WellFlorida Council

Working Together for Healthy Communities

Spinal Cord Injury in Florida

A Needs and Resources Assessment

January 2010

THIS PAGE WAS INTENTIONALLY LEFT BLANK

WellFlorida Council

Working Together for Healthy Communities

Spinal Cord Injury in Florida

A Needs and Resources Assessment

January 2010

WellFlorida Council Contributing Staff

Shane Bailey
Senior Planner

Sandra Carroll
Data and Technology Coordinator

Jill Dygert
Design and Communications

Jeff Feller
Chief Operations Officer

Lindsey Michaels
Associate Planner

Celia Paynter
Associate Planner

FAAST Spinal Cord Injury Resource Center
Advisory Group

Bob Melia

Dr. Mario Olavarria

Barb Page

Susan Redmon

Kris Shields

WellFlorida Council

1785 NW 80th Blvd.

Gainesville, FL 32606

Tel: (352) 313-6500

Fax: (352) 313-6515

Web: www.wellflorida.org

THIS PAGE WAS INTENTIONALLY LEFT BLANK

Table of Contents

THIS PAGE WAS INTENTIONALLY LEFT BLANK

Executive Summary

The Florida Department of Health, Brain and Spinal Cord Injury Program (BSCIP), the Florida Alliance for Assistive Services and Technology (FAAST), and the FAAST Spinal Cord Injury Resource Center (FSCIRC) have come together to conduct Florida's first comprehensive needs and resources assessment of individuals with Spinal Cord Injury (SCI). The goal of this assessment, conducted under the guidance of the FSCIRC Advisory Group, is to identify and understand the most critical the needs of individuals living with SCI.

Assessment activities included:

- Demographic and socioeconomic data analysis
- Analysis of SCI-related data indicators
- SCI community input (i.e., focus groups, one-on-one interviews, and an online survey).

Please note the Technical Appendix is available electronically for this assessment that includes the detailed data tables for all the indicators presented in this report as well as research protocols and methodologies.

Summary of Findings

Demographic and Socioeconomic Profile

Demographic and socioeconomic characteristics of a region are associated with healthcare access and health outcomes. Key indicators that may be associated with SCI in Florida and its BSCIP Regions include:

- The population of the state of Florida is projected to increase through the year 2030.
- Florida's population tends to be "older" than the population of the country as a whole. Additionally, nearly 25 percent of Florida's population is between the ages of 15 and 34 years, which represents the most frequently injured age group by the National Spinal Cord Injury Statistics Center(NSCISC).
- Differences in the racial and ethnic makeup across BSCIP Regions may be contributing to differences observed in SCI-related indicators.

Spinal Cord Injury Profile

The prevalence and incidence of SCI in the state of Florida is fairly unreliable based on the lack of recent studies and consistency of research methodologies. Therefore, SCI-related indicators are used as proxy measures to provide insights into the SCI population in the state.

The national incidence of SCI is 40 cases per million of the population. Based on Florida's population, approximately 761 SCIs occurred in Florida during 2009 (Table 1). As the population of Florida increases through 2030, it is anticipated that the incidence of SCI will increase as well.

Table 1: Estimated Number of New SCI in Florida, 2009, 2015, 2030.

Year	Total Population	New SCI
2009	19,021,613	761
2015	20,055,865	802
2030	23,979,032	959

Source: National Spinal Cord Injury Statistical Center. Spinal Cord Injury Facts and Figures at a Glance, April 2009; ESRI, 2009.

Over 800 SCI-related hospitalizations occur in Florida per year (Table 2). Floridians between the ages of 45 and 64 years and 15-34 years accounted for over half of all SCI-related hospitalizations and males were nearly three times more likely to be hospitalized for SCI than females. Falls and motor vehicle accidents were the leading cause of SCI-related hospitalizations.

Table 2: Average Annual SCI-Related Hospitalization Characteristics, 2006-2008.

Characteristics	Number	Percent	Rate
Total Hospitalizations	807	100.0	4.1
Age Group*			
0-14 years	21	2.4	0.6
15-24 years	134	16.6	5.6
25-34 years	89	11.0	3.9
35-44 years	115	14.3	4.5
45-64 years	229	28.4	4.8
65 years +	219	27.1	6.8
Race			
White	623	77.2	3.8
Black	139	17.2	4.7
Other	38	4.7	8.3
Ethnicity			
Hispanic	84	10.4	2.2
Gender			
Male	583	72.2	6.2
Female	224	27.8	2.1
Cause			
Assaults	46	5.7	0.3
Falls	309	38.3	1.4
Motor Vehicle Accidents	271	33.6	1.5
Other Accidents	121	15.0	0.6
Other	37	4.6	0.2
Unknown	22	2.7	0.1

Rates are age adjusted to the standard US population per 100,000 of the population;* age-group rates represent crude rates.
Sources: AHCA Detailed Hospital Discharge Data 2006-2008; Florida Charts 2006-2008.

Florida's Central Registry (CR), which collects information on individuals who experience moderate to severe brain and SCI, reported 2,730 new injury referrals, approximately 683 per year, from calendar year 2005 through 2008. Florida's Trauma Registry, which collects patient level data from the state's verified trauma centers, reported more than 1,800 discharges for patients with SCI identified as their primary diagnosis from 2006 through 2008. For both state registries, motor vehicle accidents were identified as the cause for largest percentage of SCIs.

The Florida Department of Health, BSCIP serves individuals with SCI. From 2005 through 2008, the Trust Fund Program served nearly 2,000 individuals with SCI and the Home and Community-Based Waiver provided services to over 250 individuals with SCI.

Spinal Cord Injury Community Input

Members of the SCI community were asked to provide insights into their current service and support needs through participating in focus groups, online surveys, and one-on-one interviews. 215 members of the SCI community participated.

The SCI community identified the following as the biggest issues for SCI in the state of Florida (order does not indicate ranking):

- Access to services that promote independence (e.g., personal care and transportation)
- Financial burden
- Lack of qualified, knowledgeable SCI providers
- Decreased access to appropriate rehabilitation services
- Access to information and education
- Lack of opportunities to promote healthy living
- Lack of transition support services (e.g. transitional living facilities)

The SCI community identified the following as the most needed services or supports for SCI in Florida (order does not indicate ranking):

- Rehabilitation
- Personal care assistance
- Accessible, affordable housing
- Transportation
- Employment or vocational services
- Family/caregiver support services
- Peer support

The FSCIRC Advisory Group identified key areas for additional investigation. These areas included the identification and understanding of key issues that impact employment post injury and the identification and understanding of health-related issues as a result of SCI. Members of the SCI community shared the following:

Issues Impacting Employment:

- Personal factors (e.g., motivation, fear, and health issues)
- Impact on benefits and health insurance status
- Need to obtain vocational retraining or additional education
- Workplace accessibility

Understanding Health-Related Issues as a Result of SCI:

- Leading health issues: urinary tract infections, pressure sores, chronic pain, muscle spasms, autonomic dysreflexia, and bowel and bladder issues
- Healthcare providers are not knowledgeable about SCI and related issues
- Inaccessibility of healthcare facilities is a critical issue impacting access to needed healthcare services for SCI survivors

Next Steps

Under the guidance of the FSCIRC Advisory Group, findings from *Spinal Cord Injury in Florida: A Needs and Resources Assessment,* will be used as a critical piece when developing Florida's first five-year strategic plan for SCI. The strategic plan will identify key strategic issues, develop goals and objectives, and determine action steps for achieving the outlined goals and objectives. It is anticipated that the strategic plan will be completed by June 2010.

