue ☐ Wheelchair seating ☐ Other	
5. Is your participation in social activities limited by (Chec	
□ Illness □ A physical impairment □ Pain □ Fatigue □ Wheelchair seating □ Other	

The 5 items regarding participation limitations (PL) will be score as the following:

PL leaving home (1 questions)	PL transportation (1 questions)	PL leisure activities (1 questions)	PL Active Recreation (1 questions)	PL socializing (1 questions)
PL (score range =0 – 7)	PL (score range =0 – 7)	PL (score range =0 – 7)	PL (score range =0 – 7)	PL (score range =0 – 7)
		Total score range = $0 - 28$		

APPENDIX G

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

	□ Social attitudes □ Family attitudes □ Wheelchair □ Wheelchair seating
☐ Other (specify)	Not limited
2. Is your access to using transportation limits □ Physical factors in the environment □ Self-concept □ Wheelchair □ Lack of special equipment → Wheelch	at □ Social attitudes □ Family attitudes □ Lack of assistance □ Limited finances pair seating
☐ Other (specify)	Not limited
3. Is your access to leisure activities limited by □ Physical factors in the environment □ Self-concept □ Limited fine □ Wheelchair □ Lack of special equipment → What e	□ Social attitudes □ Family attitudes ances □ Lack of assistance seating
☐ Other (specify)	Not limited
4. Is your access to active recreational activities leads (Check all that apply.) □ Physical factors in the environment □ Social attitudes □ Family attitudes □ Lack of organized accessible teams □ Wheelchair □ Wheelchair □ Lack of special equipment → What descriptions	☐ Lack of assistance ☐ Limited finances ☐ Self-concept r seating

☐ Other (specify)	□ Not limited
☐ Self-concept☐ Lack of companion(s)	imited by (Check all that apply.) ironment □ Social attitudes □ Family attitudes □ Lack of assistance □ Limited finances □ Wheelchair □ Wheelchair seating → What equipment would be helpful?
☐ Other (specify)	□ Not limited

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

leaving home (1 questions)	transportation (1 questions)	leisure activities (1 questions)	Active Recreation (1 questions)	socializing (1 questions)	
, ,			. 1	` '	
AL (score range =0 - 8)	AL (score range =0 – 9)	AL (score range =0 – 9)	AL (score range $=0-10$)	AL (score range =0 - 10)	
Total score range = 0 – 46					

1.4 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)² 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 ³; 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); ⁴ one measure, Participation Survey/Mobility (PARTS/M) include both. ⁵

The CHART is probably the most widely used participation measure for individuals with spinal cord injury (SCI).⁴ 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. ⁵ 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. ⁶

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 ^{6,11} 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.¹² 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 ⁸ attaches to the spokes of manual wheelchair (see figure 7) and the other one replace the caster of power wheelchairs ¹³ (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

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



Figure 7. Illustrates the power data logger device.



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^a program. The custom code computed the mobility characteristic variables of daily total distance traveled and average daily speed. The daily distance (D_{day}) was calculated using:

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

where C_{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_{day}) at which the wheelchair users traveled during a single day, the total daily distance (D_{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_{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 ($N_{stop/1000m}$) was calculated using:

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

where $N_{stop/day}$ 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 $2827.75~(\pm 1746.92)$ meters at a speed of $0.70~(\pm~0.21)$ 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 $156.87~(\pm~100.09)$. The subjects were also found to be driving for an average of $57.044~(\pm~31.04)$ 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 (\pm 1762.93) meters at a speed of 0.69 (\pm 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 (\pm 155. 23). The subjects were also found to be driving for an average of 57.91 (\pm 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.

Variables	Mean ± SD (Range)	r (p-value)
Daily Distance (m) week	2815.97 ± 1762.93 (499.626104.42)	.300 (.259)
Daily Distance (m) weekend	2885.91 ± 2114.63 (84.687127.52)	.038 (.888)
Daily Speed (m/s) week	0.69 ± 0.19 $(0.33 1.08)$.615 (.011)
Daily Speed (m/s) weekend	0.72 ± 0.30 $(0.06 1.30)$.090 (.741)
Daily Number Starts/Stops week (per 1000 meters)	187.17 ± 155.23 (29.29658.06)	408 (.117)
Daily Number Starts/Stops weekend	146.15 ± 118.82 $(20.33492.32)$.319 (.228)
(per 1000 meters)		
Daily Drive minutes (min) week	57.11 ± 32.35 (9.32113.81)	.270 (.312)
Daily Drive minutes (min) weekend	57.37 ± 34.64 (5.45113.57)	.079 (.770)

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 \pm 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=-.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=.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=.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.

VARIABLES	MANUAL			POWER		
	MEAN	SD	r (p-value)	MEAN	SD	r (p-value)
Daily Total Distance (m) week	2461.57	1741.60	.093 (.843)	3091.61	1832.24	.595(.091)
Daily Total Distance (m) weekend	2486.44	2299.13	.168 (.719)	3196.62	2042.45	.043(.913)
Daily Speed (m/s) week	0.75	0.19	.760 (.047)	0.65	0.20	.449 (.225)
Daily Speed (m/s) weekend	0.74	0.19	.698 (.081)	0.69	0.38	165 (.671)

Daily Number Starts/Stops week	198.57	87.22	179 (.702)	178.31	198.18	783 (.013)
Daily Number Starts/Stops weekend	219.64	142.61	214 (.645)	88.99	53.07	.250 (.516)
Daily Drive minutes (min) week	50.23	32.12	-212 (.648)	62.46	33.39	.772 (.015)
Daily Drive minutes (min) weekend	49.94	40.54	.004 (.994)	63.14	30.52	.306 (.424)

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 21).

