Virginia Spinal Cord Injury Needs Assessment Survey:

Report of Findings

Spring 2005

Prepared by:
Kirsten Barrett, PhD
Michelle Meade, PhD
Njeri Jackson, PhD

Table of Contents

INTRODUCTION

Survey Development. The *Virginia Spinal Cord Injury (SCI) Needs Assessment Survey*, and its companion, the *Family/Caregiver Survey,* were created by the research team in 2004. During the survey development period, decisions about survey content were informed by prior research (published and unpublished), the researchers' own experiences working with individuals and families living with SCI, and the project's advisory board. The process of survey development was iterative, with repeated review and comment by the research team, the advisory board, and content experts working in the field of SCI.

After a period of review and revisions, the *Virginia SCI Needs Assessment Survey*, and its companion, the *Family/Caregiver Survey,* were piloted with a group of purposively selected individuals living with SCI and their caregivers. Instructions were provided to complete the survey and then to answer the 'Survey Feedback Worksheet', enclosed with the survey. The worksheet contained questions about the clarity of survey content, the ease of completion, the sensitivity of questions, and perceptions of survey length. Additional space was provided for comments by the respondent. Although these data were not used in the analysis, this pilot effort provided valuable feedback to the research team and the result was further refinement of the survey instruments.

Sample. The sample for the *Virginia SCI Needs Assessment Survey* was created from a number of sources. The primary source was the Virginia SCI Registry, maintained by Virginia's Department of Rehabilitative Services (DRS).[1] The sample also included individuals who heard about our study through advertising efforts and volunteered to participate. In addition, participants in the qualitative phase of the study also were included in the sample. Finally, individuals from MCV's SCI Model Systems database were included in our sample, excluding those requesting not to have their information shared.

[1] SERL attempted to verify the contact information for individuals in the registry (n=3,265) during the period in which the surveys were being developed. The result of this effort was verifying 662 records with good addresses, identifying 299 records in which the individual was deceased, identifying 532 records with bad addresses, and 107 records in which the individual either refused or was not injured. There were 1,665 records in which the individual could not be contacted.

Survey Distribution. The survey was fielded using a modified Dillman approach. Each person in the sample was sent a prenotification postcard that informed them about the survey effort. Approximately seven days thereafter, each member of the sample was mailed a survey packet containing the following items: a cover letter, a consumer survey with a postage paid return envelope, a family/caregiver survey with a postage paid return envelope, and $3 as a thank-you for participating in the study. Then, approximately ten days thereafter, a reminder postcard was mailed to the entire sample. Seven days thereafter, a second survey packet (devoid of the $3) was mailed to those not responding to the initial mailing. Once the mail survey phase was completed, SERL attempted to call non-responders in order to generate more completions. The survey was also made available via the Internet and a toll-free number was made available so that respondents could call in and complete the survey. The survey was also available in Spanish.

Response Rate. As mentioned previously, the survey was sent to 2,508 individuals. A total of 908 of these individuals were ineligible.[2] This reduced the valid sample to 1,600. SERL received a total of 539 completions[3] from consumers yielding a response rate of 34%, respectable for a mail survey. A total of 309 *Family/Caregiver Surveys* were completed.[4]

The remainder of the report highlights the findings from *Virginia SCI Needs Assessment Survey* and the Family / Caregiver Survey.

[2] Bad Address = 594, Deceased = 262, No Injury = 47, Duplicates = 5, Respondent <18 years of age = 14.
[3] Breakdown by completion method: 529 mail survey, 5 Internet survey, 5 phone survey.
[4] The number of caregiver completions reflects the valid number after excluding ineligible cases.

VIRGINIA SCI NEEDS ASSESSMENT SURVEY

DEMOGRAPHICS

Age

- The average age of respondents was 49.0 years with a standard deviation of 16 years. The median age of respondents was also 49 years. Age ranged from a low of 18 years to a high of 93 years.[5]

Gender

- 73% of the respondents were male (n=392), 27% female (n=145).

Race and Ethnicity

- 73% (n=391) of the respondents were White, 22% (n=116) were African American or Black, 2% were Asian (n=10), 2% were American Indian or Alaskan Native (n=9), and less than one percent were Native Hawaiian or Pacific Islander (n=2).

- 1.9% (n=9) of the respondents were Hispanic or Latino.

Marital Status

- Approximately one-half (n=260) of the respondents were married; 29% (n=154) were single.

Children in Household

- 21% of respondents (n=114) reported having children under the age of 18 living at home.

Educational Level

- 17% (n=93) of the respondents were not high school graduates, 34% (n=181) were high school graduates, and nearly one-half, 49% (n=259), had some college or were college graduates.

[5] Since the survey instrument was geared toward adults, five respondents who reported being younger than 18 years of age were excluded from the analysis.

Time since Injury

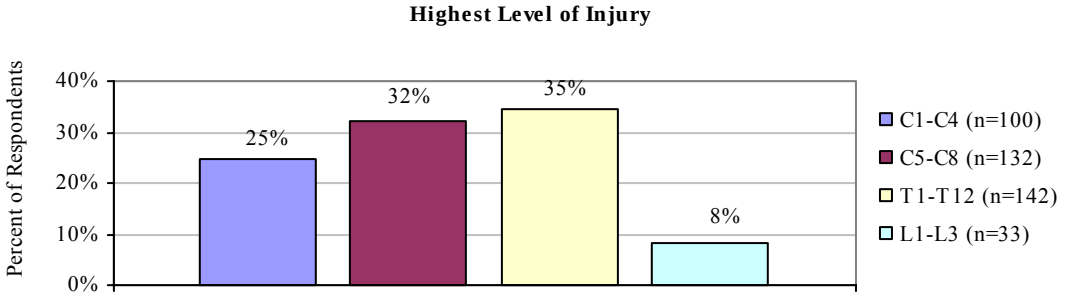
- The average length of time since sustaining the SCI was 10.3 years with a median of nine years. Length of time since injury ranged from a low of less than one year to a high of 48 years.

	'n'	*Mean +/- SD*	*Median*
Current age	539	49.0 +/- 16.0	49.0
Age at time of SCI	514	38.4 +/- 16.8	37.0
Years since SCI	514	10.3 +/- 7.9	9.0

Level of Injury

- Of the 407 respondents reporting their highest level of injury, 57% (n=232) had tetraplegia[6] and 43% (n=175) had paraplegia.

- 18% (n=95) of respondents did not know their highest level of injury and 7% (n=37) chose not to respond to the question.



- Among the 100 individuals with SCI between the levels of C1 and C4, 6% (n=6) required a ventilator to breathe.

- 60% (n=297) of the respondents were wheelchair users; 40% (n=197) were not.[7]

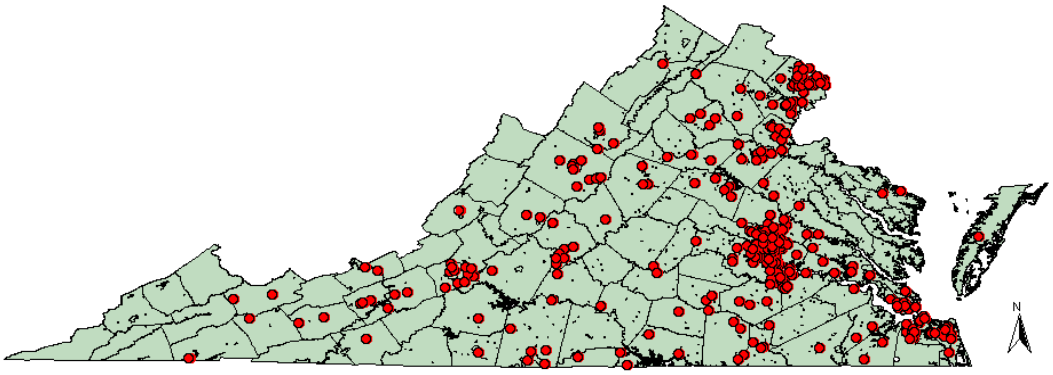
- 80% of respondents (n=412) had some feeling below the level of injury and/or some ability to control muscle activity below the level of injury.

[6] Tetraplegia is the preferred term over quadriplegia.

