# ASSESSING THE INFLUENCE OF ASSISTIVE TECHNOLOGY ON PEOPLE WITH SPINAL CORD INJURY USING A MEASURE OF PARTICIPATION

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#### ABSTRACT

### ASSESSING THE INFLUENCE OF ASSITIVE TECHNOLOGY ON PEOPLE WITH SPINAL CORD INJURY USING A MEASURE OF PARTICIPATION

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The occurrence of a spinal cord injury (SCI) leads to an enormous change in an individual's lifestyle. Limitation related to mobility can become critical affecting ability to participate in nearly all activities of daily living (ADL) <sup>1</sup>. People with SCI rely on assistive technology (AT), especially wheelchair to facilitate the return to as many pre-injury activities as possible and serve as a resource tool for community living and participation<sup>12</sup>. The purpose of this study was to investigate the wheelchair and related factors that affect the participation of individuals with SCI in activities performed in three settings including home, community and transportation.

Seventy individuals with SCI who use wheelchairs for mobility participated in this study. A written survey, which recorded AT usage in daily activities, was distributed among individuals from Pittsburgh (Pitt) and Saint Louis (SL). The wheelchair was found to be the most limiting factor in activities performed in the home, community and transportation use. The second most limiting factor was physical impairment and environment. Significant differences were shown among individuals from Pitt and SL. A higher number of individuals from SL indicated pain, fatigue, wheelchair seating, social attitudes and self-concept as factors that limit their participation. In addition, significant differences were revealed in transportation use between individuals with paraplegia and tetraplegia. Pain was shown as a limiting factor for people with paraplegia, whereas, lack of equipment was indicated by people with tetraplegia. AT and related factors impact participation of individuals with SCI. The wheelchair was the most common limiting factor, followed by physical impairment and physical environment. The wheelchair is most likely their most important mobility device while also the one that is most associated with barriers.

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I would like to thank my mom, my dad, my sister Sandra and my brothers Huguinho and Ricardo for their endless love, patience, understanding and continuing support. The best family!!!

To accomplish great things... We must not only act but also dream...

Not only plan but also believe.

Anatole France

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#### **1. INTRODUCTION**

The occurrence of a spinal cord injury (SCI) leads to an enormous change in an individual's lifestyle. Limitation related to mobility can become critical affecting ability to participate in nearly all activities of daily living (ADL)<sup>1</sup>. Quality of life (QOL) and perception of life satisfaction have also been shown to be affected <sup>2-3</sup>. Hence, the focus of research has been to identify predictors of QOL to minimize the risk of poor life contentment <sup>4-5-6</sup>. QOL associated with SCI is affected mainly by health<sup>3</sup> and social factors<sup>4,5</sup>. Treischmann et al <sup>7</sup> identified what a person with SCI has to do to avoid deterioration of his/her health. Initially, the person should be involved in self-care and health care activities. Secondly, he should maintain appropriate participation in productive activities. Participation is defined as the extent of a person's involvement in life situations in relation to impairments, activities, health condition and contextual factors<sup>8</sup>.

Assistive technology (AT) has been used by people with disabilities to facilitate the return to as many pre-injury activities as possible <sup>9</sup>. People with SCI rely on AT, and especially their wheelchairs to engage in many of life's activities. Wheelchairs are used to enhance function, improve independence and enable a person to successfully live at home and in the community <sup>9</sup>. The wheelchair may be perceived as a negative impact on an individual's life if does not enable him to fully participate in his social and community roles<sup>10</sup>. The wheelchair and seating system can be limitations or facilitors for participations dependent upon how well the seating and wheelchair meet the capacities of the person. Research has shown that the successful use of AT is dependent upon two major factors: 1) process of service delivery  $^{11}$  and 2) environmental intervention  $^{12}$ .

Regarding the service delivery, nineteen components of AT provision should be followed<sup>11</sup>. The nineteen components are illustrated in table 1. The successful use of AT is dependent on this full range of services. How the devices are applied and the training techniques that are implemented affect outcomes, which ultimately impact a person's quality of life<sup>11</sup>.

Table 1. Illustrate nineteen components of AT provision.

Nineteen components	of AT	provision
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- 1. Identify potential users
- 2. Establish needs and potential benefits of system
- 3. Select appropriate components of system from special and general market devices
- 4. Make necessary modifications
- 5. Assemble the system
- 6. Mount the system
- 7. Fit the system, including adjustments and initial customization
- 8. Select the most appropriate training materials and plan
- 9. Perform initial user training
- 10. Perform training for people in user's environment
- 11. Provide ongoing training
- 12. Be on-call for subsequent questions and needs
- 13. Provide ongoing preventative maintenance and replacement of components
- 14. Provide repairs
- 15. Update system when improvements are available
- 16. Periodically reevaluate the degree of integration of the initial system in user's life
- 17. Use updated data to refine or improve system

18. Provide a more appropriate system when needed by user

19. Provide more appropriate system when marketplace advances more appropriate products.

The combination of AT and environmental interventions have been used by people with disabilities as resource tools for community living and participation<sup>12</sup>. Hoenig et al.<sup>13</sup> concluded that individuals who lived in wheelchair accessible homes were more likely to use their wheelchairs. In addition, a new paradigm that considers the

environment and AT in the determination of disability has been proposed by Seelman and the International Classification of Functioning and Disability (ICIDH-2)<sup>8-15</sup>. The central theme of this new approach to studying disability is that while medical indicators are necessary they are not sufficient for developing complete explanations of disability. In this document the environmental factors are considered as either facilitators or barriers to participation for persons with impairments or activity limitations. This new paradigm has a great potential for demonstrating the role of AT in affecting disability and ultimately, an individual's participation.

Little empirical work has been done to assess the effects of AT interventions on the lives of consumers. Research has focused on a narrow range of activities and ignored the role of assistive technology <sup>4-5</sup>. Most of the literature on AT is focused around issues of design, consumer preferences, use, disuse, abandonment, cost and policy <sup>16-17-18</sup>. What is not known is how AT and related factors of a physical disability affect overall participation. There is also a need for outcomes research in service provision and activities that support the AT service provision system <sup>11</sup>. Hence, the AT assessment of daily participation, as well as their provision, need to be considered in order to identify gaps in activity involvement by people with SCI. The survey used in this research was specially designed with participation as defined by the ICIDH-2 in mind <sup>19</sup>.

#### **1.1 Specific Aims and Hypothesis**

The overall aim of this study was to investigate the wheelchair and related factors that affect the participation of individuals with SCI in activities performed in three settings including home, community and transportation use. The specific aims were:

**Specific Aim 1**: Determine wheelchair and related factors that individuals with SCI rank as the most limiting for participation in the three settings.

**Specific Aim 2:** Compare the perceived wheelchair and related limiting factors on participation between individuals with tetraplegia and paraplegia for activities in all three settings. It was hypothesized that the factors limiting participation for individuals with paraplegia were less than those with tetraplegia for activities in all three settings.

**Specific Aim 3:** Investigate if wheelchair users from Pittsburgh (Pitt) cite different primary limiting factors of participation when compared to wheelchair from Saint Louis (SL). It was hypothesized that the factors limiting participation for individuals from Pitt were different than those cited by the SL subjects in all three settings. Specifically, it was hypothesized that wheelchair and related factors would be less limiting for Pitt subjects when compared to SL subjects.

#### 2. METHODS

#### 2.1 Subjects

Seventy individuals 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 had to live in a community setting. There were 55 men and 15 women with a mean age of 41 years ( $\pm$  STDV 10.75). The average time post injury was 14 years ( $\pm$ STDV 9.82). Twenty-nine individuals were tetraplegic, 38 paraplegic and 3 had no classified level. Fifty-four subjects used manual wheelchairs and 16 used power wheelchairs. Pitt had a total of 37 subjects participating in this study. There were 30 men and 7 women with mean age of 42 years ( $\pm$  STDV 11.33). The time post injury was 16 years ( $\pm$  STDV 9.13). Thirteen individuals were tetraplegic and 21 were paraplegic. Thirty-two were manual wheelchair user and 5 were power wheelchair user. SL had a total of 33 subjects. There were 25 men and 8 women with the mean age of 39 years ( $\pm$ STDV 9.86). The average time post injury was 12 years ( $\pm$  STDV 10.25). Sixteen were tetraplegic and 17 were paraplegic. Twenty-two used manual wheelchairs and 11 used power wheelchairs. The subject's demographic information is presented in table 2.

Study groups	Mean age <u>+</u> Stdv (years)	Average time post injury <u>+</u> Stdv (years)		nder (%)	Level of i N (%		<b>Type of w</b> N (	
		_ ``	Μ	F	Т	Р	Manual	Power
<b>All participants</b> N=70	41 <u>+</u> 10.75	14 <u>+</u> 9.82	55 (77)	15 (21)	29(41)	38(54)	54 (77)	16 (23)
Pitt N=37	42 <u>+</u> 11.33	16 <u>+</u> 9.13	30 (81)	7 (18)	13(35)	21(56)	32 (87)	5 (13)
SL N=33	39 <u>+</u> 9.86	12 <u>+</u> 10.25	25 (76)	8 (24)	16(49)	17(51)	22 (67)	11(33)

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Table 7	Subject's	demographic	information
1 4010 2.	Subjects	demographic	mormation

# Note: data on level of injury was unavailable for three subjects. T= tetraplegia; P=paraplegia.

#### 2.2 Protocol

The Institutional Review Board (IRB) approval was obtained prior to initiation of the study. A written survey that recorded AT usage in daily activities was distributed among clients from Pitt and SL. Pitt subjects were recruited through research centers and through a comprehensive AT clinic that uses a client centered multi-disciplinary team approach. SL 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. A written informed consent was obtained from all subjects prior to engaging in the study.

#### 2.3 Questionnaire

The questionnaire used in this study was a combination of two surveys: 1) Participation Survey/Mobility (PARTS/M) and, 2) Facilitators and Barriers Survey/Mobility (FABS/M). The PARTS/M and FABS/M are available in the appendix section. The PARTS/M is composed of 25 major life activities. Analysis of the PARTS/M surveys returned by 108 polio survivors showed internal consistency values for the P-evaluative scores range from .39 to .77 with most values over .65. All but two of the test-retest values were over .68 with 18 of 25 over .74. Comparison of the cross population similarities and differences are currently underway <sup>20</sup>.