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 (\pm 1741) at a speed of 0.75 (\pm 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. found that the average distance traveled were 2456 (\pm 1195) meters per day in the home environment at a speed of 0.79 (\pm 0.19). Souza et al. examined the mobility patterns of individuals with SCI that were more severely impaired (tetraplegia) and found the average daily distance traveled to be 1816 (\pm 1730) meters at a speed of 0.62 (\pm 0.18) meter/second. In addition, Fitzgerald et al. indicated the average daily distance of individuals with paraplegia who use manual wheelchairs to be 1671.4 \pm 314.8 meters at a speed of 0.26 (\pm 0.05). Our study also indicated that individuals who use power wheelchairs travel an average daily distance of

3091 (\pm 1832) meters. This results are similar to Cooper et al. who found that the average distance traveled of power wheelchair users was 3432.8 (\pm 1741.6) meters per day at the National Veteran Wheelchair Games (NVWG) and 1667.0 (\pm 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.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.²¹ Research has pointed out that mobility, the physical and social environment are seen as important predictors of community participation.^{5,22} Other studies have revealed that the severity of injury indirectly affects quality of life (QoL) through its influence on community participation. ^{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. ^{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. ²⁶ Power wheelchair options such as tilt-in-space and recline can increase overall function simply by increasing someone's sitting tolerance. ²⁷A 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. ²⁸ Power wheelchair functions impact positively on QoL ²⁹as they allow participants to stay longer in their chairs, conserve energy, access a variety of environments and participate in more activities during the day. 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 ^{22,23} and reduced quality of life. 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.

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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 (\pm 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 (\pm 155. 23). The subjects were also found to be driving for an average of 57.91 (\pm 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

(Go to question 3 on next page.)

☐ I am unable to do this

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

☐ I choose not to do this

1. How frequently do you leave your home?

☐Never ☐ I choose not

☐ Once or tw	☐ Once or twice a month				
☐ Once or twice a week					
Once or tw	☐ Once or twice a day				
\square 3 or more t	-				
□ J of more	illies a day				
2. How frequently of	do you use	transportation?			
□Never → □	I choose n	not to do this \Box I am unable to do this			
		ion 3 on next page)			
☐ Once or twice		ion o on next page,			
□ Once or twice					
☐ Once or twice	•				
\square More than twi	ice a day				
3. For the following	leisure act	ivities, please indicate how often you do them			
Leisure Activities	How ofte	n do you do the activity			
Dine out		☐Less than once a month			
	Never	□1-2 times a month			
	$lack \Psi$	$\Box 1$ -2 times a week			
	11-2 times a week				
Attand marriag	Attend movies				
Attend movies		☐Less than once a month			
	Never •	$\Box 1$ -2 times a month			
	•	\square 1-2 times a week			
		☐More than twice a week			
<u> </u>					

Attend concerts		$\square Less than once a month$		
	Never	□1-2 times a month		
	lack	□1-2 times a week		
		☐More than twice a week		
Hobby (specify)		☐ Less than once a month		
(speegy)	Never	$\Box 1$ -2 times a month		
	¥	$\Box 1$ -2 times a week		
		☐More than twice a week		
4. How often do you	participate	e in activity recreation?		
■Never	→ □	I choose not to do this I am unable to do this		
	((Go to question 4)		
\Box Less than o	nce a mon	th (Continue)		
$\Box 1$ -2 times a	month (Co	ontinue)		
$\Box 1$ -2 times a	week (Cor	ntinue) (
☐ More than twice a week (Continue)				
5. How frequently	do vou soc	cialize with others?		
Less than once	•	\Box 1 to 2 times a week		
— 1 E 3 S 1 H () H () H () E	· II VVPPK	HILLIO A LITTEN IL 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.

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

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	\square Female
2.	What is your birthdate?	//(MM/	/DD/YY)
3.	What is your race/ethnicity?	(Check all that apply.))
	White Black/African American Other (specify)	☐ Americ	Pacific Islander can Indian/Alaskan Native
	Are you of Spanish/Hispanic <i>Yes</i> □	origin? <i>No</i>	
	<i>Divorced</i> □	ply.) Separated Never been married Member of an unmarı	ried couple
	What is the highest grade or y Never attended school or only Grades 1 through 8 Grades 9 through 11 Grade 12 or GED (high school College 1 year to 3 years College 4 years or more (college	kindergarten ol graduate)	e completed?

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 \$35,00 □ \$35,000 to less than \$50,000 □ \$50,000 to \$75,000 or □ Over \$75,000 □ Don't know/Not sure	es:			
8. Which of the following benefits are you currentl (<i>Check all that apply.</i>) □ SSI (Supplemental Security Income)	y receiving?			
☐ SSDI (disability benefits from Social Sect	ırity)			
☐ Medicare ☐ Medicaid ☐ Fo	ood 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 ☐ 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 □ Qua	adriplegia	□ Don't know		
12. Is your injury: □ Complete □ Incomplete □ Don't know				
13. When was the onset of your spinal cord injury	y?/	(month/year)		
Do you have any of the following secondary concondition?	ditions? If Yes,	how often do you experience the		
Condition Check all that apply.)	How ofter	n do you experience this condition?		
1. Pain	□ Constantly	$\square Off$ and on $\square Rarely$		
☐ 2. Osteoporosis	\Box Constantly	$\square Off$ and on $\square Rarely$		

