Characteristics of Respondents Survey

Participant ID Number: ________
Survey date: ________________ (MM/DD/YYYY)

This interview is completely voluntary on your part. Thank you for agreeing to participate.

The questions in the first section will take about 15-20 minutes of your time to answer and includes questions about you and your health status.

Please select the answers most appropriate to you. You may indicate if you prefer not to answer a question. You may choose to discontinue the survey at any time. If you decide not to complete the interview, please contact the Project Manager by email at morgank@msnotes.wustl.edu or by phone at 314-286-1659.

***********************************************************************
For Office Use Only
Participant ID Number: ________          PMD: ___________
Method of data collection:  ❑ Paper survey  ❑ Web-based survey
Data entry: Date - ________________ (MM/DD/YYYY)  ID - ______ (initials)
Data check: Date - ________________ (MM/DD/YYYY)  ID - ______ (initials)
The first questions are background for statistical purposes.

1. What is your age?  
2. What is your gender?  Male  Female
3. What is your race/ethnicity?  
   - American Indian/Alaska Native
   - Asian
   - Black/African American
   - Native Hawaiian/Other Pacific Islander
   - White
   - Other (specify) ________________________________
4. Are you of Hispanic or Latino origin?  Yes  No
5. Are you:  
   - Married  Separated
   - Divorced  Never been married
   - Widowed  Member of an unmarried couple
6. What is the highest grade or year of school you have completed?  
   - Never attended school or only kindergarten
   - Grades 1 through 11
   - Grade 12 or GED (high school graduate)
   - College 1 year to 3 years (including trade school)
   - College 4 years or more (college graduate)
7. Is your personal income from all sources:  
   - $0 - $14,999
   - $15,000 to $34,999
   - $35,000 to $54,999
   - $55,000 to $74,999
   - $75,000 or more
   - Not ascertained
   - I prefer not to answer
8. Is your annual household income from all sources, including income from other family members:  
   - $0 - $14,999
   - $15,000 to $34,999
   - $35,000 to $54,999
   - $55,000 to $74,999
   - $75,000 or more
   - Not ascertained
   - I prefer not to answer
9a. Which of the following benefits are you **currently** receiving?  
(Check all that apply.)

- ☐ SSI (Supplemental Security Income)  
- ☐ SSDI (Social Security Disability Insurance)  
- ☐ Social Security (Retirement)  
- ☐ Insurance Payment (Worker’s Compensation)  
- ☐ Long-term Disability Insurance  
- ☐ Paid Personal Care Assistance  
- ☐ Services from an Independent Living Center (Paraquad, LIFE, RAIL, etc.)  
- ☐ Vocational Rehabilitation Services  
- ☐ Other (specify) _________________________

9b. If you receive any of the benefits shown below, please indicate to what extent this benefit **influences your participation** in daily activities. Please mark N/A for any benefit you do not receive.

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Helps a lot</th>
<th>Helps some</th>
<th>No effect</th>
<th>Limits some</th>
<th>Limits a lot</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>SSI (Supplemental Security Income)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>SSDI (Social Security Disability Insurance)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Worker’s Compensation</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Vocational Rehabilitation</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

10. Do you have any of the following **impairments**?  
(Check all that apply.)

- ☐ Mobility impairment (difficulty walking or unable to walk)  
- ☐ Visual impairment (difficulty seeing)  
- ☐ Hearing impairment (difficulty hearing)  
- ☐ Cognitive impairment (difficulty with thinking/understanding)  
- ☐ Mental health impairment (difficulty controlling thoughts/emotions/actions)  
- ☐ None of these
11. Please check the **primary condition** which caused your mobility impairment.

- [ ] Spinal Cord Injury (SCI)  (Go to question 11A.)
- [ ] Multiple Sclerosis (MS)  (Go to question 11B.)
- [ ] Cerebral Palsy (CP)  (Go to question 11C.)
- [ ] Polio  (Go to question 11D.)
- [ ] Stroke  (Go to question 11E.)
- [ ] Other condition(s) that caused your mobility impairment  (Go to question 11F.)

11A. 1. Approximately what year was the onset of your SCI?  ________

2. Please circle the level of your spinal cord injury.  
   - [ ] Don’t know
   - Cervical: C1 C2 C3 C4 C5 C6 C7 C8
   - Thoracic: T1 T2 T3 T4 T5 T6 T7 T8 T9 T10 T11 T12
   - Lumbar: L1 L2 L3 L4 L5
   - Sacral: S1 S2 S3 S4 S5

3. Are you a:  
   - [ ] Paraplegic  
   - [ ] Quadriplegic  
   - [ ] Don’t know

4. Is your injury:  
   - [ ] Complete  
   - [ ] Incomplete  
   - [ ] Don’t know

   (Go to question 11G.)

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

11B. 1. Approximately what year was the onset of your MS?  ________

2. Which type do you have?  
   - [ ] Relapsing-remitting  
   - [ ] Primary progressive  
   - [ ] Don’t know
   - [ ] Secondary progressive  
   - [ ] Progressive-relapsing

   (Go to question 11G.)