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 FABS/M values for internal consistency and test retest ranged from .73 to .97 with most being above .9. The PARTS/M and FABS/M have good

psychometric properties for the polio survivor sample. For this study, only activity performance limiting factors of the home, community and transportation, were analyzed. Subjects were asked five questions within each setting related to their perceived reason of functional limitations (see Table 2-6). Final subject responses 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). The wheelchair and wheelchair seating were cited as participation limitations 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. Therefore, if the device does not assist the person in an activity, the device limits the person's participation. Access limitations were cited as inability to obtain a suitable wheelchair. However, not having the equipment would result in even greater limitations to participation.

#### 2.4 Statistical Analysis

SPSS software (SPSS, Inc.) was used to calculate frequencies of perceived limitations. The frequency of perceived reasons for limitation in activities performed at home, community and transportation were used to calculate the percentage of time that each factor was perceived as a limitation. Percentages were reported for subjects with paraplegia and tetraplegia. The differences in the perceived reasons for limitation at the Pitt and SL were examined for each task using a chi-square test or Fishers Exact if appropriate.

Differences between perceived reasons for limitations to complete a task for individuals with paraplegia and tetraplegia were analyzed using a chi-square test. To ensure groups between the two clinical settings were comparable, demographic characteristics (gender, injury level and type of wheelchair) were matched using a chi-square. The significance level was set a priori at < 0.05.

#### **3. RESULTS**

#### 3.1 All Participant

*Participation limitations:* The wheelchair most often limited participation in each of the three settings (home, community and transportation) followed by (2) physical impairment, (3) wheelchair seating, (4) pain, (5) fatigue, and (6) illness. Tables 3, 4 and 5 illustrate the relative percentages of the participation limitation for all participants.

Is your participation		Study	Location	Level of	f injury
in moving around your <i>home</i> limited by		Pitt %	SL %	Tetraplegia %	Paraplegia %
Wheelchair	69	68	70	59	74
Physical impairment	41	43	39	31	45
Wheelchair seating	16	11	21	17	13
Pain	11	5	18#	3	15
Fatigue	6	3	9	3	5
Illness	3	3	3	3	3
<b>No limitation</b> (# p<0.01)	19	24	12	17	21

Table 3. Factors limiting participation in activities in the home.

Is your participation in	% of	Study	Location	Level o	finiury
<i>leaving your home</i> limited by	participants	Pitt %	SL %	Tetraplegia	
Wheelchair	64	70	58	59	68
Physical impairment	36	27	45	38	29
Wheelchair seating	14	5	24*	10	16
Pain	13	8	18	7	16
Fatigue	11	8	15	7	13
Illness	6	3	9	7	5
No limitation (*p <0.05)	23	27	18	28	21

Table 4. Factors limiting participation in activities in the community.

Table 5. Factors limiting participation in using transportation.

Is your participation in using <i>transportation</i> limited by	% of participants	Study Pitt %	Location SL %	Level o Tetraplegia %	<b>f injury</b> Paraplegia %
Wheelchair	61	62	60	59	63
Physical impairment	39	35	42	34	37
Wheelchair seating	16	14	18	14	16
Pain	14	8	21	3	21*
Fatigue	9	3	15*	7	8
Illness	3	3	3	3	3
<b>No limitation</b> (* p<0.05)	20	21	8	24	18

<u>Access limitation</u>: Wheelchair most often limited access to the community, followed by (2) physical environment, (3) lack of assistance, (4) wheelchair seating, (5) social attitudes, (6) lack of equipment, (7) self-concept and (8) family attitudes. Wheelchair was also the most common cause for limited access to transportation use, followed by (2) physical environment, (3) limited finances, (4) wheelchair seating, (5) lack of assistance, (6) social attitudes, (7) lack of equipment and (8) self-concept (9) family attitudes. Tables 6 and 7 illustrate the relative percentages of access limitations for all respondents.

Is your access to leaving	% of	Study I	location	Level o	f injury
your home to go out into the <i>COMMUNITY</i> limited by	participants	Pitt %	SL %	Tetraplegia %	Paraplegia %
Wheelchair	53	57	49	45	60
Physical environment	47	43	58	51	53
Lack of assistance	19	16	21	14	18
Wheelchair seating	14	5	24*	14	16
Social attitudes	9	0	18*	10	8
Lack equipment	7	8	6	7	8
Self-concept	7	0	15*	3	10
Family attitudes	1	0	3	14	16
No limitation (*p<0.05)	14	16	12	14	18

Table 6. Factors limiting access to the community.

Is your participation in	% of	Study	Location	Level o	of injury
using <i>transportation</i> participants limited by	Pitt %	SL %	Tetraplegia %	Paraplegia %	
Wheelchair	67	73	60	55	74
Physical environment	41	32	51	41	42
Limited finances	16	11	21	21	13
Wheelchair seating	13	11	15	14	10
Family attitudes	1	0	3	3	3
Lack of assistance	9	10	6	7	5
Social attitudes	7	0	5*	7	8
Lack of equipment	3	3	3	7#	3
Self-concept	3	0	6	3	3
<b>No limitation</b> (* p<0.05; # p<0.01)	20	13	12	10	16

Table 7. Factors affecting access to using transportation.

#### 3.3 Level of Injury

Ninety five percent (N=38) of individuals with paraplegia used manual wheelchairs. In addition, 55% (N=29) of individuals with tetraplegia used power wheelchairs.

*Participation limitation*: Significant differences were found regarding the level of injury. Individuals with paraplegia (21%) reported pain as a limiting factor for their transportation use significantly more than people with tetraplegia (3%).

<u>Access limitations</u>: Lack of equipment limiting transportation use was the only significant difference seen in the area of access limitations with a higher percentage of

individuals with tetraplegia (tetraplegia= 7% paraplegia= 3%) citing it as a limiting factor.

#### **3.2 Study Location**

Comparisons between Pitt (N=37) and SL (N=33) regarding gender, level of injury and type of wheelchair were performed. A borderline significant difference was found only with the type of wheelchair used (p<0.05). A greater number of subjects in Pitt (87%) used manual wheelchairs and a larger number of individuals from SL (33%) used power wheelchairs.

*Participation limitation:* Significant differences were shown between Pitt (N=37) and SL (N=33) with respect to activities performed at home (Table 3), limiting factors of leaving home (Table 4) and transportation (Table 5). For activities in the home, a higher percentage of SL participant (SL=18% Pitt=5%) indicated pain as a limiting factor. For leaving the home, a higher percentage of SL individuals (SL=24% Pitt= 5%) reported wheelchair seating as a limiting factor; whereas for transportation, SL (SL=15% Pitt=3%) were more likely to report fatigue as a limiting factor.

<u>Access limitation</u>: Access limitation factors are shown in Tables 6 and 7. SL individuals were more likely to indicate that wheelchair seating (SL=24% Pitt=5%), social attitudes (SL=18% Pitt=0) and self-concept (SL=15% Pitt=0) were limiting factors. For factors affecting transportation, a greater number of participants from SL reported social attitudes (SL=15% Pitt=0) as a limiting factor.

#### 4. DISCUSSION

The data indicates that the main cause for limited participation inside the home, leaving the home, and for transportation was the wheelchair. The use of a wheelchair that did not enable individuals with SCI to participate fully in their social and community roles appears to have made a considerable impact on their lives <sup>16</sup>. However, the wheelchair is not only most likely their most important mobility device, but also the one that is most associated with barriers. According to Post et al.<sup>21</sup>, there are significant complaints about wheelchairs among individuals with SCI. Manual wheelchairs are often considered to be heavy and difficult to maneuver. The dimensions of the mobility device will determine how the wheelchair can negotiate through tight spaces. Similarly, Mann et al.<sup>10</sup> found that 26% of the problems related to the physical characteristics of the wheelchair is an extension of the user's body. Therefore, it is critical that a wheelchair must match the user's current expectations, preferences, physical needs and functional requirements based on his or her interactions with the environment <sup>22</sup>.

The second most limiting cause of decreased participation in the three settings was the physical environments and physical impairments. Problems in daily activities are viewed as a process of matching the person's capability, resulting from a physical impairment, to the most appropriate setting <sup>24</sup>. The physical environment determines the task performance and it can impact the individual's ability to live independently <sup>24</sup>. Richards et al.<sup>25</sup> reported that environmental access increases the likelihood that a person with SCI will engage in a variety of meaningful activities. Hanrison et al.<sup>26</sup> reported that ramps, wider doors, or wheelchair lifts were pointed out by individuals with SCI as

equipment that would make their homes completely accessible. People who had assistance available or who lived in wheelchair-accessible homes were more likely to use their wheelchairs. However, people with lower income levels were less likely to have their homes modified<sup>13</sup>. Dudgeon et al.<sup>27</sup> also illustrated the importance of having an accessible environment in a school setting. They highlighted that barriers within school environments do not directly affect academic achievements among students with SCI, but discourage socialization and community participation.

Our study findings indicate that wheelchair seating was the third main cause for limited participation in the three settings as well as the fourth access-limiting factor for leaving the home and for transportation use. Mann et al.<sup>10</sup> reported that 41% of wheelchair problems are related to the fit between the user and the wheelchair (e.g. uncomfortable to sit in). When comparing SL and Pitt, more SL participants reported wheelchair seating as a limiting participation factor in activities in the community. A larger number of individuals from SL cited pain and fatigue as limiting factors in activities in the home and transportation respectively. A number of possibilities may explain the differences in the results between the two locations. The type of technology might be appropriate at a given point in time, but later the AT may be obsolete for the individual and his particular needs. Therefore, the length of time a given technology is appropriate becomes an important factor to measure. It is important to keep in mind that most of the subjects were recruited during a seating assessment with the goal of improving or replacing current wheelchairs.