	1			
☐ 3. Spasticity	□Constantly	\Box Off and on	□Rarely	
☐ 4. Upper Respiratory Infection	□ Constantly	\Box Off and on	□Rarely	
☐ 5. Circulatory problems	□ Constantly	$\Box Off$ and on	□Rarely	
☐ 6. Scoliosis	□Constantly	\Box Off and on	\square Rarely	
☐ 7. Weight problems	□ Constantly	□Off and on	$\square Rarely$	
□ 8. Skin problems	□Constantly	□Off and on	□Rarely	
☐ 9. Depression	□Constantly	\Box Off and on	□Rarely	
☐ 10. Contractures – permanent limitation of joint movement	□Constantly	$\Box Off$ and on	□Rarely	
☐ 11. Bladder incontinence	□Constantly	□Off and on	\square Rarely	
☐ 12. Bowel incontinence	□ Constantly	\Box Off and on	□Rarely	
☐ 13. Stomach problems	□ Constantly	\Box Off and on	□Rarely	
☐ 14. Urinary Tract Infection	□ Constantly	\Box Off and on	□Rarely	
☐ 15. High Blood Pressure	□ Constantly	□Off and on	□Rarely	
☐ 16. Phlebitis – inflammation of blood vessels	□Constantly	\square Off and on	□Rarely	
☐ 17. Fingernail or toenail infections	□Constantly	□Off and on	□Rarely	
☐ 18. Fatigue	□Constantly	□Off and on	\square Rarely	
☐ 19. None of these				
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
Th	e 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
3а	. Do you use special equipment or help from others to get around?
	 ✓ Yes (Continue.) ✓ No special equipment or help used (Go to Question 5)
31	*************** o. 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.)
	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 \(\square \) Not applicable For HOW LONG have your activities been limited because of your major impairment or health problem?
	□ Days
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.	0 1	sual activities, such as self-care, work,	V
	11a.	☐ Number of days:	☐ None
12.	During the past 3 DEPRESSED?	30 days, for about how many days have	you felt SAD, BLUE, or
	12a.	☐ Number of days:	□ None
13.	During the past 3 TENSE, or ANXI	30 days, for about how many days have OUS?	you felt WORRIED,
	13a.	☐ Number of days:	□ None
14.	During the past 3 get ENOUGH R	00 days, for about how many days have EST or SLEEP?	you felt you did NOT
	14a.	☐ Number of days:	□ None
15.		60 days, for about how many days have D FULL OF ENERGY?	you felt VERY
	15a.	☐ Number of days:	☐ None

PARTICIPATION SURVEY / ASSISTIVE TECHNOLOGY

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.

GROOMING: The following questions are about grooming. Grooming includes shaving, combing and brushing hair, applying makeup, brushing teeth, etc.

1.		ntly do you groom? s a week □Once a day □2	3 times a day 🗖	More than 3 tin	nes a day
2.		time do you require for groon 10 minutes 10 to 20 min			
3.	Is your partic		by (Cheo □ Pain	ck all that apply □ Fatigue	v.) Wheelchair 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.		elp from another person de \square <i>Just a little</i> \square <i>A mode</i>		grooming? A great deal	
7.		sistance, who helps you with □ Family/Significant Other			
8.	How often do you use accommodations , adaptations , or special equipment to groom? Never				
9.	If you use accommodations, adaptations, or special equipment to groom, what do you use? (<i>Check all that apply</i> .)				
	□ N/A	☐ Dressing table ☐ Electric shaver ☐ Electric toothbrush ☐ Grab bars ☐ Lift ☐ Long-handled equipment ☐ Wheelchair - manual ☐ Wheelchair seating	□ Shower □ Special □ Specialized bar □ Special □ Lowere	grooming devi	ce ent

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? ☐ I choose not to do this \square None \rightarrow ☐ 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.) ☐ Just a little ☐ None ☐ A moderate amount ☐ A great deal If you use assistance, who helps you to prepare and clean up? (Check all that apply.) ☐ Family/Significant Other ☐ No one ☐ Friends ☐ People I hire 7. 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 8. If you use accommodations, adaptations, or special equipment for meal preparation, what do you use? (Check all that apply.) ☐ Cane ☐ Scooter (N/A)☐ Adaptive cooking utensils ☐ Special seat/chair ☐ Lap board/TV tray ☐ Specialized kitchen equipment ☐ Specialized wheelchair ☐ Universal cuff ☐ Lowered shelves/counters ☐ Reacher/grab stick/grabber ☐ Orthotic/prosthetic device □ Walker ☐ Wheelchair - manual ☐ Wheelchair – power ☐ Wheelchair seating □ 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.		me do you require for bladder 30 minutes 30 to 60 minu		
	(Check all	ipation in performing and man that apply.) A physical impairment		·
		ating		
3.	others withou	ent of bladder care, how much t disabilities? (Choice include A lot of choice	es when, where	and how care takes
4.		are you with your participation Satisfied Satisfied So		
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.		elp from another person do you Just a little A modera	-	adder care? A great deal
7.		istance, who helps you with bl ☐ Family/Significant Other		
8.I	for bladd		_	
	□Never □A	little of the time □Some of th	e 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/undergar	ments	☐ Grab bars
		☐ Accessible bathroom		Medication
		☐ Urinal/bedpan/potty chair		☐ Orthotic/prosthetic device
		☐ Catheter		☐ Raised toilet
		☐ Leg bag/overnight bags/be	d 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?			
Living room	□Less than 1 □1 to 4 □More than 4 □Not applicable to my home		
Dining room	□Less than 1 □1 to 4 □More than 4 □Not applicable to my home		
Kitchen	□Less than 1 □1 to 4 □More than 4 □Not applicable to my home		
Bathroom	□Less than 1 □1 to 4 □More than 4 □Not applicable to my home		
Bedroom	□Less than 1 □1 to 4 □More than 4 □Not applicable to my home		
Study	□Less than 1 □1 to 4 □More than 4 □Not applicable to my home		
Basement	□Less than 1 □1 to 4 □More than 4 □Not applicable to my home		
Other (specify)	□Less than 1 □1 to 4 □More than 4 □Not applicable to my home		
Is your participation in moving around your home limited by (Check all that apply.) □ Illness □ A physical impairment □ Pain □ Fatigue □ Wheelchair □ Wheelchair seating □ 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? (Check 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	☐ Walker		
☐ Lift	☐ Orthotic/prosthetic device		
☐ Wheelchair - manual	☐ Wheelchair - power		
☐ Wheelchair seating	☐ Widened doors		
☐ Other			
☐ 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. H	ow 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 p	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.