THIS PAGE WAS INTENTIONALLY LEFT BLANK

Introduction

By Florida Statute, a spinal cord injury (SCI) is defined as a lesion to the spinal cord or cauda equina resulting from external trauma with evidence of significant involvement of two of the following: motor deficit, sensory deficit, or bowel and bladder dysfunction.[1] Though every SCI is unique in regards to the level of impairment, the impact on Florida's residents, families, and healthcare system cannot be underestimated.

Previous studies have estimated approximately 259,000 people to be living with SCI in 2008, with an estimated 12,000 new SCIs occurring annually in the United States.[2] A recent self-report study funded by the Christopher and Dana Reeves Foundation in April 2009 estimated that 1.3 million people reported SCI to be the cause of their paralysis.[3]

Though the number of new injuries and those living with SCI may be small in comparison to other public health issues, the needs of persons with SCI and their families along with the financial burden are great.

Project Description

In attempts to identify and understand the needs of individuals living with SCI in the state of Florida, the Florida Department of Health Brain and Spinal Cord Injury Program (BSCIP), the Florida Alliance for Assistive Services and Technology (FAAST), and the FAAST Spinal Cord Injury Resource Center (FSCIRC) have come together to conduct Florida's first comprehensive needs and resources assessment of individuals with SCI. This assessment will be a critical piece in the development of Florida's first strategic plan for SCI.

WellFlorida Council (formerly the North Central Florida Health Planning Council), contracted by FAAST, was tasked with the development and implementation of the comprehensive needs and resources assessment for individuals with SCI in Florida under the guidance of the FSCIRC Advisory Group.

The findings from *Spinal Cord Injury in Florida: A Needs and Resources Assessment,* summarize the needs of individuals with SCI throughout Florida. The assessment includes the following sections:

- Introduction
- Demographic and Socioeconomic Profile
- Spinal Cord Injury Profile
- Spinal Cord Injury Community Input
- Conclusion

Please note that there is a Technical Appendix for this assessment which is available electronically that includes all of the detailed data tables for all the indicators presented in this report as well as research protocols and methodologies.

---

[1] Florida Statute. Title XXIX, Public Health Chapter 381 Public Health: General Provisions; 2006.
[2] National Spinal Cord Injury Statistical Center. Spinal Cord Injury Facts and Figures at a Glance. April 2009.
[3] Cahill, A., et al. National Prevalence Survey of Paralysis and Spinal Cord Injury in the United States, 2008. http://cdd.unm.edu/dhpd/prevalsurvey.asp.

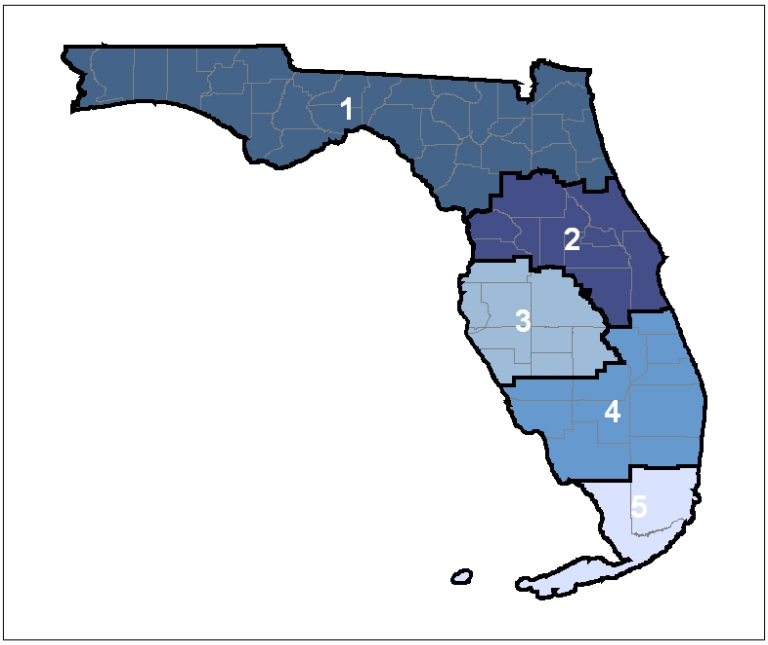
THIS PAGE WAS INTENTIONALLY LEFT BLANK

Demographic and Socioeconomic Profile

Age, race and gender are all factors that contribute to, or at the very least, help describe aspects of healthcare access and health outcome in the United States. Additionally, age, race and gender are linked to increased risk of SCI. The National SCI Statistical Center (NSCISC), which collects data from an estimated 13 percent of new SCI cases nationally through the Model SCI Care Systems, reports that most injuries occur to individuals between the ages of 16 and 30, but also reports that as the median age of the general population has increased over time, so has the average age at injury. NSCISC also reports an increase in the percentage of racial and ethnic minorities sustaining SCIs since 2005 due to trends in the general population as well as relocation of model system facilities.

Reviewing Florida's population by demographic (Table 1) and socioeconomic characteristics (Table 2) allows for factoring into health needs analyses the differences and disparities that exist between population groups or geographies and more importantly how these differences may impact the SCI population in Florida and the five BSCIP Regions (Figure 1).

Figure 1: Florida Department of Health, BSCIP Service Regions.



Region 1:
Alachua, Baker, Bay, Bradford, Calhoun, Clay, Columbia, Dixie, Duval, Escambia, Flagler, Franklin, Gadsden, Gilchrist, Gulf, Hamilton, Holmes, Jackson, Jefferson, Lafayette, Leon, Levy, Liberty, Madison, Nassau, Okaloosa, Putnam, Santa Rosa, St. Johns, Suwannee, Taylor, Union, Wakulla, Walton, Washington

Region 2:
Brevard, Citrus, Hernando, Lake, Marion, Orange, Osceola, Seminole, Sumter, Volusia

Region 3:
Desoto, Hardee, Highlands, Hillsborough, Manatee, Pasco, Pinellas, Polk, Sarasota

Region 4:
Broward, Charlotte, Collier, Glades, Hendry, Indian River, Lee, Martin, Okeechobee, Palm Beach, St. Lucie

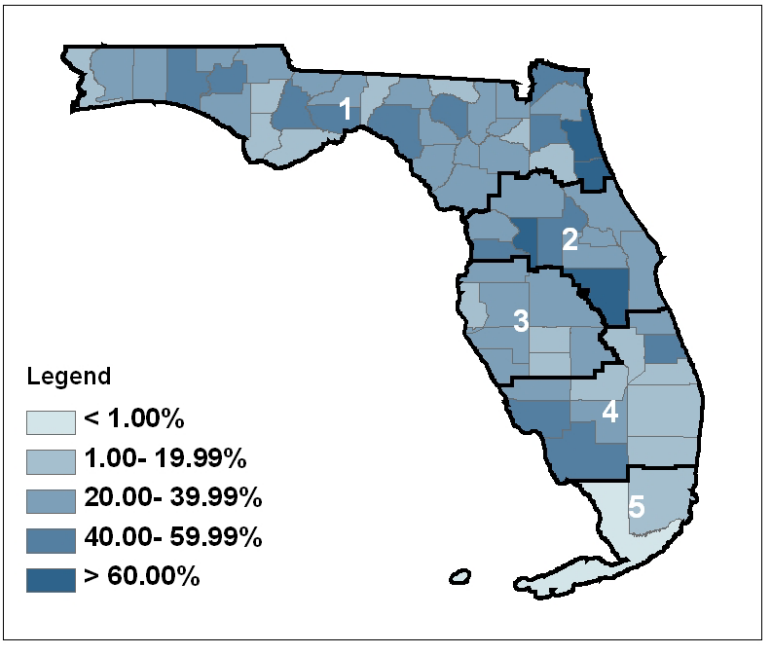
Region 5:
Miami-Dade, Monroe

Source: Florida Department of Health, Brain and Spinal Cord Injury Program.