From a different prospective, the lack of specific training for wheelchair prescription and fitting by suppliers and clinicians may also have occurred. Experts indicated that most clinicians do not receive any specific training for prescribing wheelchairs <sup>28</sup>. Only a very small number of therapy or medical residency programs dedicate more than a few hours to training students in the proper selection and use of AT, especially wheelchairs <sup>28</sup>. Another possible reason is related to the lack of consideration of the user's opinion in the AT prescription process, his level of knowledge regarding the available technology and his insight into his own needs. A client's lack of practical experiences makes him unable to fully participate in choosing wheelchair features that best fit his needs <sup>10</sup>. More active user and caregiver/family member participation in the prescription of AT is necessary to increase compliance and facilitate effective outcomes <sup>17</sup>. Moreover, the lack of financial resources, fraud, and denials of prescribed equipment by third-party payers are also among the most frequent reasons why clients receive inadequate equipment <sup>18</sup>.

A greater number of individuals with paraplegia reported pain as a transportationlimiting factor when compared with individuals with tetraplegia. This may be explained by the fact that 95% of the individuals with paraplegia were using manual wheelchairs, which require more effort to load and unload in and out of a vehicle. Another possible reason may be related to transfers in and out of the vehicle seat. Pain and injury of the upper extremities are experienced by as much as 70% of manual wheelchair users <sup>30</sup> Pain represented a form of overuse syndrome related to wheelchair usage and transfers <sup>31</sup>. Furthermore, exposure to vibrations and shock, resultant to the wheelchair rider, can also lead to neck and back pain <sup>32</sup>. Individuals with tetraplegia indicated that the lack of equipment is a limiting factor in transportation use. This may due to difficulties in transporting a power wheelchair in vehicle. Accessible transportation increases the likelihood that individuals with SCI will participate in the community <sup>21</sup>.

Our finding showed that wheelchair and related factors were less limiting for Pitt subjects when compared to SL subjects. The data also revealed that a greater number of individuals form Pitt used manual wheelchairs, whereas a higher number of people from SL used a power wheelchair. It is possible that the differences between the two sites are because of this difference in populations. Unfortunately our sample size is not large enough to allow us to control for this statistically. Other reasons that may explain the difference between the two sites include the presence of a specialized AT clinic in Pittsburgh. It is possible that such a clinic provided chairs better matched to the user and environment and this was responsible for the differences. In order to definitively determine if a specialized AT clinic makes a difference a controlled longitudinal study is needed. Another important finding indicated that a greater number of individuals from SL indicated social attitudes and self-concept as an obstacle to participation in the community and transportation use. It is difficult to understand why these differences exist; however Pierce et al.<sup>29</sup> showed that the public lack of understanding of the life of people with disabilities as well as the attitudes of others can have an impact on activities performance. Therefore, consideration of social attitudes is essential when AT is prescribed.

It was identified through this study that AT and related factors impact daily participation of individuals with SCI individuals. Unfortunately, we do not have any data

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regarding the direct cause of those reported limiting factors. For futures studies, finding the cause of the problems of each factor identified in this study would be useful to lead to an understanding of the limitations that individuals with SCI face in daily routines. Measuring the length of time a given technology is appropriate would also be useful. Investigating not only the impact of seating intervention, but also environmental modifications and related factors on changes in daily participation of an individual with SCI are needed. It is important to keep in mind that an appropriate wheelchair and seating system have only a valuable impact on activities performance if environmental intervention is made.

This study is ongoing and surveys, administered after the individual receives a seating intervention, are being collected. Therefore, analyzing and comparing the results of both surveys (prior and post receiving the new wheelchair) would be useful to understand the impact of the seating intervention, and related factors on changes in the daily participation of an individual with SCI. Determining the changes in SCI individuals lives, pre and post intervention with AT, may provide essential information for the selection of AT that best fits life styles, justification for the purchase of AT for third-party payment, and formation of a data base. A database could be used to advocate for social policy change in support of the provision of AT. Furthermore, exploration into the experiences of people who use wheelchairs would deepen the understanding of the critical success factors involved in wheelchair prescription and ultimately lead to more positive outcomes.

Clinicians should look for evidence to support clinical practice. Keeping in mind the home and community environment, outcomes need to measure the function and quality of life that interventions provide to people with SCI. Hence, incorporating clinical practice supported by evidence and documenting actual long-term outcomes are important strategies for meeting the activity participation needs of a person with SCI. More research is needed to guide the clinical interventions used for improved participation of people with SCI. Critical to all clinicians and their clients is the incorporation of these research findings into routine clinical practice.

#### **5. CONCLUSION**

The outcome of AT use and related factors that affect participation in the home, community and transportation use were identified among wheelchair users. The wheelchair was the most common limiting factor, followed by physical impairment and physical environment. The wheelchair is most likely the most important mobility device, but also the one that is most associated with barriers. Moreover, the wheelchair may be the most empowering and limiting technology at the same time.

The wheelchair is an essential device, because it provides mobility. However, the wheelchair needs to match the user's current expectations, preferences, physical needs and functional requirements based on his or her interactions with the environment. Providing a wheelchair that fits well and is easy to operate without addressing environmental access may limit the potential benefits of the equipment. Similarly, an accessible environment is of no benefit if the equipment is difficult for the user to operate.

It is important to keep in mind that it is not an isolated factor that restricts a person with SCI from successfully participating in activities at home and in the community. It has been shown through this study that many factors determine the success of wheelchair mobility. An understanding of the factors that limit participation will help us better understands the effects disability has on functioning. It is important to identify the type and severity of activity limitations so that programs can be planned and developed which will assist in full participation in society.

# APPENDIX A 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	🗆 Fen	nale
2.	What is your birthdate?	//	(MM/DD/YY)	

3. What is your race/ethnicity? (Check all that apply.)

U White	Asian/Pacific Islander
Black/African American	🗖 American Indian/Alaskan Native
□ Other (specify)	

4. Are you of Spanish/Hispanic origin?

 $\Box$  Yes  $\Box$  No

5. Are you: (*Check all that apply*.)

□ Married	□ Separated
Divorced	Never been married
□ Widowed	□ <i>Member of an unmarried couple</i>

6. What is the highest grade or year of school you have completed?

Never attended school or only kindergarten
Grades 1 through 8
Grades 9 through 11
Grade 12 or GED (high school graduate)
College 1 year to 3 years
College 4 years or more (college graduate)

7. Is your annual household income from all sources:

□ Less than \$10,000
 □ \$10,000 to less than \$15,000
 □ \$15,000 to less than \$20,000
 □ \$20,000 to less than \$25,000
 □ \$25,000 to less than \$35,000

<ul> <li>\$35,000 to less than \$50,000</li> <li>\$50,000 to \$75,000 or</li> <li>Over \$75,000</li> <li>Don't know/Not sure</li> </ul>	
<ul> <li>8. Which of the following benefits are you currentl Check all that apply.)</li> <li>□ SSI (Supplemental Security Income)</li> </ul>	y receiving?
SSDI (disability benefits from Social Sect	urity)
$\Box Medicare  \Box Medicaid  \Box Fe$	ood Stamps 🛛 Subsidized Housing
Personal Care Assistance Deals on	Wheels
□ Other	$\square$ None
9. Do you have any of the following impairments?	Check all that apply.)
<ul> <li>Mobility impairment (difficulty m</li> <li>Visual impairment</li> <li>Hearing impairment</li> <li>Cognitive impairment (difficulty v</li> <li>Mental health illness</li> </ul>	
10. What level is your spinal cord injury?	
11. Are you a person with: $\Box$ <i>Paraplegia</i> $\Box$ <i>Qua</i>	adriplegia 🛛 Don't know
12. Is your injury:  Complete Incomplete	Don't know
13. When was the onset of your spinal cord injur	y?/ (month/year)
Do you have any of the following secondary condition Condition Check all that apply.)	<i>ns? If</i> Yes, <i>how often do you experience the condition?</i> How often do you experience this condition?
□ 1. Pain	$\Box Constantly \ \Box Off and on \ \Box Rarely$
□ 2. Osteoporosis	$\Box Constantly  \Box Off and on  \Box Rarely$
□ 3. Spasticity	$\Box Constantly  \Box Off and on  \Box Rarely$
□ 4. Upper Respiratory Infection	$\Box Constantly  \Box Off and on  \Box Rarely$
5. Circulatory problems	$\Box$ Constantly $\Box$ Off and on $\Box$ Rarely
G. Scoliosis	$\Box$ Constantly $\Box$ Off and on $\Box$ Rarely

□ 7. Weight problems	$\Box$ Constantly $\Box$ Off and on $\Box$ Rarely
8. Skin problems	$\Box$ Constantly $\Box$ Off and on $\Box$ Rarely
□ 9. Depression	$\Box$ Constantly $\Box$ Off and on $\Box$ Rarely
10. Contractures – permanent limitation of joint movement	$\Box$ Constantly $\Box$ Off and on $\Box$ Rarely
□ 11. Bladder incontinence	$\Box Constantly \ \Box Off and on \ \Box Rarely$
□ 12. Bowel incontinence	$\Box$ Constantly $\Box$ Off and on $\Box$ Rarely
□ 13. Stomach problems	$\Box Constantly  \Box Off and on  \Box Rarely$
□ 14. Urinary Tract Infection	$\Box$ Constantly $\Box$ Off and on $\Box$ Rarely
□ 15. High Blood Pressure	$\Box$ Constantly $\Box$ Off and on $\Box$ Rarely
16. Phlebitis – inflammation of blood vessels	$\Box Constantly \ \Box Off and on \ \Box Rarely$
□ 17. Fingernail or toenail infections	$\Box$ Constantly $\Box$ Off and on $\Box$ Rarely
□ 18. Fatigue	$\Box$ Constantly $\Box$ Off and on $\Box$ 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? Would you say . . .
- □ Always
- Usually
- □ Sometimes
- □ Rarely
- □ Never

2. In general, how satisfied are you with your life? Would you say ...

- □ Very satisfied
- □ Satisfied
- Dissatisfied
- □ Very dissatisfied

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

- 1. Are you limited in the kind or amount of work you could do because of any impairment or health problem?
  - $\begin{array}{c|c} \blacksquare & Yes \\ \blacksquare & No \end{array}$
- 2. Because of any impairment or health problem, do you have any trouble learning, Remembering or concentrating?
  - $\begin{array}{c|c} \square & Yes \\ \hline \square & No \end{array}$

*3a. Do you use special equipment or help from others to get around?* 

- Yes (Continue.)
- □ No special equipment or help used (Go to Question 5)

\*\*\*\*

- *3b. If you use special equipment or help from others to get around, what type do you use? (*Check all that apply.)
  - Se? (Check all that apple
    - $\Box$  Other people
    - □ Cane or walking stick
    - □ Walker
  - $\hfill\square$  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?