Community	How often do you do the activity?	(Please answer corresponding follow-up
Activities		question)
C1		☐ I choose not to do this activity
Shopping for	□Never	☐ I am unable to do this activity
groceries	□ r .1 .1	D ()
	Less than once a month	Preparation time
	□1-2 times a month	Under 10 minutes
	□1-2 times a week	□10-20 minutes
	☐More than twice a week	More than 20 minutes
~! ·		☐ I choose not to do this activity
Shopping for	□Never	☐ I am unable to do this activity
clothes		
	☐Less than once a month	Preparation time
	□1-2 times a month	☐Under 10 minutes
	□1-2 times a week	□10-20 minutes
	☐More than twice a week	☐More than 20 minutes
		☐ I choose not to do this activity
Going to the	□Never	☐ I am unable to do this activity
pharmacy		
	□Less than once a month	Preparation time
	□1-2 times a month	☐Under 10 minutes
	□1-2 times a week	□10-20 minutes
	☐More than twice a week	☐More than 20 minutes
		☐ I choose not to do this activity
Going to the bank	□Never →	☐ I am unable to do this activity
	☐Less than once a month	Preparation time
	□1-2 times a month	☐Under 10 minutes
	□1-2 times a week	□10-20 minutes
	☐More than twice a week	☐More than 20 minutes

LEAVING YOUR HOME (continued)				
Community	How often do you do the activity?	(Please answer corresponding follow-up		
Activities		question)		
		☐ I choose not to do this activity		
Going to the	□Never	☐ I am unable to do this activity		
doctor's office				
	☐Less than once a month	Preparation time		
	□1-2 times a month	☐Under 10 minutes		
	□1-2 times a week	□10-20 minutes		
	☐More than twice a week	☐More than 20 minutes		
		☐ I choose not to do this activity		
Going to the post	□Never	☐ I am unable to do this activity		
office				
	☐Less than once a month	Preparation time		
	□1-2 times a month	☐Under 10 minutes		
	□1-2 times a week	□10-20 minutes		
	☐More than twice a week	☐More than 20 minutes		
		☐ I choose not to do this activity		
Going to the	□Never	☐ I am unable to do this activity		
friend's home				
	☐Less than once a month	Preparation time		
	□1-2 times a month	☐Under 10 minutes		
	□1-2 times a week	□10-20 minutes		
	☐More than twice a week	☐More than 20 minutes		
		☐ I choose not to do this activity		
Other (specify)	□Never →	☐ I am unable to do this activity		
	☐Less than once a month	Preparation time		
	□1-2 times a month	☐Under 10 minutes		
	□1-2 times a week	□10-20 minutes		
	☐More than twice a week	☐More than 20 minutes		

. 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?
1 Other (specify)
1 Not limited

☐ Illness ☐ A physical i	aving your home limited by (Che mpairment	
without disabilities? (Chand where you go.)	w much choice do you have compared to noice includes how often, when, and ho choice Little choice No choice	w you leave
	h your participation in leaving your hored Somewhat satisfied D	me? Dissatisfied
7. How important is it for y □Very important □Somewh	ou to leave your home? at important Somewhat unimportan	t □Not important
a. Unfamiliar? □Less than	need to prepare to go to a place that is . n 10 minutes □10 to 30 minutes □Mo n 10 minutes □10 to 30 minutes □Mo	ore than 30 minutes
9. How much help from anot ☐ None ☐ Just a little	ther person do you need to leave your he A moderate amount A	
<u> </u>	o helps you with leaving your home? (Significant Other	·
	commodations, adaptations, or special me Some of the time Most of the	
12. If you use accommodation home, what do you use?	ons, adaptations, or special equipment to (Check all that apply.)	o leave your
□ N/A □ Handrails □ Level threshold □ Lift □ Pedal for car □ Elevator □ Scooter □ Grab bars □ Ramp □ Vehicle (not adapted) □ Other	□ Walker □ Wheelchair seating □ Wheelchair - manual □ Wheelchair - power □ Widened doors	

TRANSPORTATION:	The	following	questions	involve	accessing	and	using	different	forms	of
transportation.										

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

□Never	→	☐ I choo	ose not to a	lo this	☐ I am	unable	to do i	this
		(Go to g	uestion 3 d	on next	page)			
☐ Once o	r twi	ce a mon	eth					
☐ Once o	r twi	ce a wee	k					
☐ Once o	r twi	ce a day						
☐ More ti	han t	wice a d	ay					

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

Please check all forms of transportation that you use	Overall, how does this type of transportation influence your Participation in activities?
Own car/van (not adapted)	□Helps a lot □Helps some □No effect □Limits some □Limits a lot
☐Own adapted car/van	□Helps a lot □Helps some □No effect □Limits some □Limits a lot
□Buses	□Helps a lot □Helps some □No effect □Limits some □Limits a lot
□Taxis	□Helps a lot □Helps some □No effect □Limits some □Limits a lot
□Airlines	□Helps a lot □Helps some □No effect □Limits some □Limits a lot
□Light rail / subway	□Helps a lot □Helps some □No effect □Limits some □Limits a lot

Special services: □Paratransit (such as Call-A-Ride)	□Helps a lot □Helps some □No effect □Limits some □Limits a lot			
□Adapted taxi	□Helps a lot □Helps some □No effect □Limits some □Limits a lot			
☐Adapted rental car/van	□Helps a lot □Helps some □No effect □Limits some □Limits a lot			
□Other	□Helps a lot □Helps some □No effect □Limits some □Limits a lot			
□ Physical facto □ Self-concept □ Wheelchair	(continued) o using transportation limited by (Check all that apply.) ors in the environment □ Social attitudes □ Family attitudes □ Lack of assistance □ Limited finances □ Wheelchair seating al equipment → What equipment would be helpful?			
□ Not limited	iy)			
 Is your participation in using transportation limited by (Check all that apply.) ☐ Illness ☐ A physical impairment ☐ Pain ☐ Fatigue ☐ Wheelchair ☐ Not limited 				
	do you have about using transportation, compared to others? (Choice includes when, where, how and with whom you use □ Some choice □ Little choice □ No choice			
6. How satisfied are y □ Very satisfied	you with your participation in using transportation? □ Satisfied □ Somewhat satisfied □ Dissatisfied			
	it for you to use transportation? Somewhat important □Somewhat unimportant □Not important			
8. How much help fr \square <i>None</i> \square <i>Just</i>	om another person do you need when using transportation? a little $\square A$ moderate amount $\square A$ great deal			
(Check all that app	ce, who helps you to use transportation? oly.) mily/Significant Other			
when using transp	use accommodations, adaptations, or special equipment portation? the time \square Some of the time \square Most of the time \square All of the time			

□ Ada ₁ □ Can □ Crus □ Doo □ Whe	
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 □ Limited finances □ Wheelchair □ Wheelchair seating □ Lack of special equipment ■ What equipment would be helpful?
	□ Other (specify)
3.	Is your participation in taking a vacation limited by (<i>Check all that apply</i> .) ☐ <i>Illness</i> ☐ <i>A physical impairment</i> ☐ <i>Pain</i> ☐ <i>Fatigue</i> ☐ <i>Wheelchair</i> ☐ <i>Wheelchai seating</i> ☐ <i>Other</i> ☐ <i>Not limited</i>
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:

11. If you use accommodations, adaptations, or special equipment when using

transportation, what do you use? (*Check all that apply*.)