Demographic Characteristics

Florida's current population is just over 19 million, with the largest percentage of the population located in BSCIP Region 4 (25.7 percent). The population of Florida is projected to increase to nearly 24 million people by 2030, with the largest increase projected in BSCIP Region 2 (38.1 percent) (Figure 2).

Figure 2: Total Population Percentage Change, 2009 to 2030.

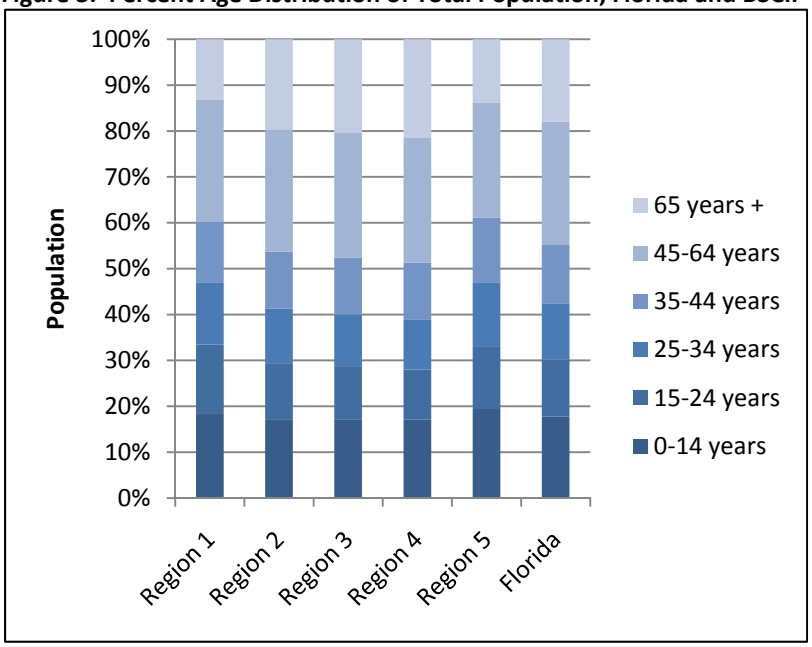


Source: ESRI, 2009; University of Florida, Bureau of Economic and Business Research, Florida Population Studies, Population Projections by Age, Sex, Race and Hispanic Origin for Florida and Its Counties, 2008-2030.

The population of the state of Florida tends to be "older" than the population of the country as a whole. Based on the identified age groups, individuals 45-65 years of age represent the largest proportion (26.8 percent) of the population. Nearly 25 percent of Florida's population is currently between the ages of 15 and 34 years, which represents the most frequently injured age group according to the NSCISC.

Differences exist among the age distribution of the population for Florida's BSCIP Regions (Figure 3). These differences may impact the frequency of SCIs and the desired need for services. BSCIP Regions 1 and 5 contain the largest percentage of individuals between the age of 15 and 34, while BSCIP Region 4 has the largest percentage of individuals over the age of 45.

Figure 3: Percent Age Distribution of Total Population, Florida and BSCIP Regions, 2009.



Source: ESRI, 2009.

As stated above, changes in the racial and ethnic makeup in the United States may be a contributing factor to the increase in the percentage of racial and ethnic minorities that sustain SCIs. Currently, Florida's population is 74.7 percent white and 15.8 percent black. Additionally, 21.5 percent of Florida's population is identified as being of Hispanic ethnicity.

Racial and ethnic differences across BSCIP Regions include:

- BSCIP Regions 1 and 5 have the largest percentage of racial minorities (29.1 percent and 28.9 percent, respectively).
- Nearly 65 percent of the BSCIP Region 5 population identifies themselves as being of Hispanic ethnicity, compared to less than 20 percent in each of the other BSCIP Regions.

As reported by the NSCISC, males are over 4 times more likely to sustain a SCI than females. In Florida, 51.2 percent of residents are female and 48.8 percent are male. Like the state, each BSCIP region has a slightly higher percentage of females than males.

Table 1: Selected Demographic Characteristics, Florida and BSCIP Regions.

Characteristics	BSCIP Region 1		BSCIP Region 2		BSCIP Region 3	
	Number	Percent	Number	Percent	Number	Percent
Total Population	3,510,267	18.5	3,969,166	20.9	4,108,518	21.6
Population Projections						
2015	3,794,467	18.9	4,262,191	21.3	4,269,514	21.3
2020	4,075,207	19.0	4,652,256	21.7	4,538,858	21.2
2030	4,608,294	19.2	5,385,748	22.5	5,045,629	21.0
Age Group						
0-14 years	649,918	18.5	686,561	17.3	705,987	17.2
15-24 years	525,268	15.0	491,379	12.4	474,798	11.6
25-34 years	471,387	13.4	484,531	12.2	461,542	11.2
35-44 years	465,588	13.3	500,984	12.6	511,498	12.4
45-64 years	937,905	26.7	1,075,267	27.1	1,121,542	27.3
65 years +	460,201	13.1	730,444	18.4	833,151	20.3
Race						
White	2,485,971	70.8	3,031,968	76.4	3,245,475	79.0
Black	777,021	22.1	513,437	12.9	480,521	11.7
Other	247,275	7.0	423,761	10.7	382,522	9.3
Ethnicity						
Hispanic	197,497	5.6	659,634	16.6	626,436	15.2
Non-Hispanic	3,312,770	94.4	3,309,532	83.4	3,482,082	84.8
Gender						
Male	1,739,277	49.5	1,941,985	48.9	1,993,608	48.5
Female	1,770,990	50.5	2,027,181	51.1	2,114,910	51.5

Characteristics	BSCIP Region 4		BSCIP Region 5		Florida	
	Number	Percent	Number	Percent	Number	Percent
Total Population	4,892,405	25.7	2,541,257	13.4	19,021,613	100.0
Population Projections						
2015	5,094,918	25.4	2,634,775	13.1	20,055,865	100.0
2020	5,424,838	25.3	2,726,291	12.7	21,417,450	100.0
2030	6,043,301	25.2	2,896,060	12.1	23,979,032	100.0
Age Group						
0-14 years	835,804	17.1	493,195	19.4	3,371,465	17.7
15-24 years	535,314	10.9	344,168	13.5	2,370,927	12.5
25-34 years	529,584	10.8	357,810	14.1	2,304,854	12.1
35-44 years	610,558	12.5	356,998	14.0	2,445,626	12.9
45-64 years	1,329,201	27.2	639,299	25.2	5,103,214	26.8
65 years +	1,051,944	21.5	349,787	13.8	3,425,527	18.0
Race						
White	3,634,293	74.3	1,807,686	71.1	14,205,393	74.7
Black	768,075	15.7	456,875	18.0	2,995,929	15.8
Other	490,037	10.0	276,696	10.9	1,820,291	9.6
Ethnicity						
Hispanic	957,009	19.6	1,645,374	64.7	4,085,950	21.5
Non-Hispanic	3,935,396	80.4	895,883	35.3	14,935,663	78.5
Gender						
Male	2,371,464	48.5	1,235,562	48.6	9,281,896	48.8
Female	2,520,941	51.5	1,305,695	51.4	9,739,717	51.2

Sources: Total Population, Age Group, Race, Ethnicity, and Gender: ESRI, 2009; Population Projections: University of Florida, Bureau of Economic and Business Research, Florida Population Studies, Population Projections by Age, Sex, Race and Hispanic Origin for Florida and Its Counties, 2008-2030.