 $\Box$  Yes  $\Box$  No (Go to question 9.)

- 7. What is the MAJOR impairment or health problem that limits your activities?
  - □ Arthritis/rheumatism
    - Back or neck problem
    - □ Fractures, bone/joint injury
    - □ Walking problem
    - □ Lung/breathing problem
    - □ Hearing problem
    - □ Eye/vision problem
    - □ Heart problem
    - □ Stroke problem
    - □ Hypertension/high blood pressure
    - Diabetes
    - □ Cancer
    - Depression/anxiety/emotional problem
    - $\Box$  Other impairment/ problem  $\Box$  Not applicable
- 8. For HOW LONG have your activities been limited because of your major impairment or health problem?

Days		How many days?	
Weeks		How many weeks?	
Months		How many months?	
Years		How many years?	
Not applica	ble		

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?

 $\Box$  Yes  $\Box$  No  $\Box$  Not applicable

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

*11a.*  $\square$  Number of days:  $\square$  None

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

*12a.*  $\Box$  Number of days:  $\Box$  None

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

*13a.* Number of days: \_\_\_\_\_ None

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

14a.  $\Box$  Number of days:  $\Box$  None

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

15a.  $\Box$  Number of days:  $\Box$  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. How **frequently** do you groom?  $\Box 2$  or 3 times a week  $\Box Once a day \Box 2 - 3$  times a day  $\Box More$  than 3 times a day 2. How much time do you require for grooming on a typical day? Less than 10 minutes 10 to 20 minutes More than 20 minutes 3. Is your participation in grooming **limited** by ... (*Check all that apply.*) Pain Illness □ A physical impairment **G** Fatigue U Wheelchair UWheelchair seating Other □ *Not limited* 4. When grooming, how much choice do you have compared to others without disabilities? (Choice includes how often, when, where and how you groom.)  $\Box$  A lot of choice  $\Box$  Some choice  $\Box$  Little choice  $\Box$  No choice 5. How satisfied are you with your participation in grooming? Urv satisfied □ Satisfied Somewhat satisfied Dissatisfied 6. How much help from another person do you require for grooming? □ *A* moderate amount □ None **J***ust a little* A great deal 7. If you use assistance, who helps you with grooming? (*Check all that apply.*) Family/Significant Other □ No one 🖵 Friends People I hire 8. How often do you use **accommodations**, adaptations, or special equipment to groom?  $\square$ *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 to groom, what do you use? (*Check all that apply*.) Dragging table  $\square N/A$ 

N/A	Dressing table	Urthotic/prosthetic device
	Electric shaver	Shower chair
	Electric toothbrush	Special grooming device
	Grab bars	Specialized bathroom equipment
	$\Box$ Lift	Special seat/chair
	Long-handled equipment	Lowered shelves/counters
	🖵 Wheelchair - manual	🗖 Wheelchair - power
	Wheelchair seating	• Other

# MEAL PREPARATION and CLEAN-UP: The following questions involve meal preparation and cleaning after the meal is finished.

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

Under 1 hour

<ul> <li>2. Is your participation in meal preparation limited by</li> <li>Illness  A physical impairment  Pain  F</li> <li>Wheelchair seating  Other</li> </ul>	Fatigue DWheelchair
<ul> <li>3. For meal preparation and clean-up, how much choice do others without disabilities?</li> <li>(Choice includes when, what, where and with whom you</li> <li>A lot of choice Some choice Little choice </li> </ul>	u prepare meals.)
4. How satisfied are you with your participation in meal pr □Very satisfied □ Satisfied □ Somewhat satisfied □	
<ul> <li>5. How much help from another person do you need to pre (Check all that apply.)</li> <li>None <ul> <li>Just a little</li> <li>A moderate amount</li> </ul> </li> </ul>	pare/clean up? □ A great deal
If you use assistance, who helps you to prepare and clean u (Check all that apply.) No one Family/Significant Other Friends	-
<ul> <li>7. How often do you use accommodations, adaptations, or to prepare and clean up?</li> <li>□ Never □A little of the time □ Some of the time □Mo</li> </ul>	
<ul> <li>8. If you use accommodations, adaptations, or special equipreparation, what do you use? (Check all that apply.)</li> <li>(N/A</li> <li>Cane</li> <li>Adaptive cooking utensils</li> <li>Lap board/TV tray</li> <li>Specialized wheelchair</li> <li>Lowered shelves/counters</li> <li>Orthotic/prosthetic device</li> <li>Wheelchair - manual</li> <li>Wheelchair seating</li> </ul>	<ul> <li>pment for meal</li> <li>Scooter</li> <li>Special seat/chair</li> <li>Specialized kitchen equipment</li> <li>Universal cuff</li> <li>Reacher/grab stick/grabber</li> <li>Walker</li> <li>Wheelchair – power</li> <li>Other</li> </ul>

# **BLADDER CARE:** The next questions involve emptying your bladder, which includes getting to a bathroom, adjusting clothing, using accommodations, or using special equipment.

1.	How much time do you require for bladder care on a typical day? Less than 30 minutes 30 to 60 minutes More than 60 minutes	
	s your participation in performing and managing bladder care limited by (Check all that apply.) Iness	
3.	For management of bladder care, how much choice do you have compared to others without disabilities? (Choice includes when, where and how care takes blace.) $\Box$ A lot of choice $\Box$ Some choice $\Box$ Little choice $\Box$ No choice	
4.	How satisfied are you with your participation in bladder care? Very satisfied Satisfied Somewhat satisfied Dissatisfied	
5.	Do problems associated with bladder care affect your participation in Daily activities, such as attending a movie, going shopping, or working? No, not at all Once in a while Sometimes Most of the time	
6.	How much help from another person do you require for bladder care? I None I Just a little A moderate amount A great deal	
7.	f you use assistance, who helps you with bladder care? (Check all that apply.) No one Family/Significant Other Friends People I hire	
8.	How often do you use accommodations, adaptations, or special equipment for bladder care? Never DA little of the time DSome of the time DMost of the time DAll of the time	e
9.	f you use accommodations, adaptations, or special equipment for bladder care, what do you use? (Check all that apply.)	
	<ul> <li>N/A</li> <li>Absorbency pads/undergarments</li> <li>Accessible bathroom</li> <li>Urinal/bedpan/potty chair</li> <li>Catheter</li> <li>Leg bag/overnight bags/bed bags</li> <li>Shower chair</li> <li>Wheelchair - manual</li> <li>Wheelchair seating</li> <li>Other</li> </ul>	e

#### 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?

nome?				
Living room	$\Box$ Less than 1 $\Box$	<b>□</b> 1 to 4	$\Box$ More than 4	□Not applicable to my home
Dining room	$\Box$ Less than 1	<b>□</b> 1 to 4	Generation More than 4	□Not applicable to my home
Kitchen				□Not applicable to my home
Bathroom	$\Box$ Less than 1 $\Box$	<b>□</b> 1 to 4	Generation More than 4	□Not applicable to my home
Bedroom	$\Box$ Less than 1 $\Box$	<b>□</b> 1 to 4	□More than 4	□Not applicable to my home
Study	$\Box$ Less than 1	<b>□</b> 1 to 4	□More than 4	□Not applicable to my home
Basement	$\Box$ Less than 1 $\Box$	<b>□</b> 1 to 4	□More than 4	□Not applicable to my home
Other (specify)	$\Box$ Less than 1	<b>□</b> 1 to 4	$\Box$ More than 4	□Not applicable to my home

Is your participation in moving around your home limited by ...

(Check all	that apply.)
- T11	<b> 1</b> ·

Illness	🖵 A phys	ical impairment	🖵 Pain	🖵 Fatigue	Wheelchair
U Wheelchai	ir 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).

- 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?

  Do, not at all

  Once in a while

  Sometimes

  Most of the time
- 7. If you use assistance, who helps you move around your home? (Check all that apply.)
  I No one I Family/Significant Other I Friends I 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 seating
  Wheelchair seating
  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. How frequently do you leave your home?

1. 110		Jour nonie.	
	□Never →	□ I choose not to do this	□ I am unable to do this
		(Go to question 3 on next page	ge.)
	□ Once or twice a month	(Continue)	
	□ Once or twice a week	(Continue)	
	□ Once or twice a day	(Continue)	
	$\Box$ 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 Activities	How often do you do the activity?	(Please answer corresponding follow-up question)
Shopping fo groceries	or DNever →	<ul> <li>I choose not to do this activity</li> <li>I am unable to do this activity</li> </ul>
	Less than once a month	Preparation time
	$\Box$ 1-2 times a month $\rightarrow$	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 fo	or Never →	□ I am unable to do this activity
	Less than once a month	Preparation time
	$\Box$ 1-2 times a month $\rightarrow$	-
	□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 th pharmacy	e □Never →	□ I am unable to do this activity
provide y	Less than once a month	Preparation time
	$\Box$ 1-2 times a month $\rightarrow$	-
	□1-2 times a week	□10-20 minutes
	Given 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
	$\Box$ 1-2 times a month $\rightarrow$	Under 10 minutes
	□1-2 times a week	□10-20 minutes
	☐More than twice a week	☐More than 20 minutes

#### **LEAVING YOUR HOME (continued)**

How often do you do the activity?	(Please answer corresponding follow-up
	question)
	□ I choose not to do this activity
□Never →	I am unable to do this activity
Less than once a month	Preparation time
$\Box$ 1-2 times a month $\rightarrow$	Under 10 minutes
□1-2 times a week	$\Box$ 10-20 minutes
□More than twice a week	□More than 20 minutes
	□ I choose not to do this activity
□Never →	□ I am unable to do this activity
Less than once a month	Preparation time
$\Box$ 1-2 times a month $\rightarrow$	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
□Never →	□ I am unable to do this activity
Less than once a month	Preparation time
$\Box$ 1-2 times a month $\rightarrow$	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
□Never →	□ I am unable to do this activity
Less than once a month	Preparation time
$\Box$ 1-2 times a month $\rightarrow$	Under 10 minutes
□1-2 times a week	□10-20 minutes
Generation More than twice a week	□More than 20 minutes
	□Never→□Less than once a month □1-2 times a month □1-2 times a week □More than twice a week→□Never→□Less than once a month □1-2 times a month □1-2 times a week □More than twice a week→□Never→□Never→□Never→□Never→□Never→□Never→□Never→□Less than once a month □1-2 times a month □1-2 times a week □More than twice a week□Never→□Less than once a month □1-2 times a week □More than twice a week□Never→

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

Physical factors	in the environment	Social attitudes	Family attitudes
□ Self-concept	Lack of assistant	ce 🖵 Wheelchair	U Wheelchair seating
Lack of special of	equipment 🗲 Wha	at equipment would b	e helpful?