8.

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How much time do you need to **prepare** for a vacation? (This might include

	0 0	ine seating or accessible lodging ur 1 to 3 hours More to	0 /				
ТА	KING A VACAT	TION (continued)					
9.		elp from another person do y ust a little					
10.	(Check all that	istance, who helps you with ta apply <u>.)</u> Family/Significant Other	G				
11.	for a vacation?		aptations, or special equipment Most of the time All of the time				
12.	12. If you use accommodations, adaptations, or special equipment to take a vacation, what do you use? (<i>Check all that apply.</i>)						
	□ N/A	□ Accessible parking permit □ Adapted vehicle □ Cane □ Crutches □ Lift □ Wheelchair - manual □ Wheelchair seating □ Other	□ Ramp □ Scooter □ Special chair □ Walker □ Orthotic/Prosthetic device □ Wheelchair - power □ Vehicle				

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?
	\square Never \longrightarrow \square I choose not to do this \square 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
	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?
	\square None \square Just a little \square A moderate amount \square 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?
	\square Never \square A little of the time \square Some of the time \square Most of the time \square 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.

Leisure Activities	How often do you do the activity		Preparation time (in minutes)
Dine out	Never	☐ Less than once a month☐ 1-2 times a month☐ 1-2 times a week☐ More than twice a week☐	□ <i>Under 10</i> □ 10-20 □ <i>More than 20</i>
Attend movies	Never	☐ Less than once a month ☐ I-2 times a month ☐ I-2 times a week ☐ More than twice a week	□ <i>Under 10</i> □ 10-20 □ <i>More than 20</i>
Attend concerts	□ Never •	☐ Less than once a month☐ 1-2 times a month☐ 1-2 times a week☐ More than twice a week☐	□ <i>Under 10</i> □ 10-20 □ <i>More than 20</i>
Play cards	□ Never •	☐Less than once a month ☐1-2 times a month ☐1-2 times a week ☐More than twice a week	□ <i>Under 10</i> □ 10-20 □ <i>More than 20</i>
Play board games	□ Never •	☐Less than once a month ☐1-2 times a month ☐1-2 times a week ☐More than twice a week	□ <i>Under 10</i> □ 10-20 □ <i>More than 20</i>
Watch sports	□ Never •	☐Less than once a month ☐1-2 times a month ☐1-2 times a week ☐More than twice a week	□ <i>Under 10</i> □ <i>10-20</i> □ <i>More than 20</i>
Read	□ Never •	☐Less than once a month ☐1-2 times a month ☐1-2 times a week ☐More than twice a week	□ Under 10 □ 10-20 □ More than 20
Hobby (specify)	□ Never •	☐Less than once a month ☐1-2 times a month ☐1-2 times a week ☐More than twice a week	□ <i>Under 10</i> □ 10-20 □ <i>More than 20</i>
Other (specify)	Never	☐Less than once a month ☐1-2 times a month ☐1-2 times a week ☐More than twice a week	□ <i>Under 10</i> □ 10-20 □ <i>More than 20</i>

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 □ Wheelchain □ 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.) \$\sum A \text{ lot of choice} \sum Some \choice \sum Little \choice \sum 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:
	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
	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? (<i>Check all that apply</i> .)
	□ N/A □ Card holder □ Scooter □ Computer (adaptive) □ Remote control □ Computer (regular) □ Wheelchair - manual

☐ Wheelchair - power	
☐ Wheelchair seating	
□ Other	

ACTIVE RECREATION: The following questions are about active recreational activities, such as a team sport or camping.

1.	How often do you part □Never →	icipate in this type of act I choose not to do the	•		
	☐ Less than once a	(Go to question 4)			
	□1-2 times a month				
	\Box 1-2 times a week	,			
	☐ More than twice a	,			
2.	If you participate in acti in the most?	ve recreation, what is on	e activity that you participate		
3.	How long does it take y □Under 10 minutes	you to prepare to do this a □10-20 minutes	activity? □More than 20 minutes		
4.	——————————————————————————————————————	recreational activities lin	nited by		
	(Check all that apply.)	.1			
	☐ Physical factors i				
	☐ Lack of assistance ☐ Social attitudes	ę			
	☐ Social attitudes ☐ Family attitudes				
	☐ Family attitudes ☐ Limited finances				
	☐ Lack of organized	l accessible teams			
	☐ Self-concept				
	☐ Wheelchair				
	Wheelchair seatir	· ·			
	☐ Lack of special eq	quipment → What equi	pment would be helpful?		
	☐ Other (specify) _				
	☐ Not limited				
	(Check all that apply.)	n active recreational activ	•		
		Other			

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.)