[7] Status as a wheelchair user was inferred from responses on questions about need for assistance. Respondents were asked to what extent they needed assistance 'getting around in a wheelchair'. Those indicating that they did not need to do this activity were coded as non-wheelchair users. Those stating that they could do the task without help, did the task with help, or would like to do the task but is unable to were coded as wheelchair users.

Geographic Distribution

- As can be seen in the map below, most respondents were clustered in the central, northern, and eastern regions of the Commonwealth.



Individuals with SCI responding to Virginia's Spinal Cord Injury Needs Assessment

NOTE: Map depicts the 335 respondent addresses that successfully geocoded.

HEALTH-RELATED DATA

Health Insurance Coverage

- 87% of respondents (n=447) reported currently having health insurance; 13% did not (n=70).
  - Those who had health insurance were more likely to be satisfied with their medical than those who did not have health insurance, 87% vs. 64% respectively (X^2=23.52, p<.001).
  - There was little difference in health insurance status based on completeness of injury (X^2=.874, p=.408). Similarly, there was little difference in health insurance status based on extent of wheelchair use (X^2=.761, p=.413).
  - Health insurance status was unaffected by employment. Eighty-nine percent of employed respondents had health insurance as compared to 85% of unemployed respondents (X^2=1.59, p=.130).
  - Whites were significantly more likely to have health insurance than non-Whites, 90% vs. 77% respectively (X^2=13.79, p<.001).
  - Those with health insurance tended to be older, on average, than those without health insurance, 49.6 years vs. 43.8 years respectively (|t|=3.59, p<.001).
- Among those reporting to have health insurance, 66% (n=291) reported having one type only and 34% (n=153) reported having two types. The following table highlights the findings with regards to type of health insurance:

Type of Health Insurance	*Number*	*%*
Medicare	200	45%
Employer health plan	169	38%
Medicaid	100	22%
Individual health insurance policy	70	16%
Other*	54	12%
Veterans Administration	20	5%
Don't know / not sure	3	<1%

Note: Respondents could check more than one insurance type. Counts within insurance type are unduplicated. Counts across categories are duplicated, to some degree.
*Examples of 'other' responses included COBRA, workman's comp, Kaiser, and spouse's policy.

Access to Health Care

- 16% of respondents (n=83) reported having had a time within the past 12 months when they needed medical care but could not get it. These 83 respondents were asked why they were unable to receive the medical care they needed. Of the 74 respondents answering this question, the majority, 66% (n=49), cited an inability to afford care as the primary reason for not receiving care. Only 8% (n=6) cited transportation.

  - Interestingly, of those who cited an inability to afford care (n=49), 47% (n=23) had health insurance. Of these 23 respondents, 21 reported having one type of insurance. Among these 21 respondents, 9 had Medicare and 5 had Medicaid.

Experience with Receipt of Medical Care

- 27% of respondents (n=136) reported, at some point in time since their SCI, having had a bad experience when receiving or attempting to receive medical care.

- The majority of bad experiences were related to a perceiving lack of provider sensitivity to the individual's disability and a perceived lack of provider understanding about patient SCI-related needs. The following table summarizes these findings:

Experience related to…….	***Number (max 'n'=136)***	***%***
Health care provider did not understand my needs as an individual with an SCI.	89	65%
My opinion was not respected by the health care provider.	54	40%
Uncomfortable with the way I was treated due to my disability.	47	35%
Uncomfortable with the way I was treated due to my race.	7	5%
Uncomfortable with the way I was treated due to my gender.	5	4%

Note: Respondents could check more than experience. Counts within experience type are unduplicated. Counts across categories are duplicated, to some degree.

  - Unemployed individuals were more likely to report having had a bad experience than an employed individual, 30% vs. 22% (X^2=4.05, P=.03).

  - Women were more likely to reporting having had a bad experience than men, 35% vs. 24% (X^2=5.58, p=.02).

  - Race was not a significant factor. Thirty-one percent of non-Whites reported a bad health care experience as compared to 26% of Whites (X^2=1.19, p=.31).

  - Individuals with complete injuries were more likely to report having had a bad experience than those with incomplete injuries, 37% vs. 25% (X^2=6.30, p=.01).

  - Wheelchair users were much more likely to report having had a bad experience than non-wheelchair users, 33% vs. 18% (X^2=12.39, p<.001).

Experience with Receipt of Medical Care (con't)

- As expected, those who were most satisfied with their medical care were least likely to report having had a bad health care experience. Twenty percent of satisfied individuals reported a bad experience as compared to 64% of dissatisfied individuals (X^2=66.13, p<.001).

- Those reporting bad experiences, on average, were 45.6 years old. Those not experiencing a bad health care experience were, on average, 49.5 years old (|t|=2.69, p=.008).

Dental Insurance

- Less than one-half of the respondents, 40% (n=201), reported currently having dental insurance. The remaining 60% (n=296) do not have dental insurance currently.

  - Individuals with paraplegia were more likely to have dental insurance than those with tetraplegia, 48% vs. 39% respectively (X^2=2.94, p=.09).

  - Whites were more likely than non-Whites to have dental insurance, 43% vs. 34% (X^2=3.09, p=.05).

  - Those who reported being employed were much more likely to have dental insurance than their counterparts who were not employed, 62% vs. 28% respectively (X^2=53.59, p<.001).

Tobacco

- 27% (n=137) of respondents reported currently smoking cigarettes. Of these 137 respondents, 56% (n=76) smoked less than one pack per day, 36% (n=48) smoked one pack per day, and 8% (n=11) smoked more than one pack per day.

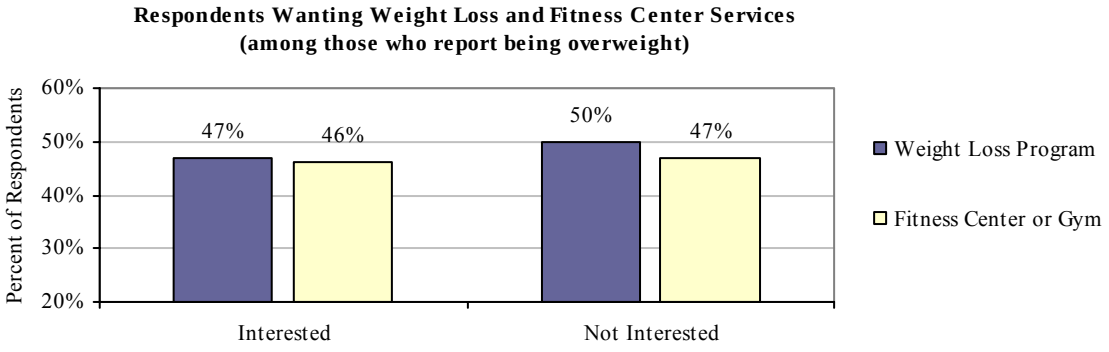
  - Associations between smoking and employment, gender, race (White, non-White), completeness of injury, wheelchair use, and level of injury were all non-significant.

- Among current smokers, 61% (n=74) reported that they were NOT interested in a program to quit smoking; 36% (n=44) reported that they would like to participate in a program to quit smoking.

Weight Control

- 37% (n=199) of respondents considered themselves to be overweight. Of these 204 respondents, 87% were currently trying to lose weight; 13% were not.

- Among those who indicated they were overweight, 47% (n=84) indicated that they would like to participate in a program to lose weight; 50% (n=89) were not interested in such a program. Similar results were seen when respondents were asked about wanting access to a fitness center or gym. Forty-six percent of respondents (n=82) were interested and 47% were not interested. Results were similar for wheelchair users and non-wheelchair users.



Note: Totals do not add up to 100% because a small percent of respondents reported they had received the service and were either satisfied or unsatisfied (less than <=5% for each service).

Weight Control and Wheelchair Use

- Wheelchair users were more likely to consider themselves overweight than non-wheelchair users, 41% vs. 33% (X^2=2.89, p=.05).

- Among those who considered themselves overweight, wheelchair users were more likely to want a program to lose weight (49% vs. 40%) and were more likely to want fitness center / gym access (47% vs. 40%) than their counterparts not using wheelchairs.