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

11C. 1. Approximately what year was the onset of your CP?  ________

2. Which type do you have?  
   - [ ] Spastic  
   - [ ] Athetoid  
   - [ ] Ataxic  
   - [ ] Mixed  
   - [ ] Don’t know

   (Go to question 11G.)

*****************************************************************************
11D. 1. Approximately what year was the onset of your Polio? ________
2. Following recovery from polio, did you have paralysis and/or muscle weakness anywhere?
   ❑ Yes… Which parts of your body were affected?
   (Check all that apply.)
   ❑ Arms ❑ Legs ❑ Neither of these
   ❑ No
3. Have you experienced the late effects of polio (post-polio syndrome)?
   ❑ Yes… What was the approximate year of onset? ________
   ❑ No
   (Go to question 11G.)

11E. 1. Approximately what year was the onset of your Stroke? ________
2. Which parts of your body were affected? (Check all that apply.)
   ❑ Arms ❑ Legs ❑ Neither of these
3. Due to the stroke, are you having difficulty with any of the following? (Check all that apply.)
   ❑ Thinking ❑ Emotions ❑ Speech ❑ None of these
   (Go to question 11G.)

11F. 1. What is the medical name of the Other Condition(s) that caused your mobility impairment?
   ____________________________________________________
2. Approximately what year was the onset? ____________
3. Which parts of your body were affected? (Check all that apply.)
   ❑ Arms ❑ Legs ❑ Neither of these
4. Are you having difficulty with any of the following? (Check all that apply.)
   ❑ Thinking ❑ Emotions ❑ Speech ❑ None of these
   (Go to question 11G.)

11G. The next page contains a list of other conditions. Please mark whether you have experienced these conditions within the past 30 days. If you have not experienced a condition within the past 30 days, indicate whether you have ever experienced it.
11G. Have you experienced the following conditions during the **past 30 days**? If not in the past 30 days, have you **ever** experienced this condition?

<table>
<thead>
<tr>
<th></th>
<th>Past 30 Days</th>
<th>Ever Experienced</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Pain</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>2. Fatigue</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>3. Spasticity</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>4. Shoulder, elbow, or wrist problems</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>5. Upper Respiratory Infection</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>6. Circulatory problems</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>7. High blood pressure</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>8. Depression</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>9. Urinary Tract Infection</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>10. Bladder incontinence</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>11. Bowel incontinence</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>12. Stomach problems</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>13. Weight problems</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>14. Skin problems</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>15. Fingernail or toenail infections</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>16. Poor balance</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>17. Osteoporosis</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>18. Scoliosis</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
<tr>
<td>19. Contractures - permanent limitation of joint movement</td>
<td>☐ Yes, ☐ No</td>
<td>☐ Yes, ☐ No</td>
</tr>
</tbody>
</table>
12. Because of a physical, mental, or emotional problem, do you need the help of other persons with PERSONAL CARE NEEDS, such as eating, bathing, dressing, or getting around inside your home?
   - Yes
   - No

13. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
   - _______ days

**Note: In the next question you will be asked about the mobility device that you use most often doing activities in the community. This device is referred to as your primary mobility device.**

14. Which of the following do you use MOST OF THE TIME in your community?
   (Choose ONLY one.)
   - Power wheelchair
   - Scooter
   - Crutches
   - Manual wheelchair
   - Cane
   - Walker
   - Do not use a mobility device*

*(Go to question #16.)*

15. Using your primary mobility device, 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

16. What is the farthest distance you can walk by yourself, without your primary mobility device (or without a mobility device, if you do not use one)?
   - 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
17. For you, reaching items on shelves above your shoulders (at the grocery store, in cabinets above the counters in your kitchen, etc.) is …

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult
☐ Cannot do at all

18. For you, going up or down stairs with your primary mobility device is …

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult
☐ Cannot do at all

19. For you, getting on a sidewalk higher than 4” that has no curb cut is …

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult
☐ Cannot do at all

20. For you, moving across rough terrain, such as gravel or sand, using your primary mobility device is …

☐ Very easy
☐ Easy
☐ Difficult
☐ Very difficult
☐ Cannot do at all

If your primary mobility device is a cane, crutches or a walker OR if you do not use a mobility device …
Go to page 9.

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

If your primary mobility device is a power wheelchair, manual wheelchair, or scooter … Continue below.

21. Does the seat of your primary mobility device go up and down?

☐ Yes
☐ No
☐ N/A

22. Does your primary mobility device put you in a standing position with your knees straight?

☐ Yes
☐ No
☐ N/A
The following questions involve forms of transportation you might have used during the past year. Please answer the follow-up questions for those you have used.