	\square A lot of choice \square Some choice \square Little choice \square No choice	
7.	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 □ Not importa	ortant
	IF YOU PARTICIPATE IN ACTIVE RECREATIONAL AC	TIVITIES:
9.	9. How much help from another person do you need to participate? • None • Just a little • A moderate amount • A great deal	
10.	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.	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 t	
12.	12. If you use accommodations, adaptations, or special equipment to do active recreational activities, what do you use? (<i>Check all that apply</i> .)	
	□ 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	e with others?		
	Less than once a week \Box 1 to 2 times a week			
	□ 3 to 4 times a week	☐ Daily or almost daily		
2.	Is your access to social activities Physical factors in the env Social attitudes Family attitudes Self-concept Lack of assistance Limited finances Lack of companion(s) Wheelchair Wheelchair seating Lack of special equipment	ironment		
	☐ Other (specify)			
	Is your participation in social a Illness	iirment	□ Pain □ Fatigue	☐ Wheelchair
	When socializing, how much ch (Choice includes how often, whe $\square A$ lot of choice $\square Some$ cho	n, how and wit	th whom you socialize.)	thout disabilities?
5.	How satisfied are you with your □ <i>Very satisfied</i> □ <i>Satisfied</i>			isfied
6.	How important is it for you to particle <i>description description </i>	. •		lot important
7.	How much help from another production of the state of	person do you l <i>A moderate a</i>		ıl
8.	If you use assistance, who helps □ <i>No one</i> □ <i>Family/Significe</i>	•		
9.	How often do you use accomm \square <i>Never</i> \square <i>A little of the time</i> \square	-		_
10.	If you use accommodations , ac (<i>Check all that apply</i> .)			·
	□ N/A □ Accessible parki	~ .	☐ Orthotic/prosthetic de	evice
	☐ Adapted vehicle		□ Scooter	
	🗖 Adapted telepho	ne	□ Walker	

☐ Cane/crutches	☐ Wheelchair seating
☐ Computer	☐ Wheelchair – manual
☐ Hearing aid	☐ Wheelchair - power
☐ Lift	□ Other

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?
\square None \Rightarrow \square I choose not to do this \square I am unable to do this
$\Box 1$ to 5 hours a week
☐ More than 5 hours a week
2. Is your access to religious activities limited by (<i>Check all that apply</i> .) □ <i>Physical factors in the environment</i> □ <i>Social attitudes</i> □ <i>Family attitudes</i> □ <i>Self-concept</i> □ <i>Lack of assistance</i> □ <i>Wheelchair</i> □ <i>Wheelchair seating</i> □ <i>Lack of special equipment</i> → <i>What equipment would be helpful?</i>
□ Other (specify) □ Not limited
3. Is your participation in religious activities 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 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

10. If you use accommodations , adaptations , or special equipment to participate in religious activities, what do you use? (<i>Check all that apply</i> .)	
□ 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? \square <i>Yes</i> \square <i>No</i>	
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 (<i>Check all that apply</i> .) ☐ 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	

-	nt is it for you to work? nt □Somewhat important □Some	ewhat unimportant \(\sigma\)Not important
IF YOU ARE EM	PLOYED:	
b. In a typica	of work do you do? l week, how many hours do you wan 10	
8. How much he None	Ip from another person do you re ☐ Just a little ☐ A moderate	1 1
(Check all th	11 0	oating in work? Friends □ People I hire
•	ou use accommodations, adaptat le of the time \(\sigma\)	ions or special equipment to participate in work? ■ Most of the time ■ All of the time
-	ommodations, adaptations, or sp do you use? (Check all that apply.)	
□ N/A	☐ Accessible parking permit ☐ Adaptive computer equipment ☐ Adapted vehicle ☐ Cane ☐ Computer ☐ Crutches ☐ Hearing aid	☐ Lift Int ☐ Orthotic/Prosthetic device ☐ Scooter ☐ Walker ☐ Wheeelchair seating ☐ Wheelchair – power ☐ Wheelchair – manual
	D Other	

FACILITATORS AND BARRIERS SURVEY / ASSISTIVE TECHNOLOGY

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* $\square Parking$ □ Lack of personal Not Limited assistance □ *Lack of special equipment* → *What equipment would be helpful?* $\square Other$

	□Helps a lot ❖❖❖❖	r place of employment in □Helps some □Has no •••••••••••••••••••••••••••••••••••	effect	tion in working? □Limits a lot □Not employed ❖❖❖❖❖❖❖❖❖❖❖
Not Limited	☐Lack of child care	□Workstation □Lack of personal assista ipment → What equipme	v 1	₀

3. How do	ses 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 ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★
	oout your grocery store limits you? (Check all that apply.)
Not	□ Entrance
Limited	□Lack of personal finances □Parking
↓	□Lack of child care
	□Accessibility of shelves and freezers □Lack of transportation
	□Lack of scooter/wheelchair at the store □Lack of personal assistance
	☐ Lack of special equipment → What equipment would be helpful?
	□ <i>Other</i>
4. How doe	es the accessibility of your doctor's office influence your participation in health care?
	\square Helps a lot \square Helps some \square Has no effect \square Limits some \square Limits a lot
	□Do not go to a doctor
3371 4 1	
What ab	out your doctor's office limits you? (Check all that apply.)
Not	□ Entrance □ Lack of personal finances □ Parking □ Lack of personal assistance □ Lack of child care □ Lack of insurance
Limited	□ Lack of personal assistance □ Lack of child care □ Lack of insurance □ Lack of transportation □ Waiting rooms and exam rooms
V	□ Lack of special equipment → What equipment would be helpful?
	□ <i>Other</i>
5 II 1.	
religious a	pes the accessibility of your religious institution or place of worship influence your participation in
Teligious at	envines:
	□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
	pout your religious institution limits you? (Check all that apply.)
<u> </u>	□Entrance □Seating □Lack of personal finances □Parking
Not	☐ Lack of personal assistance ☐ Lack of child care ☐ Lack of transportation
Limited ↓	☐ Lack of special equipment → What equipment would be helpful?
•	
	□Other

6. How do	es 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 ab	out restaurants limits you ? (Check all that apply.)
□ Not Limited •	□ Lack of personal finances □ Lack of personal finances □ Lack of transportation □ Lack of special equipment □ La
	□Other
7. How do	es the accessibility of movie theaters influence your participation in going to movies?
What ab	☐Helps a lot ☐Helps some ☐Has no effect ☐Limits some ☐Limits a lot ☐Do not go to movie theaters ❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖
Not Limited	□ Entrance □ Stadium seating □ Lack of personal finances □ Parking □ Lack of child care □ Lack of personal assistance □ Lack of transportation □ Lack of special equipment → What equipment would be helpful?
8. How do	es the accessibility of shopping malls influence your participation in shopping?
	a lot \square Helps some \square Has no effect \square Limits some \square Limits a lot
W/h of oh	Do not go to shopping malls
w nat ac	out shopping malls limits you? (Check all that apply.)
□ Not Limited •	□ Entrance □ Lack of personal finances □ Parking □ Lack of personal assistance □ Lack of child care □ Lack of transportation □ Lack of special equipment → What equipment would be helpful?
	□Other