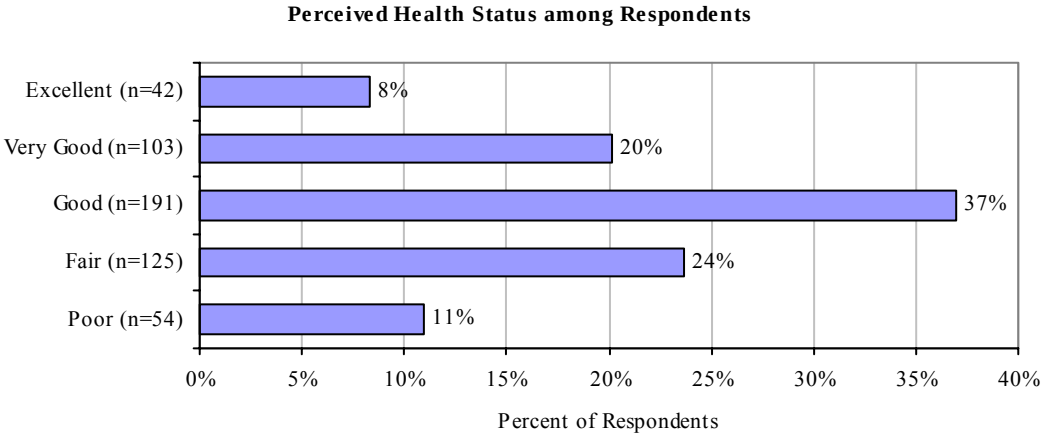
Gym / Fitness Center Access for Non-Overweight Individuals

- Among those who did not consider themselves overweight, (n=284), 25% (n=72) were interested in accessing a fitness center or gym.

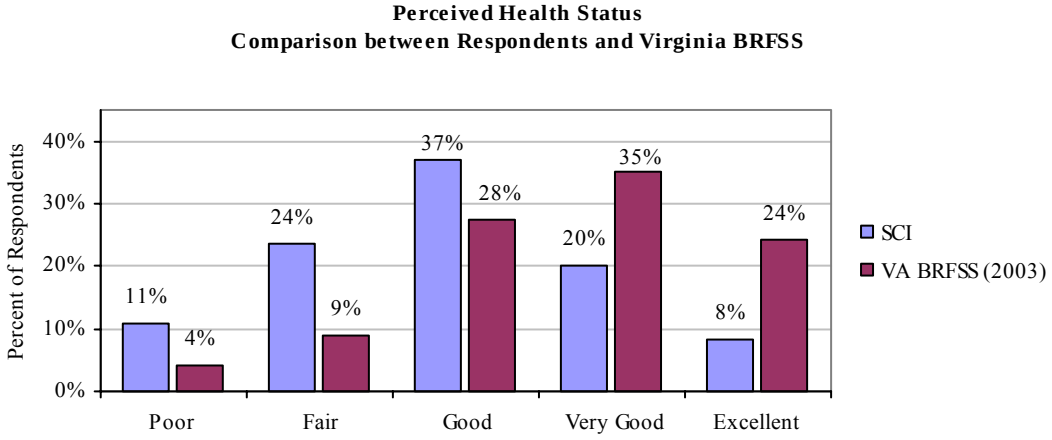
- Among non-overweight wheelchair users (n=152), 31% (n=47) wanted fitness center or gym access as compared to 19% (n=23) of their non-wheelchair using counterparts (n=119).

Perceived Health

- 65% (n=336) of respondents reported that their health was 'good', 'very good', or 'excellent'. The remaining 35% (n=179) reported that their health was 'fair' or 'poor'.



- As compared to the general population of Virginian's[8], individuals with SCI were more likely to rate their health as poor to fair (35% vs. 13%) and less likely to rate their health as good to excellent (65% vs. 87%).



[8] Virginia Behavioral Risk Factor Surveillance Survey, 2003.

Perceived Health (con't)

- Perceived health varied depending on one's level of satisfaction with medical care, completeness of injury, extent of wheelchair use, employment status, and level of injury.
  - 73% (n=119) of those with paraplegia reported good to excellent health as compared to 66% (n=148) of those with tetraplegia (X^2=1.86, p=.10).
  - 83% (n=154) of those who were employed post-SCI reported good to excellent health as compared to 55% (n=176) of those who were not employed post-SCI (X^2=42.25, p<.001).
  - 64% (n=240) men reported good to excellent health as compared to 68% (n=94) of women (X^2=.532, p=.53).
  - 67% (n=251) of White respondents reported good to excellent health as compared to 61% (n=85) of non-White respondents (X^2=1.84, p=.11).
  - 70% (n=69) of those with complete injuries reported good to excellent health as compared to 65% (n=255) of those with incomplete injuries (X^2=.927, p=.35).
  - 70% (n=198) of wheelchair users reported good to excellent health as compared to 61% (n=116) of non-wheelchair users (X^2=4.12, p=.03).
  - 57% (n=76) of respondents who have had a bad health care experience since their SCI reported good to excellent health as compared to 70% (n=254) of those who have not had a bad health care experience since their SCI (X^2=7.48, p=.005).
  - 70% (n=294) of those who where satisfied to very satisfied with their care reported good to excellent health as compared to 46% (n=35) of those who were dissatisfied to very dissatisfied with their care (X^2=16.78, p<.001).
  - 68% (n=301) of those with health insurance reported good to excellent health as compared to 48% (n=33) of those without health insurance (X^2=10.84, p=.001).
- There was a significant difference in mean age between those who reported good to excellent health as compared to those who reported poor to fair health, 46.8 years and 52.3 years respectively (|t|= 3.76, p=.000).

Type of Medical Care Provider

- 51% (n=236) of the respondents received the majority of medical care from a family practice doctor.
- Sixteen percent (n=71) received the majority of their care from an internal medicine doctor.

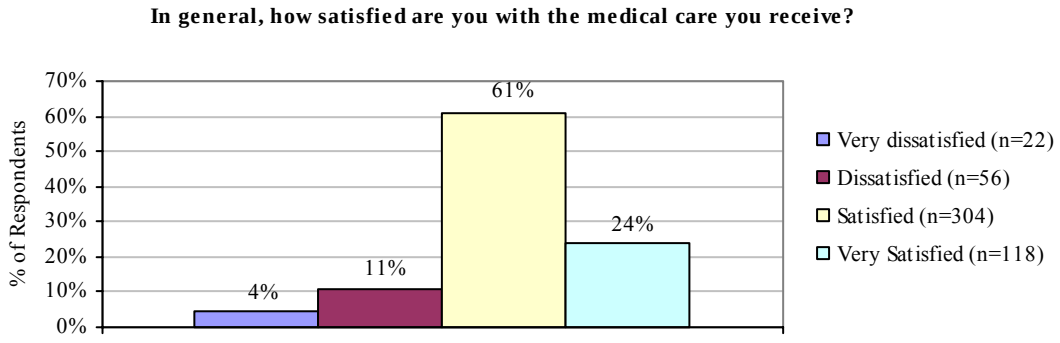
Type of Medical Care Provider (con't)

- Only 12% of respondents (n=54) received the majority of their care from a rehabilitation doctor or physiatrist.

Type of Doctor	*'N'*	*% of Total (n=459)*
Family Practice	236	51%
Internal Medicine	71	16%
Rehabilitation Medicine	54	12%
Other	37	8%
Doctor at a general clinic	30	7%
Emergency Room Doctor	17	4%
Nurse Practitioner	10	2%
Physician Assistant	4	<1%

Satisfaction with Medical Care

- 84% of respondents (n=422) were 'satisfied' or 'very satisfied' with the medical care they are receiving.



- There was little association between satisfaction with medical care and employment status, gender, race, level of injury, status as a wheelchair user, or completeness of injury.

- Those who were dissatisfied with their care were less likely to have health insurance than those who were satisfied with their care, 71% vs. 90% (X^2=23.52, p<.001).

- Not unexpectedly, those who were dissatisfied with their care were more likely to have had a bad experience receiving medical care since their SCI occurred than their counterparts who were satisfied with their care, 64% vs. 20% (X^2=66.13, p<.001).

- Those who were dissatisfied with their care tended to be younger than those who were satisfied with their care, 44 years old vs. 49 years old (|t|=3.16, p=.002).

Health-Related Issues within the Last 12 Months

- Respondents were asked to indicate, from a list provided, what health-related issues they have experienced within the past 12 months. Twenty percent of the respondents (n=105) reported experiencing none of the health-related issues listed, 47% (n=255) experience between one and three, and the remaining 33% (n=179) experienced four or more.