Socioeconomic Characteristics

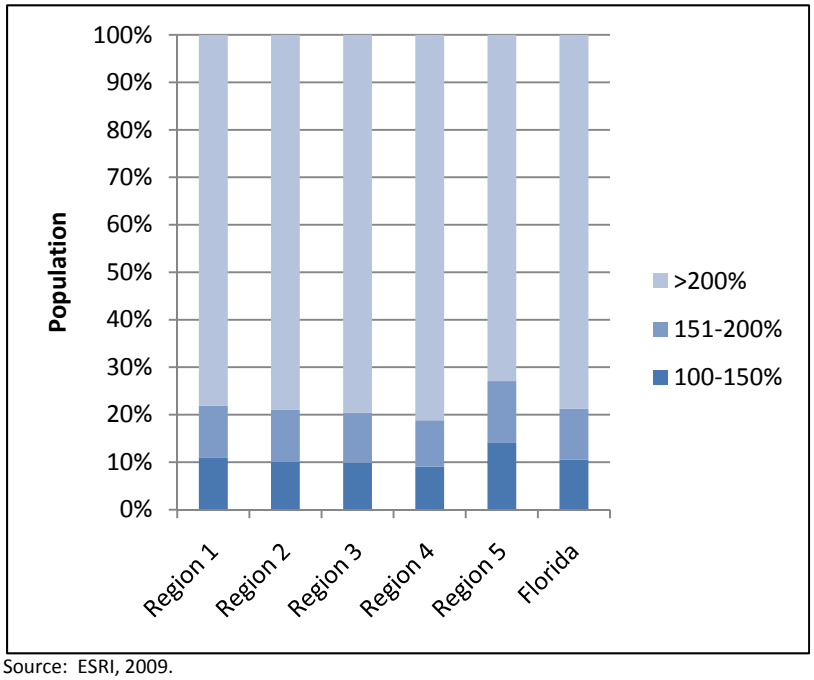
Lower poverty and better employment have all been shown to impact favorably health access and health outcomes. Conversely, higher poverty and poorer employment are definite predictors of a lack of access to healthcare and adverse health outcomes. Table 2 outlines select socioeconomic indicators for Florida and each of the five BSCIP Regions.

Per capita income is the total income for a given population divided by the number of people within the population. Florida's income is $27,128 per capita. BSCIP Regions 3 and 4 have per capita income levels higher than the state. BSCIP Region 5 has the lowest income per capita ($23,300).

Median household income is the amount that divides the income distribution into two equal groups, half of the population having an income above that amount and half of the population having an income below that amount. The median household income in Florida is $46,736.

Approximately 12.5 percent of Florida's population is estimated to be living in poverty (i.e., 100 percent of the federal poverty level) and 18.7 percent of residents are estimated to be between 100 percent and 200 percent of the federal poverty level (Figure 4). BSCIP Region 5 has the greatest percentage of residents at or below 200 percent of the federal poverty level and BSCIP Region 4 has the lowest.

Figure 4: Percent of Total Persons Living in Poverty, Florida and BSCIP Regions, 2009.



Source: ESRI, 2009.

Being employed with health benefits or being the spouse or dependent of someone whose employer provides health insurance is still the most common way to obtain private health insurance in the United States. Current unemployment rates in Florida, from the Florida Research and Economic Database, are 6.2 percent of the number of people in the labor force, with the greatest percentage in BSCIP Regions 3 and 4 (6.6 percent and 6.5 percent, respectively). Along those same lines, it is estimated that 24.9 percent of Floridians are uninsured, with the largest percentage residing in BSCIP Region 5 (30.9 percent).

Those with higher educational levels generally utilize healthcare systems somewhat more effectively and efficiently than their counterparts without higher levels of educational attainment, suggesting that educational level is related to health outcomes.

- Approximately 20 percent of Florida residents (age 25 and over) have no high school diploma, while 29.4 percent have earned a college degree.
- BSCIP Region 5 has the greatest percentage (31.5 percent) of residents without a high school diploma.

Table 2: Selected Socioeconomic Characteristics, Florida and BSCIP Regions.

Characteristics	BSCIP Region 1		BSCIP Region 2		BSCIP Region 3	
	Number	Percent	Number	Percent	Number	Percent
Uninsured	660,504	21.7	738,646	22.8	740,128	22.6
Poverty Estimates						
<100%	489,583	13.9	432,463	10.9	465,971	11.3
100-150%	332,045	9.5	355,881	9.0	358,660	8.7
151-200%	327,691	9.3	390,235	9.8	385,096	9.4
>200%	2,360,948	67.3	2,790,586	70.3	2,898,791	70.6
Per Capita Income						
Income	$25,947	NA	$25,386	NA	$27,195	NA
Unemployment						
Unemployed	92,657	5.5	122,629	6.3	126,124	6.6
Educational Attainment						
No High School Diploma	424,095	18.2	493,122	17.7	562,492	19.2
High School Diploma	1,217,389	52.1	1,489,576	53.4	1,541,904	52.7
College Degree	693,597	29.7	808,528	29.0	823,337	28.1
Characteristics	**BSCIP Region 4**		**BSCIP Region 5**		**Florida**	
	Number	**Percent**	**Number**	**Percent**	**Number**	**Percent**
Uninsured	1,069,011	27.8	676,783	30.9	3,889,668	24.9
Poverty Estimates						
<100%	527,876	10.8	449,904	17.7	2,380,088	12.5
100-150%	396,829	8.1	296,503	11.7	1,745,729	9.2
151-200%	424,090	8.7	269,762	10.6	1,798,609	9.5
>200%	3,543,610	72.4	1,525,087	60.0	13,097,187	68.9
Per Capita Income						
Income	$30,989	NA	$23,300	NA	$27,128	NA
Unemployment						
Unemployed	158,537	6.5	71,664	5.7	572,000	6.2
Educational Attainment						
No High School Diploma	634,534	18.0	536,075	31.5	2,673,935	20.1
High School Diploma	1,793,332	50.9	687,456	40.3	6,707,738	50.5
College Degree	1,093,422	31.1	480,363	28.2	3,897,549	29.4

Sources: Uninsured: US Census Bureau, Small Area Health Insurance, Estimates, 2006; Poverty Estimates: US Census Summary File 3, 2000; ESRI 2009. Per Capita Income: ESRI, 2009; Unemployment: Florida Research and Economic Database, Area Profiles, Annual 2008; Educational Attainment: US Census Summary File 3, 2000; ESRI 2009.

Spinal Cord Injury Profile

Quantifying the prevalence and incidence of SCI in Florida and each BSCIP region is very important when attempting to understand the needs of the population. This section includes a review of SCI-related indicators, with the hopes of providing proxy measures for the true prevalence and incidence of SCI in the state of Florida and each of the five BSCIP Regions. Analysis of available SCI-related data in Florida will enable the state and key stakeholders to identify at-risk populations and geographies, which will ultimately help to facilitate future planning and guide service delivery decisions to improve the lives of individuals with SCI in Florida.