□Helps a	lot	00	ect 🗆 Limits some 🗀 Limits a lot						
		$\Box D$	o not go to clothing stores						
What ab									
w nat au	out clothing sto	res mints you?	(Check all that apply.)						
	□ Entrance		□Lack of personal finances	□Parking					
Not	☐ Lack of trans	portation	□Lack of child care	☐Width of aisles					
Limited		onal assistance	· ·						
$lack \Psi$	· ·		What equipment would be helpful?	,					
		cu equipinent 2	,, nan equipment ,, emu ee neipjint						
	□ <i>Other</i>								
			arks and recreation areas influence	ce your participation in outdoor					
activities, s	uch as picnicking	•							
			ne □Has no effect □Limits some						
		$\Box Do not$	go to parks or recreation areas						
3371									
		-	Check all that apply.)						
	☐Lack of pavea	l paths							
Not	□Picnic areas								
Limited ↓	□Parking								
		•	Lack of transportation						
	□Lack of child		ack of personal assistance						
	□ Lack of speci	al equipment 🗩	• What equipment would be helpful?						
									
	□Oth or								
	□ <i>Other</i>								
11. How ac	ccessible are the	following types of	of transportation?						
		2 71	•						
(Please che	eck all the follow	wing that you use	e, then mark the response that is cl	losest to your own experience					
regarding a	ccessibility of ea	.ch.)	_	-					
□Your own	n car/van								
(not ada	pted)	$\square Not$	accessible Somewhat accessible	□Very accessible					
			□Don't know □Not applied	able					
□Your own	n adapted								
car/van		$\square Not$	accessible Somewhat accessible	□Very accessible					
			□Don't know □Not applied	able					
□Buses									
		$\square Not$	accessible Somewhat accessible	□Very accessible					
			□Don't know □Not applied	able					
□Taxis									
		$\square Not$	accessible \(\sigma\)Somewhat accessible	•					
			□Don't know □Not applica	able					
□ Airlines									

□Not accessible □Somewhat accessible □Very accessible
□Don't know □Not applicable
□Not accessible □Somewhat accessible □Very accessible
□Don't know □Not applicable
□Not accessible □Somewhat accessible □Very accessible
□Don't know □Not applicable
□Not accessible □Somewhat accessible □Very accessible
□Don't know □Not applicable
□Not accessible □Somewhat accessible □Very accessible
□Don't know □Not applicable
□Not accessible □Somewhat accessible □Very accessible
□Don't know □Not applicable

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 <u>home</u>, do the following <u>influence your participation in activities</u>?

1.	Stairs □No •	☐Yes How much? How often?	*	□Help some □Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly
_	_	_				
2.	Ramps □No •	☐Yes How much? How often?	-	□Help some □Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly
3.	Doors □No •	☐Yes How much? How often?		□Help some □Weekly	□Limit some □Monthly	
4.	Carpets □No •	□Yes How much? How often?	*	□Help some □Weekly	□Limit some □Monthly	

5. Hardwood floors □No •	□Yes How much? □H How often? □H		i Help some i Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly
6. Handrails □ <i>No</i> ◆	☐Yes How much? ☐H How often? ☐H	-	-	□Limit some □Monthly	□Limit a lot □Less than monthly
7. Adapted computer	□Yes How much? □H How often? □D	•	•	□Limits some □Monthly	□Limits a lot □Less than monthly
0 D					
8. Room temperatures	☐ Yes How much? ☐ H How often? ☐ I	-	Help some Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly
around a In y	nd carry out activity your community, d	ties. Please not the following	nark the choing influence	ce that is closes your participation	
□No •	How much?	□Help a los □Daily	t ⊔Heip son □Weekly	ne □Limit sor □Monthly	
2. Ramps □No	□Yes How much?				ne □Limit a lot □Less than monthly
3. Elevators □ <i>No</i>	□Yes How much? How often?		t □Help sor	ne	ne □Limit a lot □Less than monthly
4. Flat terrain □ <i>No</i>	□Yes How much? How often?		t □Helps so □Weekly	me □Limits so □Monthly	ome □Limits a lot □Less than monthly
5. Gravel surfaces	□Yes How much? How often?		t □Help sor	ne □Limit sor □Monthly	
6. Paved surfaces					ne Limit a lot

7.Summer weather	$\square Yes$
(heat and humidity)	How much? □ <i>Helps a lot</i> □ <i>Helps some</i> □ <i>Limits some</i> □ <i>Limits a lot</i>
□No J	How often? □ Daily □ Weekly □ Monthly □ Less than monthly
▼	
8. Winter weather	$\Box Yes$
(ice and snow)	How much? □ <i>Helps a lot</i> □ <i>Helps some</i> □ <i>Limits some</i> □ <i>Limits a lot</i>
$\square No$	How often? \square <i>Daily</i> \square <i>Weekly</i> \square <i>Monthly</i> \square <i>Less than monthly</i>
•	(During the season)
9. Rain	\square Yes
$\square No$	How much? □ <i>Helps a lot</i> □ <i>Helps some</i> □ <i>Limits some</i> □ <i>Limits a lot</i>
Ψ	How often? □ Daily □ Weekly □ Monthly □ Less than monthly
10. Crowds	$\square Yes$
$\square No$	How much? □ <i>Help a lot</i> □ <i>Help some</i> □ <i>Limit some</i> □ <i>Limit a lot</i>
•	How often? □ Daily □ Weekly □ Monthly □ Less than monthly

Do you work? If you have and If you work A spend the most Please mark th	swered "No" to both questi AND attend school, please	Do you attend ions, please sk e answer the School your experience	ip to next page. following queste.	No tions based on where you
1. Ramps □No ↓	☐Yes How much? ☐Help a lot How often? ☐Daily	□Help some □Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly
2. Elevators □No •	☐Yes How much? ☐Help a lot How often? ☐Daily	□Help some □Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly
3. Floor surfaces □No •	□Yes How much?□Help a lot How often? □Daily	□Help some □Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly
4. Distances between rooms □ <i>No</i> ↓	□Yes How much?□Help a lot How often? □Daily	□Help some □Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly
5. Work or school cafeteria □No	☐Yes How much?☐Helps a lot How often? ☐Daily	□Helps some □Weekly	□Limits some □Monthly	□Limits a lot □Less than monthly