- The most commonly reported conditions were urinary tract infections, uncontrolled spasticity or muscle spasms, and persistent, chronic pain. Substance abuse issues and blood clots were reported least frequently. The following table illustrates the findings with regard to frequency of health-related issues:

Health-Related Issue	***Experiencing Condition***	
	Number	***% of total (n=539)***
Urinary tract infections	212	39%
Uncontrolled spasticity or muscle spasms	199	37%
Persistent, chronic pain	198	37%
Depression or anxiety	147	27%
Constipation	145	27%
Pressure sores or skin breakdown	107	20%
Frequent urinary accidents	102	19%
Uncontrolled edema or swelling	87	16%
Blood pressure issues	84	16%
Frequent bowel accidents	54	10%
Respiratory infections	44	8%
Fractures or broken bones	27	5%
Substance abuse issues	23	4%
Blood clots	11	2%

- Some conditions were reported more frequently by wheelchair users than non-wheelchair users and by individuals with complete injuries rather than incomplete injuries. Wheelchair users were more likely to report having had pressure sores, urinary tract infections, and uncontrolled edema or swelling within the past 12 months as compared to their counterparts who were not wheelchair users. Similar trends were seen with regard to completeness of injury.

Health-Related Issues within the Last 12 Months (con't)

- The two tables on the following page highlight differences between wheelchair and non-wheelchair users and between individuals with complete and incomplete injuries.

Health-Related Issue	*Experiencing Condition*			
	W/C User (n=297)	*%*	*Non-W/C User (n=197)*	*%*
Urinary tract infections	163	55%	39	20%
Uncontrolled spasticity or muscle spasms	121	41%	61	31%
Persistent, chronic pain	103	35%	79	40%
Pressure sores or skin breakdown	92	31%	9	5%
Constipation	88	30%	50	25%
Depression or anxiety	78	26%	58	29%
Frequent urinary accidents	65	22%	27	14%
Uncontrolled edema or swelling	63	21%	16	8%
Blood pressure issues	45	15%	29	15%
Frequent bowel accidents	37	13%	11	6%
Respiratory infections	27	9%	12	6%
Fractures or broken bones	16	5%	9	5%
Substance abuse issues	12	4%	11	6%
Blood clots	5	2%	4	2%

Health-Related Issue	*Experiencing Condition*			
	Complete (n=106)	*%*	*Incomplete (n=412)*	*%*
Urinary tract infections	71	67%	136	33%
Uncontrolled spasticity or muscle spasms	46	43%	147	36%
Persistent, chronic pain	30	28%	165	40%
Pressure sores or skin breakdown	47	44%	58	14%
Constipation	22	21%	119	29%
Depression or anxiety	21	20%	118	29%
Frequent urinary accidents	29	27%	70	17%
Uncontrolled edema or swelling	23	22%	61	15%
Blood pressure issues	12	11%	67	16%
Frequent bowel accidents	16	15%	33	8%
Respiratory infections	8	8%	35	9%
Fractures or broken bones	4	4%	23	6%
Substance abuse issues	4	4%	18	4%
Blood clots	4	4%	7	2%

Function

- Respondents were given a list of activities ranging from basic self-care to transportation to work. The respondents indicated, for each activity, if they performed it without help, if they could perform it with help, if they could not do it but would like to do it, or if they had no need to do it.

  - Forty-eight percent (n=262) of the respondents did all activities independently or had no need to perform the activity. The remaining 52% (n=277) received help with one or more the activities listed.

- 80% of more of the respondents reported that they were independent with telephone use, brushing their teeth and combing their hair, and eating. Car / van transfers, transportation to and from work, and housekeeping were least likely to be done, by respondents, independently.

Activity	*Do without help*	*Do with help*	*Would like to do*	*No need to do*
Eating (n=455)*	91%	8%	1%	
Brushing teeth, combing hair (n=464)*	88%	10%	2%	
Using the telephone (n=515)	83%	7%	1%	9%
Managing bladder activities (n=417)*	77%	19%	4%	
Managing bowel activities (n=425)*	72%	24%	4%	
Getting dressed / undressed (n=459)*	72%	25%	3%	
Positioning in bed (n=513)	71%	16%	2%	11%
Getting in or out of bed (n=510)	70%	18%	3%	9%
Bathing or showering (n=470)*	70%	27%	3%	
Managing medications (n=512)	70%	16%	1%	12%
Preparing meals (n=442)*	63%	31%	6%	
Banking, paying bills (n=507)	63%	23%	3%	12%
Getting to/from appointments (n=510)	56%	22%	5%	17%
Getting to and from social activities (n=499)	56%	22%	5%	17%
Pressure relief in w/c (n=481)	53%	6%	1%	41%
Getting around in w/c (n=494)	51%	8%	1%	40%
Car /van transfer (n=464)	43%	6%	7%	44%
Getting to and from work (n=464)	43%	6%	7%	44%
Housekeeping (n=500)	42%	35%	8%	15%

*Some respondents indicated that they did not need to perform these activities. These cases were excluded from the analysis of the particular item based on the fact that regardless of circumstance, the task would need to occur (e.g., eating, bathing, etc).

Function (con't)

- The following table excludes respondents who did not have to perform a particular task. With this exclusion, using the telephone, eating, and pressure reliefs in the wheelchair were the activities performed independently by the majority of the respondents. Housekeeping, getting to and from appointments, and preparing meals were performed independently least frequently.

Activity	*Do without help*	*Do with help*	*Would like to do*
Using the telephone (n=468)	92%	7%	1%
Eating (n=455)	91%	8%	1%
Pressure relief in w/c (n=284)	89%	10%	1%
Getting around in w/c (n=297)	85%	13%	2%
Brushing teeth, combing hair (n=464)	88%	10%	2%
Managing medications (n=450)	80%	19%	1%
Positioning in bed (n=458)	80%	18%	2%
Getting in or out of bed (n=462)	78%	20%	3%
Managing bladder activities (n=417)	77%	19%	4%
Getting to and from work (n=259)	77%	11%	12%
Car /van transfer (n=458)	74%	23%	3%
Managing bowel activities (n=425)	72%	24%	4%
Banking, paying bills (n=448)	71%	25%	3%
Getting dressed / undressed (n=459)	72%	25%	3%
Bathing or showering (n=470)	70%	27%	3%
Getting to and from social activities (n=414)	67%	27%	6%
Preparing meals (n=442)	63%	31%	6%
Getting to/from appointments (n=464)	61%	35%	3%
Housekeeping (n=424)	49%	42%	9%

- Among 255 respondents receiving help with one or more activities, 48% (n=121) received the help from their spouse, significant other, or partner. Twenty-four percent (n=61) received help from a relative and 14% (n=35) from Personal Assistance Services (PAS).

- Most individuals receiving help were satisfied with their care. Ninety-four percent (n=255) rated the quality of assistance as good, very good, or excellent.

EMPLOYMENT

Employment - Overall Results

- Nearly 75% of respondents were employed prior to their SCI (n=393). Only 37% reported currently working at a job for which they receive pay (n=196).

  - 44% worked before their SCI but not after (n=228).
  - 31% worked before and after their SCI (n=164).
  - 20% worked neither before nor after their SCI (n=103).
  - 5% did not work before their SCI but did work after sustaining their injury (n=28).

- Males were slightly more likely to be employed than females, 39% vs. 32% (X^2=2.62, p=.13).

- Whites were more likely than non-Whites to be employed, 41% vs. 26% (X^2=9.52, p=.001).

- Individuals with incomplete injuries were more likely to be employed than individuals with complete injuries, 40% vs. 28% (X^2=5.34, p=.01). And, not surprisingly, non-wheelchair using individuals were more likely than their wheelchair using counterparts to be employed, 48% vs. 30% (X^2=16.58, p<.001).

- Among those currently employed,

  - 13% (n=26) worked 20 hours or less per week.
  - 11% (n=22) worked between 21 and 30 hours per week.
  - 52% (n=101) worked between 31 and 40 hours per week.
  - 24% (n=47) worked more than 40 hours per week.

- 32% (n=60) of employed respondents reported earning less than $20,000 per year. Forty-four percent (n=89) reported earning between $20,000 and $59,999. The remaining 24% (n=46) reported earning $60,000 per year or more.