Other (specify) \_\_\_\_\_\_
Not limited

4. Is your par	rticipation i	n leaving your ho	me limited	by (Chee	ek all that apply.)
Illness	A physic	cal impairment	🖵 Pain	Fatigue	Wheelchair
U Wheelchair	seating	□ Other			Not limited

\_\_\_\_\_

<ul> <li>5. To leave your home, how much choice do you have compared to others without disabilities? (Choice includes how often, when, and how you leave and where you go.)</li> <li>A lot of choice Some choice Little choice No choice</li> </ul>
<ul> <li>6. How satisfied are you with your participation in leaving your home?</li> <li>□ Very satisfied □ Satisfied □ Somewhat satisfied □ Dissatisfied</li> </ul>
7. How important is it for you to leave your home? □Very important □Somewhat important □Somewhat unimportant □Not important
<ul> <li>8. How much time do you need to prepare to go to a place that is</li> <li>a. Unfamiliar? □Less than 10 minutes □10 to 30 minutes □More than 30 minutes</li> <li>b. Familiar? □Less than 10 minutes □10 to 30 minutes □More than 30 minutes</li> </ul>
<ul> <li>9. How much help from another person do you need to leave your home?</li> <li>□ None</li> <li>□ Just a little</li> <li>□ A moderate amount</li> <li>□ A great deal</li> </ul>
<ul> <li>10. If you use assistance, who helps you with leaving your home?</li> <li>(Check all that apply.)</li> <li>No one  Family/Significant Other  Friends  People I hire</li> </ul>
<ul> <li>11. How often do you use accommodations, adaptations, or special equipment to leave your home?</li> <li>□Never □A little of the time □Some of the time □Most of the time □All of the time</li> </ul>
12. If you use accommodations, adaptations, or special equipment to leave your home, what do you use? (Check all that apply.)
<ul> <li>N/A</li> <li>Handrails</li> <li>Level threshold</li> <li>Walker</li> <li>Wheelchair seating</li> <li>Wheelchair - manual</li> </ul>

🗅 Lift

- Wheelchair powerWidened doors
- Pedal for car
- □ Elevator
- □ Scooter
- Grab bars
- RampVehicle (not adapted)
- □ Other\_\_\_\_\_

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

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

■Never → □ I choose not to do this □ I am unable to do this (Go to question 3 on next page)

 $\Box Once or twice a month$ 

 $\Box Once or twice a week$ 

Once or twice a day

□ *More than twice a day* 

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

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	□ <i>Helps a lot</i> □ <i>Helps some</i> □ <i>No effect</i> □ <i>Limits some</i> □ <i>Limits a lot</i>
Buses	$\Box$ <i>Helps a lot</i> $\Box$ <i>Helps some</i> $\Box$ <i>No effect</i> $\Box$ <i>Limits some</i> $\Box$ <i>Limits a lot</i>
□Taxis	$\Box$ <i>Helps a lot</i> $\Box$ <i>Helps some</i> $\Box$ <i>No effect</i> $\Box$ <i>Limits some</i> $\Box$ <i>Limits a lot</i>
Airlines	$\Box$ Helps a lot $\Box$ Helps some $\Box$ No effect $\Box$ Limits some $\Box$ Limits a lot
Light rail / subway	□ <i>Helps a lot</i> □ <i>Helps some</i> □ <i>No effect</i> □ <i>Limits some</i> □ <i>Limits a lot</i>

Special services: Paratransit (such as Call-A-Ride)	$\Box$ Helps a lot $\Box$ Helps some $\Box$ No effect $\Box$ Limits some $\Box$ Limits a lot
Adapted taxi	$\Box$ Helps a lot $\Box$ Helps some $\Box$ No effect $\Box$ Limits some $\Box$ Limits a lot
□Adapted rental car/van	$\Box$ Helps a lot $\Box$ Helps some $\Box$ No effect $\Box$ Limits some $\Box$ Limits a lot
Other	$\Box$ <i>Helps a lot</i> $\Box$ <i>Helps some</i> $\Box$ <i>No effect</i> $\Box$ <i>Limits some</i> $\Box$ <i>Limits a lot</i>
	□ Lack of assistance □ Limited finances □ Wheelchair seating ial equipment → What equipment would be helpful? 
Not limited	y)
Illness	<b>Dation</b> in using transportation limited by       (Check all that apply.) <b>A</b> physical impairment <b>P</b> ain <b>F</b> atigue <b>W</b> heelchair         teating <b>O</b> Other <b>D</b> Not limited
	do you have about using transportation, compared to others s? (Choice includes when, where, how and with whom you use Some choice Little choice No choice
6. How <b>satisfied</b> are 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 from another person** do you need when using transportation? *None Just a little A moderate amount A great deal*
- 9. If you use assistance, who helps you to use transportation? (Check all that apply.)
  □ No one □ Family/Significant Other □ Friends □ People I hire
- 10. How often do you use accommodations, adaptations, or special equipment when using transportation?
  □Never □A little of the time □Some of the time □Most of the time □All of the time

11. If you use **accommodations**, **adaptations**, **or special equipment** when using transportation, what do you use? (*Check all that apply*.)

$\Box N/A$	
Accessible parking permit	$\Box$ Lift
Adapted vehicle	Ramp
Cane	Scooter
Crutches	Walker
Door opener	Orthotic/prosthetic device
🖵 Wheelchair - manual	🗖 Wheelchair - power
UWheelchair seating	<b>D</b> Other

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

1.	How often do you take a vaca	tion?		
	<ul> <li>□Never → □</li> <li>□Less than once a year</li> <li>□Once or twice a year</li> <li>□More than twice a year</li> </ul>	I choose not to do this	I am una	ble to do this
2.	Is your <b>access</b> to vacations lim <i>Physical factors in the envir</i> <i>Self-concept</i> <i>Wheelchair</i> <i>Lack of special equipment</i>	ronment 🛛 Social attitude Limited finance Wheelchair se	es ces eating	□ Family attitudes □ Lack of assistance
	Other (specify) Not limited			
3.	Is your <b>participation</b> in taking Illness I A physical in Wheelchai seating I O	npairment 🖸 Pain 🖬	Fatigue	11, 2 ->
4.	When taking a vacation, how a without disabilities? (Choice is take a vacation.) $\Box A \ lot \ of \ choice$ $\Box \ Some \ choice$		nd how often	
5.	How <b>satisfied</b> are you with yo <i>Very satisfied Satisfied</i>			d
6.	How <b>important</b> is it for you to <i>Wery important Somewhat</i>		mportant 🖵	Not important
7.	If you haven't taken a vacation	n in the last year, would you	like to? $\Box Y$	es 🗆No
		IF YOU TAKE VACATI	IONS:	
0	Harry much time do you good t	a mumana far a vasation?	This might in	aluda

8. How much time do you need to prepare for a vacation? (This might include arranging airline seating or accessible lodging.)
□ Under 1 hour □ 1 to 3 hours □ More than 3 hours

#### **TAKING A VACATION (continued)**

- 9. How much **help from another person** do you need to take a vacation? *None Just a little A moderate amount A great deal*
- 10. If you use assistance, who helps you with taking a vacation? (*Check all that apply*.)
  No one Family/Significant Other Friends People I hire
- 11. How often do you use accommodations, adaptations, or special equipment for a vacation? *Never A little of the time Some of the time Most of the time All of the time*
- 12. If you use **accommodations**, **adaptations**, **or special equipment** to take a vacation, what do you use? (*Check all that apply*.)

 $\Box N/A$ 

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. This topic includes washing dishes, doing laundry, cleaning house, or making repairs.