Spinal Cord Injury Prevalence

The prevalence of SCI is defined as the proportion of persons in the population at a given time who are living with a SCI. Previous studies have estimated the national SCI prevalence to be approximately 259,000 people, with a range from 229,000 to 306,000 people in 2008.[1] A recent self-report study funded by the Christopher and Dana Reeves Foundation in April 2009 estimated the prevalence of paralysis to be nearly 5.6 million people. Of that number, 1.3 million people reported SCI to be the cause of their paralysis.[2] Based on the varying degree of prevalence estimates as well as varying methodologies, SCIs in Florida could range between 16,000 and nearly 80,000 persons. Therefore, it is recommended that these estimates be viewed with considerable caution until additional studies are available.

Incidence of Spinal Cord Injury

Incidence of SCI is defined as the proportion of new SCIs within a selected population during a given time period. The national incidence of SCI is estimated to be approximately 40 cases per million of the population in the United States, which results in an estimated 12,000 new cases annually.[1] The most current SCI incidence studies were conducted in the 1970's; how this incidence rate has changed over time is unknown.

Based on the national incidence studies, approximately 761 SCIs occurred in Florida during 2009 (Table 3). It is projected that the number of SCIs that occur annually in the state of Florida and each BSCIP Region will increase as the population increases.

Table 3: SCI Incidence Estimates, Florida and BSCIP Regions, 2009, 2015, 2030.

Geographic Area	2009		2015		2030	
	Population	SCI	Population	SCI	Population	SCI
BSCIP Region 1	3,510,267	140	3,794,467	152	4,608,294	184
BSCIP Region 2	3,969,166	159	4,262,191	170	5,385,748	215
BSCIP Region 3	4,108,518	164	4,269,514	171	5,045,629	202
BSCIP Region 4	4,892,405	196	5,094,918	204	6,043,301	242
BSCIP Region 5	2,541,257	102	2,634,775	105	2,896,060	116
Florida	19,021,613	761	20,055,865	802	23,979,032	959

Source: National Spinal Cord Injury Statistical Center. Spinal Cord Injury Facts and Figures at a Glance, April 2009; ESRI, 2009.

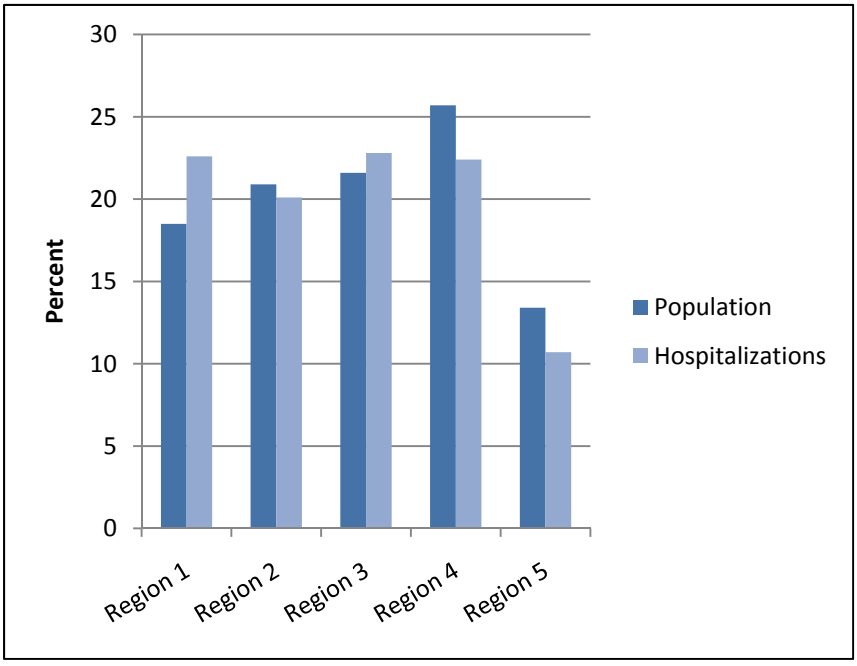
Spinal Cord Injury Related Hospitalizations

SCI-related hospitalizations from 2006 through 2008 were identified from the Florida Agency for Healthcare Administration (AHCA) Detailed Discharge Data. The case selection criteria is outlined in the Technical Appendix of this report. Please note that the Central Nervous System Injury Surveillance Data Submission Standards developed in 2002 reports that the evaluation of hospital discharge data has found that the predictive value positive (PVP) of the identified ICD-9 codes is low (60 percent).[3] Therefore, they recommend conducting medical record reviews to confirm the SCI diagnosis for these cases. Due to the timeframe and budgetary limitations of this project, medical records reviews were not feasible. It is also important to note that these estimates do not include SCI-related hospitalizations that occurred in the Veteran's Administration health system.

Table 4 highlights selected average annual SCI-related hospitalizations characteristics for Florida and the BSCIP Regions from 2006 through 2008. In Florida, an average of 807 SCI-related hospitalizations (4.1 per 100,000) occurred each year. The most SCI-related hospitalizations occurred in BSCIP Region 4 (197 per year) compared to BSCIP Region 5 with the fewest (82 per year). The largest disparity between the percentage of SCI-related hospitalizations and total population were in BSCIP Regions 1 (4.1 percent) and 4 (3.3 percent) (Figure 5).

- The highest rate of SCI-related hospitalizations is in BSCIP Region 1 (5.1 per 100,000), with the lowest in BSCIP Region 5 (3.1 per 100,000).

Figure 5: Percent Total Population and SCI-Related Hospitalizations by BSCIP Regions.



Source: ESRI, 2009; AHCA Detailed Hospital Discharge Data 2006-2008.

Approximately 56 percent of all SCI-related hospitalizations occurred in Floridians between the ages of 45-64 years and 15-34 years. For Florida and each BSCIP Region, adults over the age of 65 had the greatest risk (6.8 per 100,000) for SCI-related hospitalizations. While the youngest age group, 0-14 years, was at the lowest risk (0.6 per 100,000) in Florida and each BSCIP Region.

Over 77 percent of all SCI-related hospitalizations were of individuals identified as being of the white race, which is slightly more than the percentage (74.7 percent) seen in the distribution of Florida's population. The black population experiences a similar increase in the percentage of SCI-related hospitalizations (17.2 percent) compared to Florida's total population (15.8 percent).

Conversely, the percentage of Hispanics (10.4 percent) who experienced an SCI-related hospitalization is much less than the percentage of Hispanics (21.5 percent) who reside in the state of Florida. This trend is seen in BSCIP Region 5 as well, where only 37.8 percent of all SCI-related hospitalizations were experienced by individuals of Hispanic ethnicity, even though Hispanics comprise nearly 65 percent of the region's entire population.

In Florida, males are nearly three times more likely to experience an SCI-related hospitalization than females. This disparity is seen across all of the BSCIP regions.

Over 38 percent of all SCI-related hospitalizations were caused by falls. Motor vehicle accidents (33.6 percent) were the second leading cause of SCI-related hospitalizations in Florida. The greatest percentage (66.5 percent) of motor vehicle accidents were identified as occupant accidents, while nearly 18 percent were motorcycle accidents.

As detailed in the Technical Appendix of this report, the average length of stay for an individual who experienced a SCI-related hospitalization in Florida is 17.6 days. The most frequent funding sources for these stays were from commercial insurance (40.5 percent), Medicare (26.4 percent), and Medicaid (12.3 percent). Nearly 27 percent of individuals who experienced an SCI-related hospitalization were discharged to their homes, while nearly 25 percent were discharged to an inpatient rehabilitation facility for further care.