- Less than 10% (n=19) of respondents reported working at home or traveling less than 1 mile to work. Approximately 66% (n=127) of respondents traveled between one mile and 20 miles to get to work. Approximately one-quarter (n=47) traveled more than 20 miles to get to work.

- In terms of benefits, 61% (n=120) of employed respondents received health insurance benefits, 59% (n=115) had paid vacation, and 49% (n=95) had sick leave.

Employment - Overall Results (con't)

- Among those not currently working (n=335), health-related issues and retirement were cited by 60% of respondents (n=169). Five percent of respondents (n=13) identified a lack of job opportunities as the primary reason for not currently working. Only 1% of respondents reported a lack of transportation as the primary issue (n=4).

  - Among the 84 respondents who reported being retired, the average age was 71 years with a standard deviation of 9.5 years. The median age was 73. Age ranged from a low of 51 to a high of 93.

  - Among the 85 respondents reporting health issues as a limiting factor to employment, persistent, chronic pain and uncontrolled spasticity or muscle spasms were the most common conditions occurring within the past 12 months.

Health-Related Issue	***Experiencing Condition***	
	Total (n=85)	***%***
Persistent, chronic pain	52	61%
Uncontrolled spasticity or muscle spasms	47	55%
Depression or anxiety	37	44%
Constipation	34	40%
Urinary tract infections	31	37%
Frequent urinary accidents	22	26%
Pressure sores or skin breakdown	21	25%
Uncontrolled edema or swelling	19	22%
Blood pressure issues	17	20%
Frequent bowel accidents	12	14%
Respiratory infections	11	13%
Fractures or broken bones	5	6%
Substance abuse issues	4	5%
Blood clots	4	5%

Employment by Significance of Disability

- Pre-SCI employment history was similar between those currently using a wheelchair (72%, n-210) and those not using a wheelchair (79%, n=153). However, those using a wheelchair were less likely to have post-SCI employment as compared to those not using a wheelchair, 30% (n=87) versus 48% (n=94) respectively.

- 75% of employed respondents, in both groups, reported working 31 or more hours per week. Those not reliant on a wheelchair were more likely to work in excess of 40 hours per week as compared to those reliant on a wheelchair, 30% vs. 18%.

- In terms of earnings, 45% (n=41) of non-wheelchair users and 40% (n=34) of wheelchair users reported earning $40,000 or more per year.

Employment by Significance of Disability (con't)

- Wheelchair users were slightly more likely to work within 10 miles of their home than non-wheelchair users.

- Wheelchair and non-wheelchair users were similar with regard to receipt of health insurance benefits and paid vacations. Those using wheelchairs were slightly more likely to reporting having sick leave benefits through their employer, 56% vs. 45%.

- Health-related issues and retirement were the two most frequently cited reasons for not working among wheelchair and non-wheelchair users.

Employment by Level of Disability

- 39% (n=89) of those with tetraplegia and 40% (n=70) of those with paraplegia are currently employed.
  - 43% (n=98) of those with tetraplegia and 45% (n=78) of those with paraplegia worked before their SCI but not after.
  - 32% (n=74) of those with tetraplegia and 34% (n=58) of those with paraplegia worked both before and after their SCI.
  - 6% of respondents, in each group, did not work before their SCI but did work after.
  - 19% (n=43) of those with tetraplegia and 14% (n=24) of those with paraplegia worked neither before nor after their SCI.
- Approximately 50% of employed respondents in both groups reported working between 31 and 40 hours per week.

- Individuals with tetraplegia had higher earnings than those with paraplegia; 48% (n=41) in the former group earned less than $40,000 per year as compared to 67% (n=45) in the latter group.

- 47% (n=41) of those with tetraplegia reporting traveling more than 10 miles to get to work as compared to 51% (n=35) of those with paraplegia.

- Individuals with tetraplegia were slightly more likely to report receipt of health insurance benefits (64% vs. 57%), paid vacation (63% vs. 54%), and sick leave (55% vs. 43%) from their employer than their counterparts with paraplegia.

- Among both groups, health issues and retirement were the two most frequently cited reasons for not currently working.

SERVICES

Counseling and Support Groups

- 23% (n=111) of respondents reported interest in receiving SCI support group services.
- 13% (n=63) of respondents reported interest in receiving one-on-one, peer support services.
- Less than 10% (max n=42) of respondents were interested in the other counseling / support group activities.

Service / Activity	Would like to receive	Receive(d) but Not Satisfied	Receive(d) and Satisfied	Not interested in this
Counseling / Support Groups				
Mental health counseling (n=491)	8%	2%	7%	83%
Substance abuse counseling (n=484)	2%	<1%	2%	96%
Family support / counseling (n=481)	9%	1%	7%	83%
Support to address domestic violence issues (n=480)	2%	<1%	2%	97%
Spinal cord injury support group (n=489)	23%	1%	7%	70%
Peer support in one-on-one format (n=480)	13%	<1%	5%	82%

Pap Smears and Mammograms

- Among female respondents (max n=131), 54% (n=70) reported have had received a Pap smear with which they were satisfied, at some point in time. An additional 4% (n=5) reported having had received a Pap smear but not being satisfied with the service. The mean age of these women was 50 (S.D. = 15). Age ranged from 24 years to 89 years.

- 48% (n=63) reported having received a mammogram with which they were satisfied, at some point in time. An additional 3% (n=4) reported having received a mammogram but not being satisfied with the service. The mean age of these women was 55 (S.D. = 14). Age ranged from 28 years to 89 years.

  - When limiting the analyses to women 40 years and older (n=97), the commonly recommended age for first mammogram, 58% (n=56) reported having received a mammogram with which they were satisfied, at some point in time. An additional 3% (n=3) reported having received a mammogram but not being satisfied with the service. This is well below the 75% of women statewide who reported having had a mammogram within the past two years (BRFSS, 2002-2003). It is also below the Healthy People 2010 goal of 70% of women will have had a mammogram within the past two years.

  - Interestingly, 23% (n=22) of female respondents 40 years of age or older were not interested in receiving a mammogram.

Service / Activity	Would like to receive	Receive(d) but Not Satisfied	Receive(d) and Satisfied	Not interested in this
Cancer Screening				
Pap smear, all women (n=130)	16%	4%	54%	26%
Mammogram, all women (n=131)	18%	3%	48%	31%
Mammogram, women 40+ (n=97)	17%	3%	58%	23%

Prostate Cancer Screening

- Among male respondents (n=326), 26% (n=83) reported wanting the prostate cancer screening service and 49% (n=159) reported no interest in the service. Approximate one-quarter (n=84) reported having received the service, at some point in time.

- When limiting the analysis to male respondents 50 years of age or older (n=149), the commonly recommended age for first prostate cancer screen, 24% (n=36) reported an interest in receiving the service, 42% (n=62) reported receiving the service in the past, and 34% (n=51) reported no interest in receiving the service.

Service / Activity	Would like to receive	Receive(d) but Not Satisfied	Receive(d) and Satisfied	Not interested in this
Cancer Screening				
Prostate cancer screening, all men (n=326)	25%	-----	26%	49%
Prostate cancer screening, men 50+ (n=149)	24%	-----	42%	34%

Reproductive Health

- 18% (n=83) of respondents reported interest in receiving information about sexual functioning and 8% (n=37) reported interest receiving information about having children.
- Men were slightly more likely than women to express interest in receiving information about having children, 9% vs. 5%. Also, men were more likely to report interest in receiving information about sexual functioning, 20% vs. 13%.

Service / Activity	Would like to receive	Receive(d) but Not Satisfied	Receive(d) and Satisfied	Not interested in this
Reproductive Health (ALL)				
Information about sexual functioning (n=466)	17%	2%	11%	69%
Information about having children (n=444)	8%	<1%	8%	84%
Reproductive Health (MEN)				
Information about sexual functioning (n=329)	20%	2%	13%	66%
Information about having children (n=308)	9%	<1%	8%	83%
Reproductive Health (WOMEN)				
Information about sexual functioning (n=136)	13%	4%	7%	76%
Information about having children (n=116)	6%	1%	7%	86%

Dental Care

- Approximately one-third of respondents expressed interest in receiving preventive and restorative dental care. When limiting the analysis to those without dental insurance, the percent interested in these two services increases to 50%.