<table>
<thead>
<tr>
<th>Question</th>
<th>If yes ...</th>
</tr>
</thead>
</table>
| **A. Non-adapted car/van/truck/SUV** | How often have you used this form of transportation in the past year? ❏ Daily ❏ Weekly ❏ Monthly ❏ Less than once a month  
Overall, how does this type of transportation influence your participation in community activities? ❏ Helps ❏ Helps ❏ Has no ❏ Limits ❏ Limits  
a lot some effect some a lot  
For you, using this form of transportation is… ❏ Very easy ❏ Easy ❏ Difficult ❏ Very difficult |
| **B. Adapted car/van/truck/SUV** | How often have you used this form of transportation in the past year? ❏ Daily ❏ Weekly ❏ Monthly ❏ Less than once a month  
Overall, how does this type of transportation influence your participation in community activities? ❏ Helps ❏ Helps ❏ Has no ❏ Limits ❏ Limits  
a lot some effect some a lot  
For you, using this form of transportation is… ❏ Very easy ❏ Easy ❏ Difficult ❏ Very difficult |
| **C. Non-adapted taxis** | How often have you used this form of transportation in the past year? ❏ Daily ❏ Weekly ❏ Monthly ❏ Less than once a month  
Overall, how does this type of transportation influence your participation in community activities? ❏ Helps ❏ Helps ❏ Has no ❏ Limits ❏ Limits  
a lot some effect some a lot  
For you, using this form of transportation is… ❏ Very easy ❏ Easy ❏ Difficult ❏ Very difficult |
| **D. Adapted taxis** | How often have you used this form of transportation in the past year? ❏ Daily ❏ Weekly ❏ Monthly ❏ Less than once a month  
Overall, how does this type of transportation influence your participation in community activities? ❏ Helps ❏ Helps ❏ Has no ❏ Limits ❏ Limits  
a lot some effect some a lot  
For you, using this form of transportation is… ❏ Very easy ❏ Easy ❏ Difficult ❏ Very difficult |
## Characteristics Of Respondents

### Survey (CORE) 2006 ©

<table>
<thead>
<tr>
<th>23. (continued)</th>
<th>If yes …</th>
</tr>
</thead>
<tbody>
<tr>
<td>During the past year have you used …</td>
<td>How often have you used this form of transportation in the past year?</td>
</tr>
<tr>
<td>E. Buses</td>
<td>❑ Daily ❑ Weekly ❑ Monthly ❑ Less than once a month</td>
</tr>
<tr>
<td>❑ No ❑ Yes ➔</td>
<td>Overall, how does this type of transportation influence your participation in community activities?</td>
</tr>
<tr>
<td></td>
<td>❑ Helps ❑ Helps ❑ Has no ❑ Limits ❑ Limits</td>
</tr>
<tr>
<td></td>
<td>❑ a lot ❑ some ❑ effect ❑ some ❑ a lot</td>
</tr>
<tr>
<td></td>
<td>For you, using this form of transportation is…</td>
</tr>
<tr>
<td></td>
<td>❑ Very easy ❑ Easy ❑ Difficult ❑ Very difficult</td>
</tr>
<tr>
<td>F. Light rail (Metrolink) / Subway</td>
<td>How often have you used this form of transportation in the past year?</td>
</tr>
<tr>
<td>❑ No ❑ Yes ➔</td>
<td>❑ Daily ❑ Weekly ❑ Monthly ❑ Less than once a month</td>
</tr>
<tr>
<td>Overall, how does this type of transportation influence your participation in community activities?</td>
<td></td>
</tr>
<tr>
<td>❑ Helps ❑ Helps ❑ Has no ❑ Limits ❑ Limits</td>
<td></td>
</tr>
<tr>
<td>❑ a lot ❑ some ❑ effect ❑ some ❑ a lot</td>
<td></td>
</tr>
<tr>
<td>For you, using this form of transportation is…</td>
<td></td>
</tr>
<tr>
<td>❑ Very easy ❑ Easy ❑ Difficult ❑ Very difficult</td>
<td></td>
</tr>
<tr>
<td>G. Paratransit (accessible, shared-ride, door-to-door transportation service. Example: Call-A-Ride)</td>
<td>How often have you used this form of transportation in the past year?</td>
</tr>
<tr>
<td>❑ No ❑ Yes ➔</td>
<td>❑ Daily ❑ Weekly ❑ Monthly ❑ Less than once a month</td>
</tr>
<tr>
<td>Overall, how does this type of transportation influence your participation in community activities?</td>
<td></td>
</tr>
<tr>
<td>❑ Helps ❑ Helps ❑ Has no ❑ Limits ❑ Limits</td>
<td></td>
</tr>
<tr>
<td>❑ a lot ❑ some ❑ effect ❑ some ❑ a lot</td>
<td></td>
</tr>
<tr>
<td>For you, using this form of transportation is…</td>
<td></td>
</tr>
<tr>
<td>❑ Very easy ❑ Easy ❑ Difficult ❑ Very difficult</td>
<td></td>
</tr>
</tbody>
</table>

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THIS IS THE END OF THE SURVEY.

THANK YOU VERY MUCH FOR YOUR TIME AND EFFORT!