Table 4: Selected Average Annual SCI-Related Hospitalizations Characteristics, Florida and BSCIP Regions 2006-2008.

Characteristics	BSCIP Region 1			BSCIP Region 2			BSCIP Region 3		
	Number	Percent	Rate	Number	Percent	Rate	Number	Percent	Rate
Total Hospitalizations	182	22.6	5.1	162	20.1	4.0	184	22.8	4.2
Age Group*									
0-14 years	3	1.6	0.4	6	1.6	0.8	5	2.7	0.7
15-24 years	34	18.7	6.1	29	18.7	5.8	30	16.3	6.3
25-34 years	23	12.6	5.2	20	12.6	4.2	18	9.8	3.8
35-44 years	27	14.8	5.7	21	14.8	4.1	23	12.5	4.4
45-64 years	56	30.8	6.3	44	30.8	4.4	50	27.2	4.8
65 years +	40	22.0	8.9	43	22.0	6.4	57	31.0	7.3
Race									
White	136	74.7	4.9	129	79.6	3.8	153	83.2	4.1
Black	38	20.9	5.6	23	14.2	4.7	22	12.0	4.8
Other	8	4.4	8.1	6	3.7	5.5	8	4.3	9.1
Ethnicity									
Hispanic	4	2.2	1.7	18	11.1	2.8	16	8.7	3
Gender									
Male	130	71.4	7.6	119	73.5	6.3	134	72.8	6.9
Female	52	28.6	3	43	26.5	2.2	50	27.2	2.4
Causes									
Assaults/Homicide	12	6.6	0.3	7	4.3	0.2	6	3.3	0.2
Falls	68	37.4	1.9	53	32.7	1.2	71	38.6	1.5
Motor Vehicle	62	34.1	1.7	56	34.6	1.5	67	36.4	1.7
Other Accidents	32	17.6	0.9	30	18.5	0.8	24	13.0	0.6
Other	7	3.8	0.2	8	4.9	0.2	10	5.4	0.2
Unknown	1	0.5	<0.1	9	5.6	0.2	5	2.7	0.1

Characteristics	BSCIP Region 4			BSCIP Region 5			Florida		
	Number	Percent	Rate	Number	Percent	Rate	Number	Percent	Rate
Total Hospitalizations	197	24.2	3.8	82	10.2	3.1	807	100.0	4.1
Age Group*									
0-14 years	7	3.6	0.8	1	1.2	0.2	21	2.6	0.6
15-24 years	26	13.2	4.8	15	18.3	4.5	134	16.6	5.6
25-34 years	18	9.1	3.4	10	12.2	2.9	89	11.0	3.9
35-44 years	31	15.7	4.9	12	14.6	3.2	115	14.3	4.5
45-64 years	55	27.9	4.4	24	29.3	3.8	229	28.4	4.8
65 years +	59	29.9	6.1	20	24.4	5.8	219	27.1	6.8
Race									
White	148	75.1	3.4	57	69.5	2.7	623	77.2	3.8
Black	36	18.3	4.7	20	24.4	3.7	139	17.2	4.7
Other	11	5.6	10.4	4	4.9	8.2	38	4.7	8.3
Ethnicity									
Hispanic	15	7.6	1.8	31	37.8	1.9	84	10.4	2.2
Gender									
Male	184	93.4	5.8	58	70.7	4.6	583	72.2	6.2
Female	55	27.9	1.8	25	30.5	1.7	224	27.8	2.1
Causes									
Assaults	12	6.1	0.3	9	11.0	0.4	46	5.7	0.3
Falls	88	44.7	1.5	30	36.6	1.1	309	38.3	1.4
Motor Vehicles	55	27.9	1.2	31	37.8	1.2	271	33.6	1.5
Other Accidents	27	13.7	0.6	7	8.5	0.3	121	15.0	0.6
Other	9	4.6	0.2	3	3.7	0.1	37	4.6	0.2
Unknown	5	2.5	0.1	2	2.4	0.1	22	2.7	0.1

Rates are age adjusted to the standard US population per 100,000 of the population; * age-group rates represent crude rates.
Sources: AHCA Detailed Hospital Discharge Data 2006-2008; Florida Charts 2006-2008.

Spinal Cord Injury Related Program Data

This section reports the findings from programs who work with individuals with SCI including the Florida Department of Health, Brain and Spinal Cord Injury Program (BSCIP) and the Florida Department of Health, Office of Trauma.

The state of Florida has a government administered program, BSCIP, housed within the Florida Department of Health, whose purpose is to assist eligible residents who sustain a SCI the with opportunity to obtain the necessary services enabling them to return to their community. The program is funded by the BSCIP Rehabilitation Trust Fund through traffic-related fines, surcharges for driving under the influence and boating under the influence, temporary license fees and a percentage of funds from the motorcycle specialty tags. These funds are used to assist individuals and their families in identifying and accessing all available federal, state, community, and third party resources. Services include: case management, acute care, inpatient and outpatient rehabilitation, transitional living, assistive technology, home and vehicular modification, and long-term community based supports. Additionally, BSCIP funds education, prevention and research activities. Finally, for those individuals who need lifetime support, BSCIP provides its Home and Community-Based Medicaid Services Waiver.

Central Registry New Injury Referrals

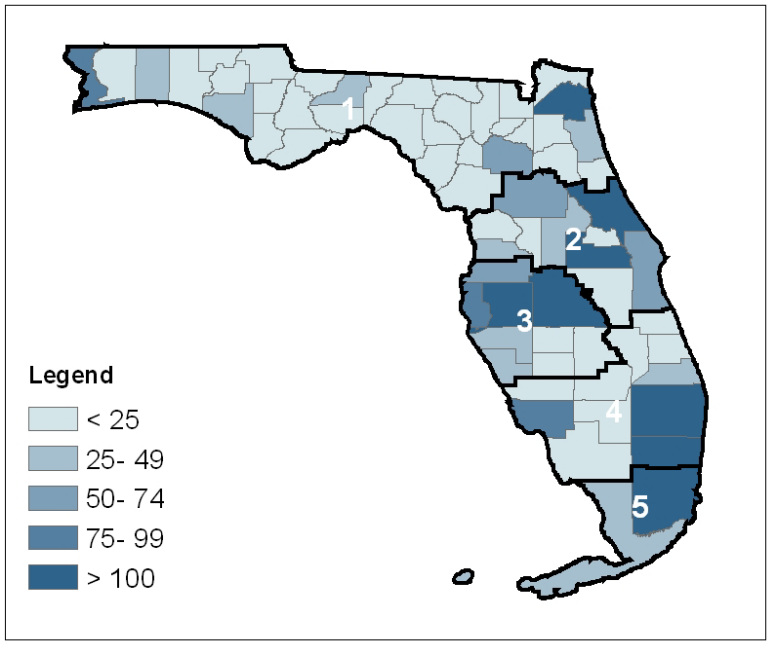
This section highlights the average annual number of new SCIs reported to the Central Registry (CR) from 2005 through 2008. Mandated by the Florida legislature (Florida Statute 381.74), the CR collects information on individuals who experience a moderate-to-severe brain or spinal cord injury including name, age, residence, type of disability of the individual and other information as deemed necessary by the department.[4]

From 2005 through 2008, 2,730 SCIs were referred to the CR, resulting in approximately 683 new injury referrals per year (Table 5). Unlike the total population percentage distribution, the greatest percentage (24.3 percent) of new injury referrals to the CR came from injuries sustained in BSCIP Region 1. Nearly 7 percent of all new injury referrals to the CR came from injuries sustained either out of state or out of country.