Service / Activity	Would like to receive	Receive(d) but Not Satisfied	Receive(d) and Satisfied	Not interested in this
Dental Care (ALL)				
Preventive dental care (cleanings, x-rays) (n=473)	34%	1%	36%	28%
Restorative dental care (fillings, crowns) (n=470)	34%	2%	29%	35%
Dental Care (NO DENTAL INSURANCE)				
Preventive dental care (cleanings, x-rays) (n=256)	53%	<1%	22%	25%
Restorative dental care (fillings, crowns) (n=254)	51%	1%	18%	31%

Vision Care

- 31% (n=146) of respondents were interested in receiving a vision exam and 29% (n=131) were interested in eyeglasses and contact lenses.

Service / Activity	Would like to receive	Receive(d) but Not Satisfied	Receive(d) and Satisfied	Not interested in this
Vision Care				
Vision exam (n=466)	31%	2%	37%	29%
Eyeglasses / contact lenses (n=457)	29%	2%	34%	36%

Education, Employment, and Finances

- In the area of education, employment, and finances, assistance with developing a new job skill, retirement planning, and assistance with finding a job were the three most frequently cited services of interest to respondents, 21%, 19%, and 18% respectively.

- English as a second language programs and GED programs were the least frequently cited services of interest, 3% and 6% respectively.

Service / Activity	Would like to receive	Receive(d) but Not Satisfied	Receive(d) and Satisfied	Not interested in this
Education, Employment, and Finances				
Assistance with developing a new job skill (n=466)	21%	<1%	2%	77%
Retirement planning (n=458)	19%	<1%	5%	76%
Assistance with finding a job (n=464)	18%	2%	2%	78%
Budgeting and money management (n=461)	15%	<1%	2%	83%
Enrollment in a two- or four-year college (n=458)	12%	<1%	8%	80%
Assistance with workplace modifications / making the workplace more accessible (n=456)	12%	1%	2%	86%
Assistance with keeping a job (n=454)	11%	<1%	1%	88%
GED program (n=468)	6%	-----	6%	87%
English as a second language program (n=462)	3%	-----	1%	96%

- Among those who indicated that they wanted help finding a job,

  - 26% (n=21) were employed already.
  - 74% (n=62) were male and 26% (n=22) were female.
  - 54% (n=46) were White and 46% (n=39) non-White.
  - 64% (n=53) had an incomplete injury and 36% (n=30) had a complete injury.
  - 29% (n=24) were non-wheelchair users and 70% (n=57) were wheelchair users.

- Among those who indicated that they wanted help learning a new job skill,

  - 30% (n=28) were employed.
  - 70% (n=67) were male and 30% (n=28) were female.
  - 54% (n=52) were White and 46% (n=44) non-White.
  - 73% (n=67) had an incomplete injury and 27% (n=25) had a complete injury.
  - 36% (n=33) were non-wheelchair users and 64% (n=59) were wheelchair users.

- Those wanting help finding a job or developing a new skill were approximately 10 years younger, on average, than those not wanting or needing these services.

Equipment and Supplies

- Among the 277 respondents using wheelchairs, 28% (n=77) reported an interest in receiving wheelchair maintenance services. Nearly one-third reported receiving these services already and being satisfied with them.

Service / Activity	Would like to receive	Receive(d) but Not Satisfied	Receive(d) and Satisfied	Not interested in this
Equipment and Supplies				
Wheelchair maintenance, among w/c users (n=277)	28%	7%	31%	35%
New, updated equipment (n=476)	27%	1%	17%	56%
Medical supplies (n=473)	18%	2%	26%	54%

- Among wheelchair users who indicated that they would like to receive w/c maintenance services,

  - 15% (n=11) were employed.
  - 70% (n=53) were male and 30% (n=23) were female.
  - 64% (n=49) were White and 36% (n=28) non-White.
  - 56% (n=41) had an incomplete injury and 44% (n=32) had a complete injury.
  - 29% (n=24) were non-wheelchair users and 70% (n=57) were wheelchair users.

- Among those who indicated that they would like new, updated equipment,

  - 21% (n=25) were employed.
  - 70% (n=87) were male and 30% (n=38) were female.
  - 58% (n=73) were White and 42% (n=53) non-White.
  - 65% (n=77) had an incomplete injury and 35% (n=42) had a complete injury.
  - 9% (n=10) were non-wheelchair users and 92% (n=108) were wheelchair users.

Other Services

- Respondents were most interested in participating in fitness center / gym activities (33%, n=154), obtaining assistive technology (21%, n=92), and weight loss programs (20%, n=91).

- Child care was the least frequently cited service of interest (3%, n=12) followed by smoking cessation programs (11%, n=48).

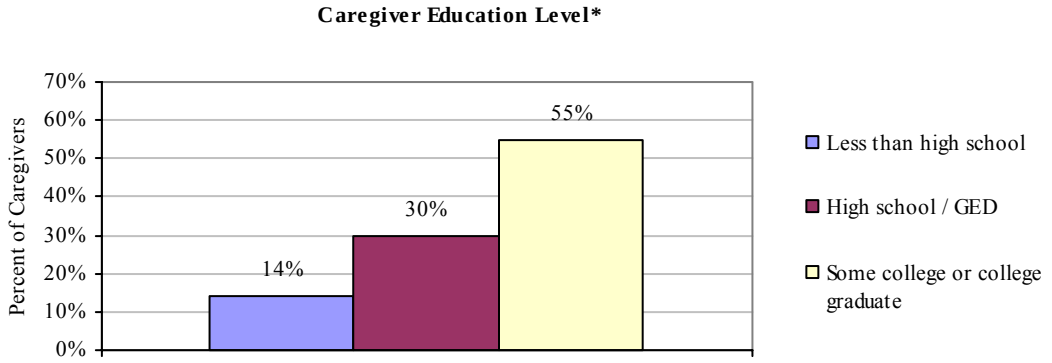
Service / Activity	Would like to receive	Receive(d) but Not Satisfied	Receive(d) and Satisfied	Not interested in this
Other				
Fitness center / gym (n=466)	33%	1%	7%	59%
Obtaining assistive technology (n=448)	21%	1%	6%	72%
Program to lose weight (n=454)	20%	<1%	1%	78%
Using assistive technology (n=444)	19%	1%	7%	73%
Help finding accessible, affordable housing (n=443)	18%	<1%	3%	79%
Social activities (n=445)	17%	<1%	5%	78%
Transportation (n=444)	14%	2%	8%	76%
Program to quit smoking (n=442)	11%	1%	1%	88%
Child care (n=440)	3%	<1%	1%	96%

FAMILY/CAREGIVER SURVEYS SURVEY RESULTS[9]

CAREGIVER CHARACTERISTICS

Education Level

- 14% of caregivers (n=43) did not complete high school.
- 30% of caregivers (n=91) had a high school diploma or GED.
- 55% of caregivers (n=166) had some college education or a college degree.



*Based on a valid 'n' of 300.

Age

- The average age of caregivers was 52.4 years with a median of 53.0. Age ranged from a low of 21 years to a high of 85 years with a standard deviation of 13.5 years.

Employment

- Approximately one-half of respondents reported working at least 30 hours per week (53%, n=156). The remaining 48% (n=141) did not work at least 30 hours per week.

Race

- 78% of caregivers were white and 19% were black.

Race	***Frequency (n=301)***	***Percent***
White	235	78%
Black or African-American	56	19%
Asian	5	2%
American Indian or Alaskan Native	2	1%
Other	3	1%

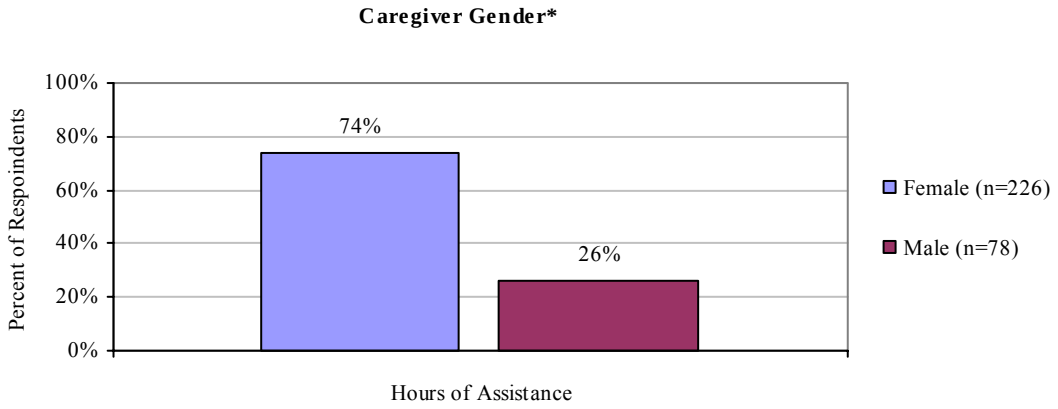
[9] Analyses in this section were done using a combined consumer-caregiver data file. Therefore, counts and percents for individuals with SCI, in this section, will vary, to some degree, from results in the prior section.