1. How **frequently** do you participate in housework or home maintenance activities?

1. How freque	<b>ntly</b> do you participate in	housework or home mai	ntenance activities?
Never	r → □I	choose not to do this	I am unable to do this
🗆 1 to 2	2 times a week		
	4 times a week		
	more times a week		
	more times a week		
	icipation in housework or all that apply.)	home maintenance limit	<b>ed</b> by
	A physical impairment	🗖 Pain 🗖 Fation	e 🗖 Wheelchair
	seating Other	0	
	sealing Giner		
you have co when, how	tte in housework or home not compared to others without and by whom these activite for the sector of	disabilities? (Choice in ties are completed.)	cludes how often,
4. How <b>satisfied</b> are you with your participation in housework or home maintenance? <i>Very satisfied Satisfied Somewhat satisfied Dissatisfied</i>			
-	<b>rtant</b> is it for you to particities <i>rtant</i> <b>G</b> Somewhat imported	-	
IF YO	U PARTICIPATE IN H	OUSEWORK OR HOM	ME MAINTENANCE ACTIVITIES:
6. How much	help from another person Just a little A n		A great deal
(Check	ssistance, who helps you all that apply.)		
No one	□ Family/Significant C	$Other \Box$ Friends $\Box$	People I hire

- 8. How often do you use accommodations, adaptations, or special equipment for housework or home maintenance activities?
  □Never □A little of the time □Some of the time □Most of the time □All of the time
- 9. If you use accommodations, adaptations, or special equipment for housework or home maintenance activities, what do you use? (*Check all that apply.*)
  □ N/A

Cane

Scooter

**W**alker

**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 ↓	<ul> <li>Less than once a month</li> <li>1-2 times a month</li> <li>1-2 times a week</li> <li>More than twice a week</li> </ul>	□Under 10 □10-20 □More than 20
Attend movies	□ Never ♥	<ul> <li>Less than once a month</li> <li>1-2 times a month</li> <li>1-2 times a week</li> <li>More than twice a week</li> </ul>	□Under 10 □10-20 □More than 20
Attend concerts	□ 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
Play cards	□ Never ♥	<ul> <li>Less than once a month</li> <li>1-2 times a month</li> <li>1-2 times a week</li> <li>More than twice a week</li> </ul>	□Under 10 □10-20 □More than 20
Play board games	□ Never ↓	<ul> <li>Less than once a month</li> <li>1-2 times a month</li> <li>1-2 times a week</li> <li>More than twice a week</li> </ul>	□Under 10 □10-20 □More than 20
Watch sports	□ Never ♥	<ul> <li>Less than once a month</li> <li>1-2 times a month</li> <li>1-2 times a week</li> <li>More than twice a week</li> </ul>	□Under 10 □10-20 □More than 20
Read	□ Never ↓	<ul> <li>Less than once a month</li> <li>1-2 times a month</li> <li>1-2 times a week</li> <li>More than twice a week</li> </ul>	□Under 10 □10-20 □More than 20
Hobby (specify)	□ Never ♥	<ul> <li>Less than once a month</li> <li>1-2 times a month</li> <li>1-2 times a week</li> <li>More than twice a week</li> </ul>	□ <i>Under 10</i> □ <i>10-20</i> □ <i>More than 20</i>
Other (specify)	□ Never ↓	<ul> <li>Less than once a month</li> <li>1-2 times a month</li> <li>1-2 times a week</li> <li>More than twice a week</li> </ul>	□Under 10 □10-20 □More than 20

<ul> <li>2. Is your access to leisure activities limited by (Check all that apply.)</li> <li>Physical factors in the environment</li> <li>Social attitudes</li> <li>Family attitudes</li> <li>Self-concept</li> <li>Limited finances</li> <li>Lack of assistance</li> <li>Wheelchair</li> </ul>
U Wheelchair seating
$\Box$ Lack of special equipment $\rightarrow$ What equipment would be helpful?
- Luck of special equipment - what equipment would be helpful?
Other (specify) Not limited
3. Is your <b>participation</b> in leisure activities limited by ( <i>Check all that apply.</i> )
□ Illness □ A physical impairment □ Pain □ Fatigue □ Wheelchair
□ Wheelchair seating □ Other □ Not limited
<ul> <li>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.)</li> <li></li></ul>
5 How satisfied are you with your participation in leisure activities?

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

#### IF YOU PARTICIPATE IN LEISURE ACTIVITIES:

7. How much help from another person do you need to participate?			
None	🗖 Just a little	$\Box A$ moderate amount	🖬 A great deal

- 8. If you use assistance, who helps you with leisure activities? (Check all that apply.)
  No one Family/Significant Other Friends People I hire
- 9. How often do you use accommodations, adaptations, or special equipment to do leisure activities?
  Never A little of the time Some of the time Most of the time All of the time
- 10. If you use **accommodations**, **adaptations**, **or special equipment** to do leisure activities, what do you use? (*Check all that apply*.)

N/A
Card holder
Scooter
Computer (adaptive)

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

1. How often do you participate in this type of activity?

Never → □ I choose not to do this □ I am unable to do this (Go to question 4)
 □ Less than once a month (Continue)
 □ 1-2 times a month (Continue)
 □ 1-2 times a week (Continue)
 □ More than twice a week (Continue)

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

3.	How long does it take you	to prepare to do this activ	vity?
	Under 10 minutes	$\Box$ 10-20 minutes	□ <i>More than 20 minutes</i>

4. Is your **access** to active recreational activities limited by ...

(*Check all that apply.*)

Physical factors in the environment
Lack of assistance
Social attitudes
Family attitudes
Limited finances
Lack of organized accessible teams
Self-concept
Wheelchair
Wheelchair seating
Lack of special equipment → What equipment would be helpful?

□ Other (specify) \_\_\_\_\_ □ Not limited

5. Is your **participation** in active recreational activities limited by ... (*Check all that apply*)

(encente	in man app	•			
🗅 Illness	$\Box A physics$	ical impairment	🗖 Pain	🗖 Fatigue	🖵 Wheelchair
🛛 Wheelchai	r seating	Other			Not limited

- 7. How **satisfied** are you with your participation in active recreational activities? *Very satisfied Satisfied Somewhat satisfied Dissatisfied*
- 8. How **important** is it for you to participate in active recreational activities? *Very important Somewhat important Somewhat unimportant Not important*

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

- 9. How much help from another person do you need to participate?
  □ None
  □ Just a little
  □ A moderate amount
  □ A great deal
- 10. If you use assistance, who helps you with active recreational activities? (*Check all that apply.*)
  No one Family/Significant Other Friends People I hire
- 11. How often do you use accommodations, adaptations, or special equipment for active recreational activities? *Never* A little of the time Some of the time Most of the time All of the time
- 12. If you use **accommodations**, **adaptations**, **or special equipment** to do active recreational activities, what do you use? (*Check all that apply*.)

 $\Box N/A$ 

Scooter
 Wheelchair seating
 Wheelchair - power

Wheelchair - manual

 $\Box$  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.

· ·			
	you socialize with others?week1 to 2 timkDaily or d	es a week	
<ul> <li>Physical factor</li> <li>Social attitude</li> <li>Family attitude</li> <li>Self-concept</li> <li>Lack of assistation</li> <li>Limited finance</li> <li>Lack of compare</li> <li>Wheelchair</li> <li>Wheelchair set</li> </ul>	es unce es nion(s)	,	
<ul> <li>Other (specify)</li> <li>Not limited</li> </ul>	)		
	n in social activities limite cal impairment	in 🖸 Fatigue 🛛 Wh	
disabilities? (Choic socialize.)	ow much <b>choice</b> do you has e includes how often, whe Some choice Little	n, how and with whom yo	
-	ou with your participation Satisfied Somev		tisfied
-	t for you to participate in solution of the second se		ot important
7. How much <b>help fro</b> <i>None</i> Just c	<b>m another person</b> do you <i>u little</i> A moderate d		l
-	e, <b>who helps you</b> with soc hily/Significant Other	ializing? (Check all that a Friends	/
to socialize?	use <b>accommodations, ada</b> he time <b>\Bome</b> of the time		-
what do you use? ( $\Box N/A \Box Acce$	odations, adaptations, or Check all that apply.) essible parking permit pted vehicle	<b>special equipment</b> to so <i>Orthotic/prosthetic de</i> <i>Scooter</i>	

Scooter 52

Adapted telephone
Cane/crutches
Computer
Hearing aid
Lift

**RELIGIOUS ACTIVITIES:** The following questions are about participation in religious activities. This topic includes attending *Weekly* religious services or classes or singing in a choir.

1. How much time do you spend on participation in religious activities?

None → □ I choose not to do this □ I am unable to do this
 □ I to 5 hours a week
 □ More than 5 hours a week
 2. Is your access to religious activities limited by ... (Check all that apply.)
 □ Physical factors in the environment □ Social attitudes □ Family attitudes
 □ Self-concept
 □ Lack of assistance □ Wheelchair □ Wheelchair seating
 □ Lack of special equipment → What equipment would be helpful?

□ Other (specify) \_\_\_\_\_ □ Not limited

3. Is your participation in religious activities limited by ... (Check all that apply.)
□ Illness □ A physical impairment □ Pain □ Fatigue □ Wheelchair
□ 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? Urry 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:

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? (*Check all that apply*.)

 $\Box N/A$ **Elevator** □ Scooter Grab bars □ *Vehicle (not adapted)* Handrails 🖵 Walker Level threshold U Wheelchair seating Lift Wheelchair - manual Pedal for car Wheelchair - power 🗖 Ramp U Widened • Other

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

<ol> <li>Are you currently employed?</li> <li>Is your access to employment</li> <li>Physical factors in the environ</li> <li>Self-concept</li> </ol>	nt limited by	(Check all that ap	
Lack of assistance		chair 🛛 🖬 Wh	6
□ Lack of special equipment	• what equipmen	t would be neipful	<i>.</i>
<ul> <li>Other (specify)</li> <li>Not limited</li> </ul>			
<ul> <li>3. Is your participation in emp</li> <li>□ Illness</li> <li>□ A physical imp</li> <li>□ Wheelchair □seating</li> </ul>	airment D Pai	n 🛛 Fatigue	U Wheelchair
<ul> <li>4. How much choice do you ha disabilities? (Choice includ</li> <li>□ A lot of choice □ Some</li> </ul>	les when, where, h	ow much and how	you work.)
5. How <b>satisfied</b> are you with □ Very satisfied □ Satisfi			Dissatisfied
6. How <b>important</b> is it for you □Very important □Somewhat		mewhat unimporta	ant <b>D</b> Not important

#### IF YOU ARE EMPLOYED:

 $\Box N/A$ 

7. a. What ty	pe of work do you do	o?		
b. In a typi	cal week, how many	hours do you w	ork?	
Less 1	than 10 🛛 🖬 11 to 30	□ 31 to 40	□ More	than 40
	help from another p		1 1	1
9. If you use as	sistance, who helps y	ou with partici	pating in w	vork?
(	<i>that apply</i> .) Family/Significa	int Other	Friends	Deople I hire

10. How often do you use **accommodations**, **adaptations or special equipment** to participate in work?

 $\Box$ *Never*  $\Box$ *A little of the time*  $\Box$ *Some of the time*  $\Box$ *Most of the time*  $\Box$ *All of the time* 