Figure 6 shows the average annual new injury SCI referrals by county of injury. At least one new injury was reported to occur in each of Florida's counties during the four-year period. The greatest number of new injuries occurred in Miami-Dade County annually (93). The number of new injuries reported to the CR that were sustained in Miami-Dade County was approximately two times greater than the county with the second most new injuries reported, Duval County (43).

Of the injuries reported to the CR, 80.4 percent of all new injury referrals were made by the state designated and provisional trauma centers in Florida that care for the most severely injured.

Figure 6: Total Number of New Injury Referrals to CR by County of Injury, 2005-2008.



Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, 2005-2008, accessed October 2009.

On average, individuals ages 45-64 years of age (193 referrals), were referred most frequently to the CR from 2005 through 2008, followed by individuals 15-24 years of age (156 referrals). The youngest segment of Florida's population, 0-14 years of age, was referred to the CR for new injuries least often (15 referrals) during this time frame.

Individuals who were identified as white accounted for nearly 73 percent of all new injury referrals to the CR each year. Just over 15 percent of all new injury referrals to the CR were individuals who were identified as being of Hispanic ethnicity.

On average, males (529 referrals) were 3.5 times more likely to sustain a new injury that was referred to the CR each year than females (151 referrals).

Motor vehicle accidents accounted for nearly 49 percent of all new injury referrals to the CR each year, followed by falls (22.8 percent) and assaults (12.3 percent).

As detailed in the Technical Appendix of this report, SCIs between the levels of C5 through C8 were most frequently reported to the CR. Of the injuries reported, 87.8 percent resulted in two or three reported deficits including sensory deficit, motor deficit, and bowel or bladder dysfunction.

Table 5: Selected Average Annual SCI-Related CR New Injury Characteristics, Florida and BSCIP Region of Injury, 2005-2008.

Characteristics	BSCIP Region 1		BSCIP Region 2		BSCIP Region 3	
	Number	Percent	Number	Percent	Number	Percent
New Injury Referrals	166	24.3	124	18.1	127	18.5
Age Group						
0-14 years	2	1.2	3	2.4	4	3.1
15-24 years	41	24.7	24	19.4	30	23.6
25-34 years	27	16.3	24	19.4	19	15.0
35-44 years	30	18.1	19	15.3	20	15.7
45-64 years	46	27.7	4	3.2	34	26.8
65 years +	20	12.0	14	11.3	21	16.5
Race						
White	118	71.1	91	73.4	99	78.0
Black	44	26.5	21	16.9	24	18.9
Other	3	1.8	3	2.4	1	0.8
Ethnicity						
Hispanic	7	4.2	11	9.1	14	11.0
Non-Hispanic	157	94.6	104	83.9	110	86.6
Gender						
Male	128	77.1	97	78.2	99	78.0
Female	37	22.2	26	21.0	27	21.3
Causes						
Motor Vehicle	79	47.6	61	49.2	67	5.3
Assault	18	10.8	15	12.1	11	8.7
Sport Related	11	6.6	7	5.6	5	3.9
Falls	42	25.3	24	19.4	32	25.2
Other	11	6.6	11	8.9	9	7.1
Unknown	6	3.6	5	4.0	4	3.1

Characteristics	BSCIP Region 4		BSCIP Region 5		Florida	
	Number	Percent	Number	Percent	Number	Percent
New Injury Referrals	123	18.0	97	14.2	683	100.0
Age Group						
0-14 years	3	2.4	2	2.1	15	2.2
15-24 years	27	22.0	23	27.7	156	22.8
25-34 years	22	17.9	17	17.5	122	17.9
35-44 years	23	18.7	15	15.5	113	16.5
45-64 years	33	26.8	30	30.9	193	28.3
65 years +	16	13.0	11	11.3	85	12.4
Race						
White	90	73.2	62	63.9	496	72.7
Black	28	22.8	34	35.1	159	23.3
Other	1	0.8	0	0.0	8	1.2
Ethnicity						
Hispanic	20	16.3	42	43.3	103	15.1
Non-Hispanic	99	80.5	54	55.7	560	82.0
Gender						
Male	93	75.6	76	78.4	529	77.5
Female	30	24.4	22	22.7	151	22.1
Causes						
Motor Vehicle	53	43.1	48	49.5	333	48.8
Assault	19	15.4	16	16.5	84	12.3
Sport Related	5	4.1	3	3.1	35	5.1
Falls	30	24.4	23	23.7	156	22.8
Other	8	6.5	4	4.1	37	6.9
Unknown	9	7.3	4	4.1	10	1.5

Notes: Numbers may not sum due to rounding; Unknown values are not presented in this table, but are included in total numbers.
185 referrals were not able to be categorized into BSCIP Region of Injury; they are included in FL totals.
Sources: Florida Department of Health, Brain and Spinal Cord Injury Program, RIMS, accessed October 2009.

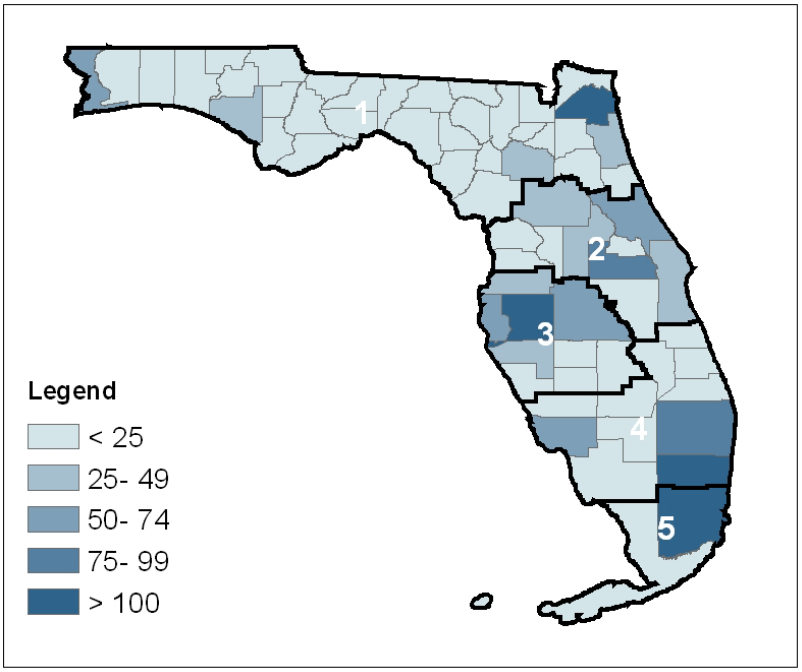
BSCIP Trust Fund Clients Served

Data presented in this section include all BSCIP Trust Fund clients with a SCI, including those who sustained both brain and spinal cord injuries. Eligibility criteria for the Trust Fund services include: being a resident of Florida, sustaining a SCI that meets the state definition and that was reported to the BSCIP CR. Program eligibility is determined once the patient is stable; the individual must be medically stable to be eligible for services and there must be a reasonable expectation that with the provision of appropriate services and support, the person can return to the community.