Hispanic or Latino

- Only 1% (n=3) of caregivers reported being Hispanic or Latino/a.

Gender

- Approximately three-quarter of the caregivers were female.



*Based on a valid 'n' of 304.

- Male and female caregivers were similar in age. Men, on average, were 54 years old (S.D.=15 years) and women, on average, were 52 years old (S.D.=13 years) (|t|= .801, p=.425).

Caregiver Relationship

- Caregivers were asked to state their relationship to the individual with the spinal cord injury. Among 302 respondents, nearly 62% (n=182) were either a spouse or partner. Fourteen percent (n=41) were parents.

Relationship	***Number (n=302)***	***Percent***
Spouse or partner	187	62%
Mother or father	41	14%
Child (18 years of age or older)	28	9%
Other	11	4%
Non-related caregiver	16	5%
Sister or brother	13	4%
Friend	6	2%

ASSISTANCE PROVIDED BY CAREGIVERS

Assistance Provided

- Approximately 45% of respondents (n=136) reported providing assistance with 1 to 3 activities, one-third (n=106) reported providing assistance with 4 to 6 activities, and 20% (n=59) reported providing assistance with 7 to 10 activities.

- Respondents were asked to indicate what type of assistance they provide for the individual with the SCI.

Type of Assistance	***Number*** ***(max n=309)***	***Percent***
Love / friendship	267	86%
Emotional support	249	81%
Assistance with personal care	164	53%
Assistance with transportation	151	49%
Financial Assistance	113	37%
Assistance with insurance companies	105	34%
Assistance negotiating the health care system	95	31%
Advocacy	57	18%
Assistance with lawyers	31	10%
Other	24	8%

Note: Respondents could check more than one type of assistance. Counts within assistance type are unduplicated. Counts across categories are duplicated, to some degree.

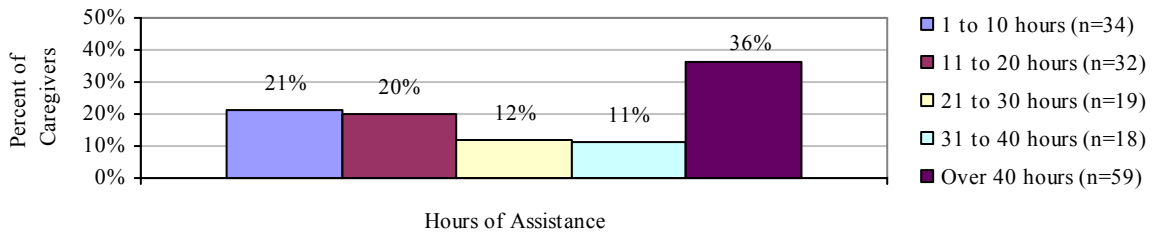
- There was no significant difference in the number of activities with which assistance was provided between caregivers of individuals with tetraplegia and paraplegia, 4.3 vs. 4.1 respectively ($|t|=.735$, $p=.463$).

Assistance with Personal Care and Caregiver Employment

- The 164 respondents providing personal care were asked how many hours per week they spend doing so and if their provision of this care limited their employment.

- The majority of respondents, 36% (n=59) reported providing more than 40 hours of personal care per week and 21% (n=34) reported providing between 1 and 10 hours of personal care per week.

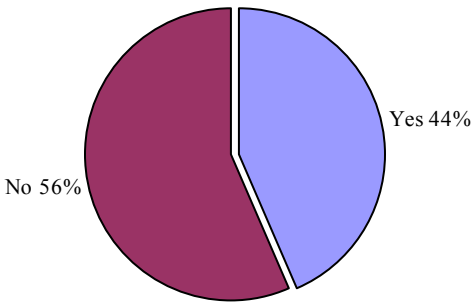
Hours Per Week Providing Personal Care*



*Based on valid 'n' of 162.

- Of the 164 respondents providing personal assistance, 138 answered the follow-up question about the impact of providing these services on employment. Forty-four percent (n=60) reported that their employment was limited because of the time spent providing personal care.
  - When comparing caregivers employed 30 or more hours per week to those not employed 30 or more hours per week, the extent of assistance was not significantly different, 4 types of assistance vs. 4.2 types of assistance respectively (|t|=.796, p=.427).

Employment Limited due to Provision of Personal Care



Pay for Services

- Among those providing at least one type of assistance, 7% received pay for their services (n=21). Of these,
  - 62% (n=13) were non-related caregivers and 38% (n=8) were relatives (by marriage or blood).
  - 91% (n=19) reported providing help with personal care, 57% (n=12) provided love and friendship, and 48% (n=10) provided help with transportation.
  - 19% (n=4) reported providing help with negotiating the health care system or advocacy.

Pay for Services (con't)

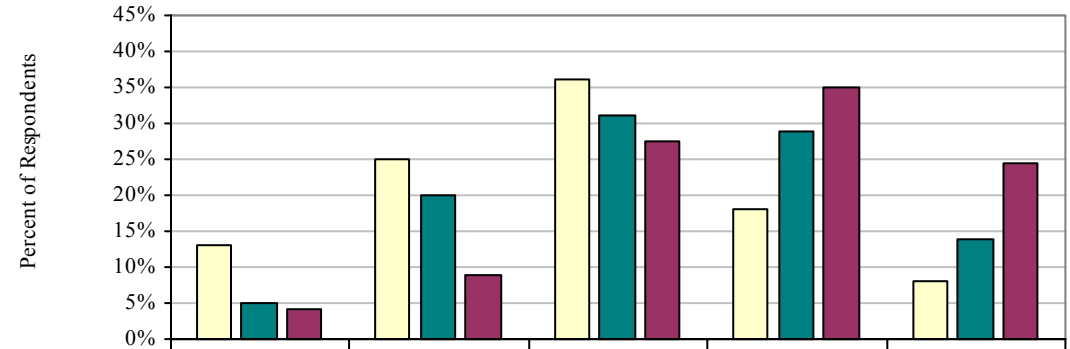
- The remainder of the respondents, 93% (n=267), did not receive pay for their services. Of these,
  - 67% (n=178) were the spouse or partner of the individual with the SCI.
  - 94% (n=250) were related to the individual with the SCI by blood or marriage.
  - 91% (n=244) provided love or friendship and 87% (n=231) provided emotional support.
  - 51% (n=137) provided help with personal care and transportation.
  - 20% (n=53) provided advocacy support.