Mobility Devices

<i>include a</i> Do you u	<i>manual</i> ise a mob	e following qu wheelchair, a pility device? ntinue below.)	power w	heelchair,	oility devices you u or a scooter. Iealth Benefits on r			ces could	l
1. <u>Name</u> MAKE: YEAR P		lity device: M. SED	ANUAL	WHEELC	<u>HAIR</u>				
. How often do yo home, at work o community?					b. How does it in participation in	•			
	Never	Sometimes	Often	Always		Helps a lot	Helps some	Limits some	Limits a lot
Iome					Home				
Vork/School					Work/School				
Community					Community				
Name of mobility device: POWER WHEELCH MAKE: YEAR PURCHASED How often do you use this device at home, at work or school, and in your community?			WHEELCH	b. How does it influence your participation in <i>Daily</i> activities?					
	Never	Sometimes	Often	Always		Helps a lot	Helps some	Limits some	Limits a lot
Iome					Home				
Vork/School	_				Work/School			_	
Community					Community				
MAKE:		device: SCO							
a. How often do home, at wor community	k or scho	this device at ool, and in you	r		b. How does it participatio			es?	
	Never	Sometimes	Often	Always		Helps a lot	Helps some	Limit s	Limit s a lot
Home					Home			some	
Work/School					Work/School				
Community					Community				

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 heath insurance or benefits do you have? □ I have NO insurance or benefits (Go to next page.)
 Name of benefit or insurance
b. Who pays for this benefit? (<i>Check all that apply</i> .) □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 $\Box A \ private \ plan \ \Box A \ public \ (government) \ plan \ \Box Don't \ know$
b. Who pays for this benefit? (Check all that apply.) $\square Self \square Employer \square Government \square Other \underline{\hspace{1cm}}$
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 organization may provide assistance to you.

followi	ou receive any of the ing?		ent does this in in daily active		uence your			
	□SSI (Supplemental	Helps a lot	Helps some	No effect	Limits some	Limits a lot		
	Security Income) SSDI (Social Security Disability Incomes)	Helps a lot	Helps some □	No effect	Limits some	Limits a lot □		
	Insurance) □Worker's Compensation	Helps a lot	Helps some	No effect	Limits some	Limits a lot		
□No ↓								
□ Never ↓	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?							
		lp some \mathbb{D}No effect \mathbb{L}Limit some \mathbb{L}Limit 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 ↓	\square Rarely \square Once or twice a year \square Once or twice a month
•	$\square Once \ or \ twice \ a \ week$ $\square More \ than \ twice \ a \ week$
	How does the <u>therapy</u> you receive influence your participation in <i>Daily</i>
	Activities?
	□Helps a lot □Helps some □No effect □Limits some □Limits a lot
	How do the <u>attitudes</u> 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?
\square Never	\square Rarely \square Once or twice a year \square Once or twice a month
Ψ	$\square Once \ or \ twice \ a \ week$
	· · · · · · · · · · · · · · · · · · ·
	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?
	\square Help a lot \square Help some \square No effect \square Limit some \square Limit a lot
\square Never	\square Rarely \square Once or twice a year \square Once or twice a month
<u> </u>	□Once or twice a week □More than twice a week
·	• • • • • • • • • • • • • • • • • • •
	How does their <u>help</u> influence your participation in <i>Daily</i> 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
4	How often do you ask for help from family members ?
т.	Thow often do you ask for help from failing members.
5	How often do you ask for help from friends?
□Never	\square Rarely \square Once or twice a year \square Once or twice a month
J	·
Y	□Once or twice a week □More than twice a week ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦ ♦
	How does their <u>help</u> influence your participation in <i>Daily</i> activities?
	\Box Helps a lot \Box Helps some \Box No effect \Box Limits some \Box Limits a lot

	How do their <u>attitudes</u> influence your participation in <i>Daily</i> activities?
	· · · · · · · · · · · · · · · · ·
	□Help a lot □Help some □No effect □Limit some □Limit a lot

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

□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 <u>help</u> influence your participation in <i>Daily</i> activities?									
	□Helps a lot □Helps some □No effect □Limits some □Limits a lot									
	How do their <u>attitudes</u> influence your participation in <i>Daily</i> activities?									
	□Help a lot □Help some □No effect □Limit some □Limit a lot									
7.	How often do you ask for help from store clerks?									
□Never	□Rarely □Once or twice a year □Once or twice a month									
lack	□Once or twice a week □More than twice a week									
	How do their services influence your participation in shopping?									
	□Helps a lot □Helps some □No effect □Limits some □Limits a lot									
	How do their <u>attitudes</u> influence your participation in shopping?									
	□Help a lot □Help some □No effect □Limit some □Limit a lot									
0	How often do you oak for holy from strongers?									
	How often do you ask for help from strangers? □Rarely □Once or twice a year □Once or twice a month									
□Never ✓										
•	□Once or twice a week □More than twice a week ••••••••••••••••••••••••••••••••••••									
	How does their <u>assistance</u> influence your participation in <i>Daily</i> activities?									
	□Helps a lot □Helps some □No effect □Limits some □Limits a lot									
	* * * * * * * * * * * * * * * * * * *									
	How do their attitudes influence your participation in Daily activities?									
	\square Help a lot \square Help some \square No effect \square Limit some \square Limit a lot									
9.	How often do you use a special equipment repair service?									
□Never	\square Rarely \square Once or twice a year \square Once or twice a month									
Ψ	\square Once or twice a week \square More than twice a week									
	How do their <u>services</u> influence your participation in <i>Daily</i> activities?									
	□Helps a lot □Helps some □No effect □Limits some □Limits a lot • • • • • • • • • • • • • • • • • • •									
	How do the attitudes of equipment repair personnel influence your									
	participation in <i>Daily</i> 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									