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

at do you use? ( <i>Check all that apply</i> .)	
Accessible parking permit	Lift
Adaptive computer equipment	Crthotic/Prosthetic device
Adapted vehicle	Scooter
🗖 Cane	🗖 Walker
Computer	Wheeelchair seating
Crutches	Wheelchair – power
Hearing aid	🖵 Wheelchair – manual
□ 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 o 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 activities?	2	of your resider	nce influence you	r participation in <i>Daily</i>				
	C	Helps a lot	Helps some	Has no effect $\Box$ Limits some $\Box$ L	imits a lot			
What abou	What about <b>your residence limits you</b> ? ( <i>Check all that apply</i> .)							
□ Not Limited	■Entrance assistance	□Bathroom	<b>G</b> <i>Kitchen</i>	Lack of personal finances	Parking	□Lack of personal		
¥		ial equipment	$\rightarrow$ What equipm	ent would be helpful?				
	□Other							

	s the accessibility of <b>your place of employment</b> influence your ion in working?
puritorputi	$\Box$ Helps a lot $\Box$ Helps some $\Box$ Has no effect $\Box$ Limits some $\Box$ Limits a lot $\Box$ Not employed
What abou	<b>*************************************</b>
Not Limited ♥	□Entrance       □Workstation       □Bathroom       □Parking         □Lack of child care       □Lack of personal assistance       □Lack of transportation         □Lack of special equipment       → What equipment would be helpful?
	□ <i>Other</i>

3. How do shoppir	bes the accessibility of <b>your grocery store</b> influence your participation in ng?
	Helps a lot Helps some Has no effect Limits some Limits a lot Do not shop for groceries
	~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~
	bout <b>your grocery store limits you</b> ? ( <i>Check all that apply</i> .)
Not Limited	□Entrance □Lack of personal finances □Parking
↓	Lack of child care
	Accessibility of shelves and freezersLack of transportation
	Lack of scooter/wheelchair at the store
	$\Box$ Lack of special equipment $\rightarrow$ What equipment would be helpful?
	$\Box Other$
	es the accessibility of your doctor's office influence your participation in
health c	are?
	$\Box$ Helps a lot $\Box$ Helps some $\Box$ Has no effect $\Box$ Limits some $\Box$ Limits a lot
	Do not go to a doctor
What ab	bout your doctor's office limits you? (Check all that apply.)
	□ <i>Entrance</i> □ <i>Lack of personal finances</i> □ <i>Parking</i>
Not	□ Lack of personal assistance □Lack of child care □Lack of insurance
Limited	Image: Second association       Image: Second association         Image: Second association       Image: Second association         Image: Second association       Image: Second association
↓	$\Box$ Lack of special equipment $\rightarrow$ What equipment would be helpful?
	□Other
	bes the accessibility of <b>your religious institution or place of worship</b> ce your participation in religious activities?
	Helps a lot Helps some Has no effect Limits some Limits a lot
	Do not go to a religious institution or a place of worship
What a	bout your religious institution limits you? ( <i>Check all that apply</i> .)
	□Entrance □Seating □Lack of personal finances □Parking
Not	□ Lack of personal assistance □Lack of child care □Lack of transportation
Limited	$\Box Lack of special equipment \rightarrow What equipment would be helpful?$
V	
	□Other

6. How does the accessibility of <b>restaurants</b> influence your participation in dining out?							
□Helps a lot □Helps some □Has no effect □Limits some □Limits a lot □Do not go to restaurants							
What about <b>restaurants limits you</b> ? ( <i>Check all that apply</i> .)							
□       □Entrance       □Lack of personal finances       □Parking         Not       □Lack of personal assistance       □Lack of child care       □Lack of transportation         Limited       □       □Lack of special equipment       □Height of counters, tables, and booths       □         →       What equipment would be helpful?       □       □       □							
□ <i>Other</i>							
7. How does the accessibility of <b>movie theaters</b> influence your participation in going to movies?							
□Helps a lot □Helps some □Has no effect □Limits some □Limits a lot □Do not go to movie theaters							
What about <b>movie theaters limits you</b> ? ( <i>Check all that apply</i> .)							
□       □Entrance       □Stadium seating       □Lack of personal finances       □Parking         Not       □Lack of child care       □Lack of personal assistance       □Lack of transportation         □       □Lack of special equipment       → What equipment would be helpful?							
□ <i>Other</i>							
8. How does the accessibility of <b>shopping malls</b> influence your participation in							
shopping? □Helps a lot □Helps some □Has no effect □Limits some □Limits a lot □Do not go to shopping malls ***********************************							
What about <b>shopping malls limits you</b> ? ( <i>Check all that apply</i> .)							
□       □       Entrance       □       Lack of personal finances       □       Parking         Not       □       Lack of personal assistance       □       Lack of child care       □       □       Lack of special equipment       →       What equipment would be helpful?							
□Other							

0 How do	as the accordibility of alothing stor	and influence your participation in							
	9. How does the accessibility of <b>clothing stores</b> influence your participation in shopping for clothes?								
11	$\Box$ Helps a lot $\Box$ Helps some $\Box$ Has no effect $\Box$ Limits some $\Box$ Limits a lot								
Helps a	1 00								
		o not go to clothing stores							
What al			•••						
what at	out clothing stores limits you? (	Check all that apply.)							
	<b>D</b> Entrance	DI ack of nonconal finances	Parking						
Not		$\Box$ Lack of personal finances	U						
Limited	Lack of transportation	6	$\Box$ <i>Width of aisles</i>						
Limiteu V	Lack of personal assistance								
•	$\Box$ Lack of special equipment $\neg$	What equipment would be helpful?							
	□Other								
10 How d	and the appropriation of public new	ly and rearration areas influence you							
		ks and recreation areas influence you	1						
partic	pation in outdoor activities, such a								
		$e \square$ Has no effect $\square$ Limits some $\square$ L	Limits a lot						
		go to parks or recreation areas							
What	about <b>public parks limits you</b> ? ((		~						
		<i>ineck all that apply.</i> )							
	Lack of paved paths								
Not	Picnic areas								
Limited	Parking								
•	$\Box$ Lack of personal finances $\Box$ L								
	$\Box$ Lack of child care $\Box$ Lack								
	$\Box$ Lack of special equipment $\rightarrow$	What equipment would be helpful?							
	□Other								

11. How accessible are the following types of **transportation**?

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

☐Your own car/van	
(not adapted)	$\Box$ Not accessible $\Box$ Somewhat accessible $\Box$ Very accessible
	$\Box$ Don't know $\Box$ Not applicable
Generation Your own adapted	
car/van	$\Box$ Not accessible $\Box$ Somewhat accessible $\Box$ Very accessible
	$\Box$ Don't know $\Box$ Not applicable
Buses	
	$\Box$ Not accessible $\Box$ Somewhat accessible $\Box$ Very accessible
	$\Box$ Don't know $\Box$ Not applicable
Taxis	

	$\Box$ Not accessible $\Box$ Somewhat accessible $\Box$ Very accessible
	$\Box$ Don't know $\Box$ Not applicable
Airlines	
	$\Box$ Not accessible $\Box$ Somewhat accessible $\Box$ Very accessible $\Box$ Don't know $\Box$ Not applicable
Light rail/subway	
	□Not accessible □Somewhat accessible □Very accessible □Don't know □Not applicable
Special services:	
Paratransit	
(such as	$\Box$ Not accessible $\Box$ Somewhat accessible $\Box$ Very accessible
Call-A-Ride)	$\Box$ Don't know $\Box$ Not applicable
Adapted taxi	
	$\Box$ Not accessible $\Box$ Somewhat accessible $\Box$ Very accessible
	$\Box$ Don't know $\Box$ Not applicable
rental car/van	$\Box$ Not accessible $\Box$ Somewhat accessible $\Box$ Very accessible
	$\Box$ Don't know $\Box$ Not applicable
<b>O</b> ther	$\Box$ Not accessible $\Box$ Somewhat accessible $\Box$ Very accessible
	$\Box$ Don't know $\Box$ 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 □ <i>No</i> ♥				Limit some Monthly	Limit a lot Less than monthly
2.	Ramps	□Yes		<b></b>	<b>-</b>	
					□Limit some □Monthly	Limit a lot Less than monthly
3.	Doors	$\Box$ Yes				
	$\Box No$	How much?	<b>D</b> <i>Help a lot</i>	Help some	Limit some	Limit a lot
	•	How often?	Daily	□Weekly	□ <i>Monthly</i>	Less than monthly
4.	Carpets	$\Box$ Yes				

4.	Carpets	$\Box$ Yes				
	$\Box No$	How much?	Help a lot	Help some	Limit some	Limit a lot
	$\mathbf{\Psi}$	How often?	Daily	Weekly	□ <i>Monthly</i>	Less than monthly
			-	-	-	

5. Hardwood floors ₩No	□Yes How much? □Help a lot How often? □Daily	□Help some □Weekly	□Limit some □Monthly	□Limit a lot □Less than monthly
6. Handrails □ <i>No</i> ♥	YesHow much?Help a lotHow often?Daily	□Help some □Weekly	□Limit some □Monthly	Limit a lot Less than monthly
7. Adapted computer □ <i>No</i> ♥	□Yes How much? □Helps a lot How often? □Daily	□Helps some □Weekly	□Limits some □Monthly	Limits a lot Less than monthly
8. Room temperatures □ <i>No</i>	YesHow much?Help a lotHow often?Daily	□Help some □Weekly	□Limit some □Monthly	Limit a lot Less than monthly

*The following items relate to your COMMUNITY environment and to devices that may influence how you move around and carry out activities. Please mark the choice that is closest to your experience.* In your community do the following influence your participation in activities?