CAREGIVER HEALTH

General Health

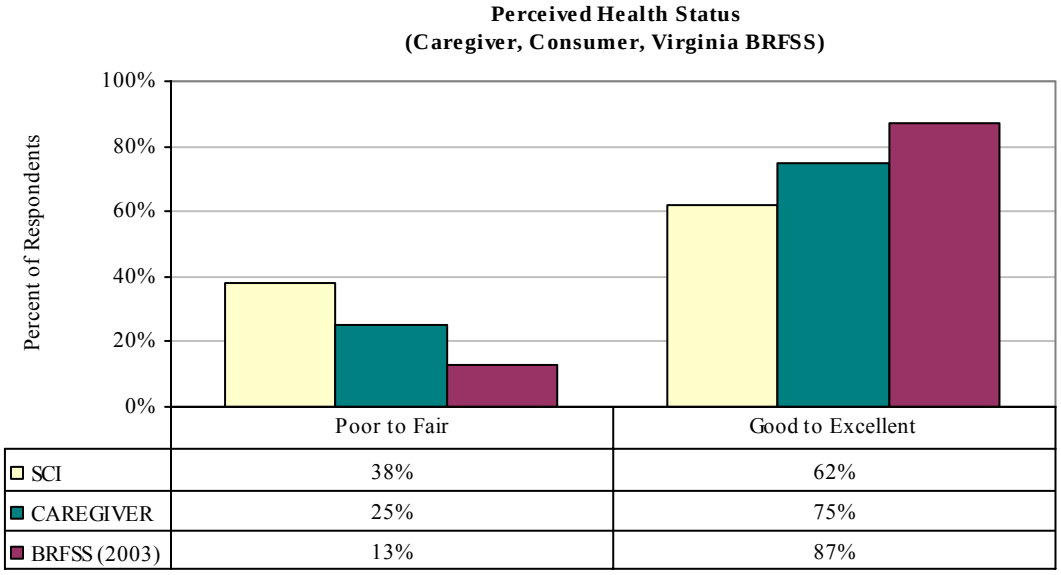
- Respondents were asked to rate their general health as poor, fair, good, very good, or excellent. In general caregivers were likely to report better health that those for whom they reported providing care. However, both the individual with the SCI and his/her caregiver lagged behind the general Virginia population with regard to perceived health.

Perceived Health Status
(Caregiver, Consumer, BRFSS)



	Poor	Fair	Good	Very Good	Excellent
SCI	13%	25%	36%	18%	8%
CAREGIVER	5%	20%	31%	29%	14%
BRFSS (2003)	4%	9%	28%	35%	24%

General Health (con't)



- There was a direct association between the caregiver's health rating and the consumer's health rating (PCC=.399, p<.001). That is, the lower the rating by the consumer the lower the rating by the caregiver and vice versa.

- As compared to caregivers reporting good to excellent health, caregivers with poor to fair health were more likely to be providing assistance to individuals with SCI who perceived their health as poor to fair (X^2=30.35, p<.001).

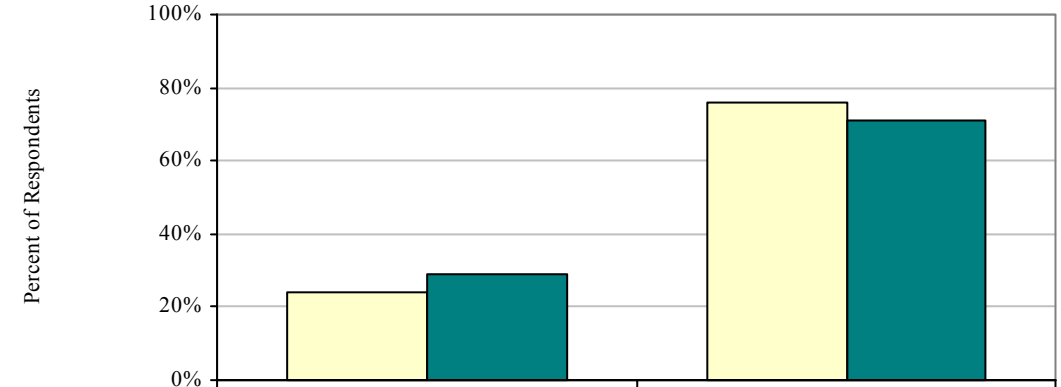
- Consumers with caregivers reporting poor to fair health had a greater number of total medical problems than consumers of caregivers that reported good to excellent health. The difference approached statistical significance (|t|=1.75, p=.082).

Caregiver's Perceived Health	***n***	***Mean number of medical problems (consumer)***	***S.D***
Poor to Fair	75	3.4	2.4
Good to Excellent	225	2.9	2.3

General Health (con't)

- The caregiver's perceived health was examined with regard to race and gender. White and non-White caregivers and male and female caregivers were similar in terms of perceived health. The following two tables illustrate these findings.

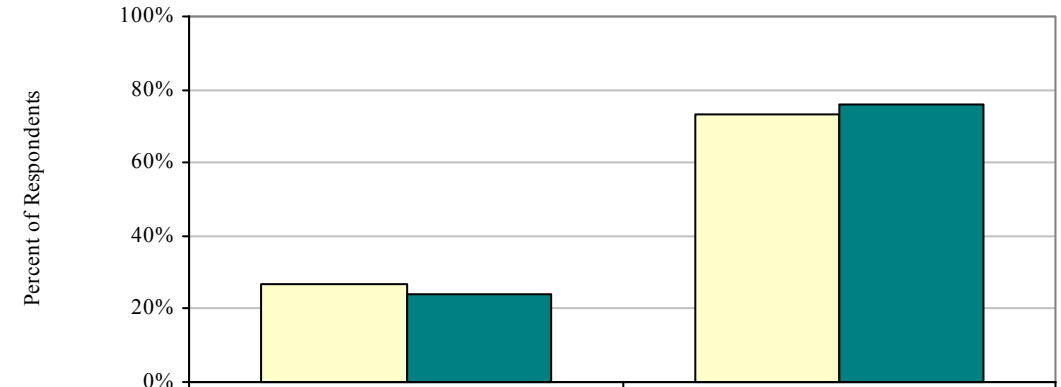
Caregiver's Perceived Health Status by Race



	Poor to Fair	Good to Excellent
White (n=231)	24%	76%
Non-White (n=69)	29%	71%

X^2=.759, p=.236

Caregiver's Perceived Health Status by Gender



	Poor to Fair	Good to Excellent
Male (n=78)	27%	73%
Female (n=221)	24%	76%

X^2=.268, p=.648

- Caregivers reporting poor to fair health were significantly older than those reporting good to excellent health, 58.5 years vs. 50.1 years respectively, on average ((|t|=4.78, p<.001).

SOURCES OF CAREGIVER SUPPORT

Sources of Emotional Support for Caregivers

- Most caregivers, 64% (n=197), reported having one or two primary sources of emotional support.

Source of Emotional Support	***Number (n=309)***	***Percent***
Family Members	241	78%
Friends	175	57%
Church	116	38%
Health care providers	37	12%
Other	30	10%
Other individuals or families with SCI	14	5%
Other community organizations	11	4%

- Only 4% (n=12) of caregivers reported no source of emotional support.

  Nine of these 12 provided assistance with two or more activities, as outlined in prior sections of this report.
  None of the 12 caregivers wanted to receive family support or counseling or peer support in a one-on-one format.
  Only one on the 12 caregivers expressed interest in support group activities for families and caregivers.

Sources of Support for Daily Activities

- Most caregivers, 75% (n=232), reported having one or two primary sources of support for daily activities.

Source of Emotional Support	***Number (n=309)***	***Percent***
Family Members	206	67%
Friends	129	42%
Church	54	18%
Health care providers	37	12%
Other	37	12%
Other community organizations	6	2%
Other individuals or families with SCI	5	2%

- 10% (n=31) of caregivers reported no source of support for daily activities. Of these 31 caregivers, 90% provided support with one or more activities.

SERVICES

Services Wanted

- Nearly 70% of the 309 respondents (n=209) did not want any of the services listed. Ten percent (n=30) wanted 1 service and 23% (n=70) wanted 2 or more services.

Service / Activity	Would like to receive	Receive(d) but not satisfied	Receive(d) and satisfied	Not interested / not applicable
Counseling / Support Groups				
Mental health counseling (n=269)	8%	2%	6%	85%
Substance abuse counseling (n=264)	3%	-----	2%	95%
Family support / counseling (n=269)	10%	1%	9%	81%
Support to address domestic violence issues (n=263)	2%	-----	<1%	98%
Support group for families / caregivers (n=270)	18%	<1%	5%	77%
Peer support in one-on-one format (n=266)	11%	-----	2%	88%
Other				
Child care outside of the home (n=253)	1%	-----	-----	99%
Child care inside of the home (n=254)	1%	-----	1%	98%
Social activities (n=256)	9%	1%	6%	84%
Financial assistance (n=263)	22%	2%	3%	73%
Care for the Individual with the SCI				
Help with bathing and dressing (n=262)	8%	2%	15%	75%
Help with eating / meal prep (n=261)	7%	2%	12%	79%
Someone to help with transfers in/out of bed (n=261)	8%	2%	13%	77%
Help with bowel / bladder program (n=263)	10%	2%	12%	76%
Help with giving medications (n=260)	4%	1%	10%	85%