In you	ar community, do	the following	g influence you	r participation if	n activities?
1. Curb cuts	$\Box Yes$				
$\Box No$	How much?	Help a lot	Help some	Limit some	Limit a lot
◆	How often?	Daily	□Weekly	□ <i>Monthly</i>	Less than monthly
2. Ramps	$\Box$ Yes				
$\Box No$	How much?	Help a lot	Help some	Limit some	Limit a lot
↓	How often?	Daily	Weekly	□ <i>Monthly</i>	Less than monthly
3. Elevators	<b>Y</b> es				
$\Box No$	How much?	Help a lot	Help some	Limit some	Limit a lot
↓	How often?	Daily	Weekly	□ <i>Monthly</i>	Less than monthly
		•	•		
4. Flat terrain	$\Box$ Yes				
$\Box No$	How much?	Helps a lot	Helps some	Limits some	Limits a lot
. ↓	How often? □	-	□Weekly	$\Box$ Monthly	Less than monthly
5. Gravel surfaces	<b>U</b> Yes				
$\Box No$	How much?	Help a lot	Help some	Limit some	Limit a lot
. ↓	How often?	1	□Weekly	□ <i>Monthly</i>	Less than monthly
6. Paved surfaces	$\Box$ Yes				
$\Box No$	How much?	Help a lot	Help some	Limit some	Limit a lot

•	How often? Daily	□Weekly	, <b>D</b> Monthly	v <b>D</b> Less than monthly	
7.Summer weather	Yes				
(heat and humidity)	How much? Helps a	lot <b>D</b> Helps s	ome 🖬 Limits	some $\Box$ Limits a lot	
	How often? Daily	-		Less than monthly	
↓		-	-	-	
	_				
8. Winter weather	Yes		— -		
(ice and snow)	How much? Helps a	-			
	How often? Daily				
		(1	During the seas	011)	
9. Rain	Yes				
□No	How much?  Helps a	lot <b>D</b> Helps s	ome 🖬 Limits	some $\Box$ Limits a lot	
$\checkmark$	How often? Daily	□Weekly			
10. Crowds	$\Box$ Yes				
	<b>How much? Help</b> <i>a</i>				
•	How often? Daily	ý	~	· · · · · · · · · · · · · · · · · · ·	
	items relate to your WOF				
Do you work?	$\Box Yes \Box No$ I	Jo you attend	school? $\Box Ye$		
If you have an	swered "No" to both question	one nlease ski	in to nevt nage		
				tions based on where you	
spend the most	_			tions suber on where you	
	e choice that is closest to yo		2.		
	ool, do the following influe	-		ivities?	
					_
1. Ramps	$\Box Yes$				
$\Box No$	How much? □ <i>Help a lot</i>				
$\mathbf{\mathbf{v}}$	How often? Daily	□Weekly	<i>Monthly</i>	Less than monthly	
					_
2. Elevators	$\Box Yes$				
$\Box No$	How much? □ <i>Help a lot</i>	1	Limit some	Limit a lot	
$\mathbf{\Psi}$	How often? Daily	□Weekly	□ <i>Monthly</i>	$\Box$ Less than monthly	
3. Floor surfaces	□Yes				٦
$\Box No$	How much? Help a lot	<b>□</b> Help some	Limit some	Limit a lot	
$\mathbf{\Psi}$	1	Weekly	$\Box$ Monthly	$\Box$ Less than monthly	
	-	-	-	-	
					_
4. Distances	□Yes				٦
between rooms	How much? <i>Help a lot</i>	Heln some	Limit some	Limit a lot	
$\Box No$	1	Weekly	□ <i>Monthly</i>	Less than monthly	
V					

5. Work or school	□Yes
cafeteria	How much? $\Box$ Helps a lot $\Box$ Helps some $\Box$ Limits some $\Box$ Limits a lot
$\Box No$	How often? Daily Dweekly Doubless than monthly
$\mathbf{+}$	

#### Mobility Devices

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

Do you use a mobility device? □*Yes* (Continue below.) 1. <u>Name of mobility device: MANUAL WHEELCHAIR</u> MAKE: YEAR PURCHASED\_\_\_\_\_

a. How often do you use this device at home, at work or school, and in your community?				b. How does it in participation					
	Never	Sometimes	Often	Always		Helps a lot	Helps some	Limits some	Limits a lot
Home					Home				
Work/School					Work/School				
Community					Community				

2. Name of mobility device: POWER WHEELCHAIR

MAKE: \_\_\_\_

YEAR PURCHASED \_\_\_\_\_

a. How often do you use this device at home, at work or school, and in your community?					b. How does it in participation i				
	Never	Sometimes	Often	Always		Helps a lot	Helps some	Limits some	Limits a lot
Home					Home				
Work/School					Work/School				
Community					Community				

Name of mobility device: SCOOTER

MAKE:\_\_\_\_\_

### YEAR PURCHASED \_\_\_\_\_

a. How often do you use this device at home, at work or school, and in your community?				b. How does it participation		-	s?		
	Never	Sometimes	Often	Always		Helps a lot	Helps some	Limit s some	Limit s a lot
Home					Home				
Work/School					Work/School				
Community					Community				

#### Health Benefits

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

What heath insurance or benefits do you have?

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

1. Name of benefit or insurance\_\_\_\_\_

a. Is this benefit *A private plan A public (government) plan Don't know* 

- b. Who pays for this benefit? (Check all that apply.)

   □Self
   □Employer

   □Government
   □Other\_\_\_\_\_
- c. How many years have you had this benefit?  $\Box 1 \text{ year or less} \quad \Box 2 \text{ to } 5 \quad \Box 6 \text{ to } 10 \quad \Box More \text{ than } 10$

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 $\Box A \text{ private plan}  \Box A \text{ public (government) plan}  \Box Don't \text{ know}$	
	to pays for this benefit? ( <i>Check all that apply</i> .) $elf \Box Employer \Box Government \Box Other$	
	w many years have you had this benefit? year or less $\Box 2$ to 5 $\Box 6$ to 10 $\Box More$ than 10	
d. To	what extent does this benefit influence your access to health care?	

 $\Box$ Helps a lot  $\Box$ Helps some  $\Box$ Has no effect  $\Box$ Limits some  $\Box$ 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 ng? all that apply.)		ent does this n in daily acti		uence your		
No		Helps a lot	Helps some	No effect	Limits some	Limits a lot	
$\mathbf{\Psi}$	(Supplemental	Í 🖬	Î 🖬	Ľ			
	Security Income)						
	SSDI (Social	Helps a lot	Helps some	No effect	Limits some	Limits a lot	
	Security Disability		Î 🗋	ũ			
	Insurance)						
	<b>Worker's</b>	Helps a lot	Helps some	No effect	Limits some	Limits a lot	
	Compensation		Î 🗖				

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

	jous. Do y	you use vocatio	Jilal Kellabili	ation services.		
	$\Box Yes$ - Hov	w do these servi	ces influence	your access to w	vork?	
$\Box No$						
$\mathbf{+}$	<b>□</b> Help a lot	□Help some	□No effect	Limit some	Limit a lot	

Services and Attitudes

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

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

	$\sim$ $\sim$
□Never	$\Box$ <i>Rarely</i> $\Box$ <i>Once or twice a year</i> $\Box$ <i>Once or twice a month</i>
$\mathbf{+}$	Once or twice a week More than twice a week
	**************
	How does the <u>care</u> you receive 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 the <u>attitudes</u> of doctors influence your use of health care services?
	$\Box$ Help a lot $\Box$ Help some $\Box$ No effect $\Box$ Limit some $\Box$ 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	□ <i>Rarely</i> □ <i>Once or twice a year</i> □ <i>Once or twice a month</i>
$\mathbf{+}$	Once or twice a week More than twice a week
	*************
	How does the <u>therapy</u> you receive 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 the <u>attitudes</u> of therapists influence your use of therapy services?
	$\Box$ Help a lot $\Box$ Help some $\Box$ No effect $\Box$ Limit some $\Box$ Limit a lot

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

Never	Rarely Once or twice a year Once or twice a month
$\mathbf{V}$	Once or twice a week More than twice a week
	*************
	How does the personal assistance you receive influence your participation in
	Daily activities?
	$\Box$ Helps a lot $\Box$ Helps some $\Box$ No effect $\Box$ Limits some $\Box$ Limits a lot
	*************
	How do the <u>attitudes</u> of personal attendants influence your use of
	Personal attendant services?
	$\Box$ Help a lot $\Box$ Help some $\Box$ No effect $\Box$ Limit some $\Box$ Limit a lot

<b>□</b> Never <b>↓</b>	□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?
	$\Box$ 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?
	$\Box$ Help a lot $\Box$ Help some $\Box$ No effect $\Box$ Limit some $\Box$ Limit a lot

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

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

Never	Rarely Once or twice a year Once or twice a month
$  \mathbf{\Psi}  $	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?
	$\Box$ Help a lot $\Box$ Help some $\Box$ No effect $\Box$ Limit some $\Box$ Limit a lot

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

Never	$\Box$ <i>Rarely</i> $\Box$ <i>Once or twice a year</i> $\Box$ <i>Once or twice a month</i>
$\mathbf{+}$	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?
	$\Box$ Help a lot $\Box$ Help some $\Box$ No effect $\Box$ Limit some $\Box$ Limit a lot

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

· · · ·
$\Box$ <i>Rarely</i> $\Box$ <i>Once or twice a year</i> $\Box$ <i>Once or twice a month</i>
Once or twice a week More than twice a week
***************
How do their <u>services</u> influence your participation in shopping?
$\Box$ 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 shopping?
$\Box$ Help a lot $\Box$ Help some $\Box$ No effect $\Box$ Limit some $\Box$ Limit a lot

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

Never	Rarely Once or twice a year Once or twice a month
$\mathbf{\Lambda}$	□ <i>Once or twice a week</i> □ <i>More than twice a week</i>
	**************
	How does their <u>assistance</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?
	$\Box$ Help a lot $\Box$ Help some $\Box$ No effect $\Box$ Limit some $\Box$ Limit a lot

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

Never	$\Box$ <i>Rarely</i> $\Box$ <i>Once or twice a year</i> $\Box$ <i>Once or twice a month</i>
<b>1</b>	Once or twice a week More than twice a week
	**************
	How do their <u>services</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 the <u>attitudes</u> of equipment repair personnel influence your
	participation in <i>Daily</i> activities?
	$\Box$ Help a lot $\Box$ Help some $\Box$ No effect $\Box$ Limit some $\Box$ Limit a lot

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

Participant *Family member*Friend

□ Paid personal attendant

Interviewer

□ Other

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