From 2005 through 2008, 1,987 individuals with SCIs were served by the BSCIP Trust Fund program (Table 6). Unlike Florida's total population percentage distribution, the greatest percentage (26.5 percent) of clients served by the BSCIP Trust Fund program lived in BSCIP Region 1. Figure 7 shows the clients served by county of residence. The greatest number of clients served lived in Miami-Dade County (273). The number of clients served in Miami-Dade County was nearly two times greater than the county with the second most number of clients served, Broward County (144).

Of the clients served by the BSCIP Trust Fund, 63.6 percent were referred to the program by the state designated and provisional trauma centers in Florida that care for the most severely injured.

Figure 7: Total Number of BSCIP Trust Fund Clients Served by County of Residence, 2005-2008.



Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, 2005-2008, accessed November 2009.

Individuals from ages 15-24 years of age (30.6 percent), were the most frequent recipient of services through the BSCIP Trust Fund 2005 through 2008, followed by individuals 45-64 years of age (23.5 percent). The youngest segment of the population, 0-14 years of age, represented the smallest percentage of BSCIP Trust Fund clients served (4 percent) during this time frame.

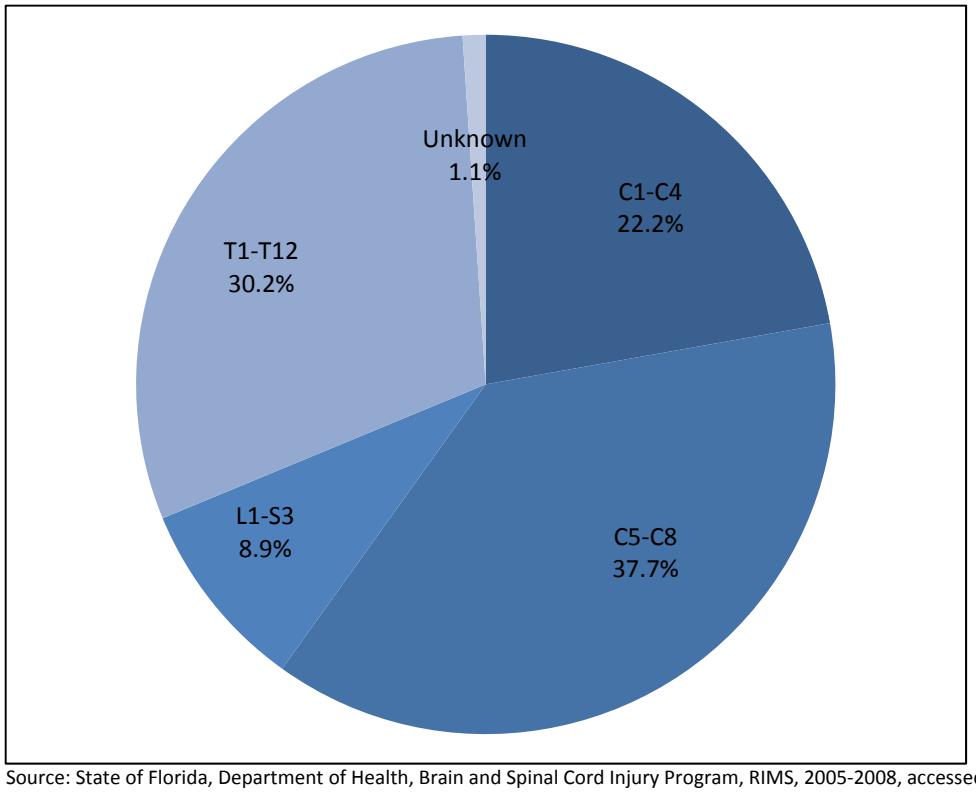
Individuals who were identified as white accounted for nearly 72 percent of all clients served by the BSCIP Trust Fund from 2005 through 2008. Just over 11 percent of all clients served were individuals who identified as being of Hispanic ethnicity.

Males (1,530 clients) were nearly 3.4 times more likely to receive services from the BSCIP Trust Fund than females (454 clients) from 2005 through 2008.

The etiology of injury was identified as motor vehicle accidents for 50 percent of all clients served by the BSCIP Trust Fund, followed by falls (17.4 percent) and assaults (13.8 percent).

Of the clients served by the BSCIP Trust Fund, SCI injuries between levels C5-C8 were most commonly reported (Figure 8). Of the clients served, 94.3 percent reported two or three deficits including sensory deficit, motor deficit, and bowel or bladder dysfunction.

Figure 8: Level of Injury for Clients Served by the BSCIP Trust Fund, 2005-2008.



Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, 2005-2008, accessed November 2009.

Table 6: Selected SCI-Related BSCIP Trust Fund Client Characteristics, Florida and BSCIP Region 2005-2008.

Characteristics	BSCIP Region 1		BSCIP Region 2		BSCIP Region 3	
	Number	Percent	Number	Percent	Number	Percent
Clients Served	526	26.5	359	18.1	424	21.3
Age Group						
0-14 years	18	3.4	17	4.7	16	3.8
15-24 years	152	28.9	118	32.9	124	29.2
25-34 years	96	18.3	75	20.9	88	20.8
35-44 years	98	18.6	48	13.4	73	17.2
45-64 years	129	24.5	87	24.2	95	22.4
65 years +	32	6.1	14	3.9	28	6.6
Race						
White	362	68.8	281	78.3	337	79.5
Black	135	25.7	62	17.3	79	18.6
Other	7	1.3	6	1.7	4	0.9
Ethnicity						
Hispanic	10	1.9	30	5.6	40	9.4
Non-Hispanic	513	97.5	509	94.4	384	90.6
Gender						
Male	413	78.5	284	79.1	326	76.9
Female	112	21.1	75	20.9	97	22.9
Causes						
Motor Vehicle	269	51.1	198	55.2	211	49.8
Assault	67	12.7	34	9.5	44	10.4
Sport Related	39	7.4	31	8.6	34	8.0
Falls	100	19.0	52	14.5	87	20.5
Other	22	4.2	25	7.0	26	6.1
Unknown	29	5.5	19	5.3	22	5.2

Characteristics	BSCIP Region 4		BSCIP Region 5		Florida	
	Number	Percent	Number	Percent	Number	Percent
Clients Served	373	18.8	278	14.0	1,987	100.0
Age Group						
0-14 years	25	6.7	4	1.4	80	4.0
15-24 years	113	30.3	92	33.1	608	30.6
25-34 years	64	17.2	47	16.9	378	19.0
35-44 years	82	22.0	50	18.0	353	17.8
45-64 years	74	19.8	74	26.6	466	23.5
65 years +	15	4.0	11	4.0	101	5.1
Race						
White	259	69.4	166	59.7	1,428	71.9
Black	102	27.3	105	37.8	505	25.4
Other	6	1.6	0	0.0	25	1.3
Ethnicity						
Hispanic	41	11.0	100	36.0	222	11.2
Non-Hispanic	326	87.4	172	61.9	1,1736	87.4
Gender						
Male	282	75.6	203	73.0	1530	77.0
Female	91	24.4	74	26.6	454	22.8
Causes						
Motor Vehicle	177	47.5	122	43.9	993	50.0
Assault	65	17.4	64	23.0	275	13.8
Sport Related	21	5.6	16	5.8	142	7.1
Falls	64	17.2	39	14.0	345	17.4
Other	28	7.5	17	6.1	121	6.1
Unknown	18	4.8	20	7.2	111	5.6

Notes: Numbers may not sum due to rounding; Unknown values are not presented in this table, but are included in the total.
27 clients were not able to be categorized into BSCIP Region of Residence; they are included in FL totals.
Sources: Florida Department of Health, Brain and Spinal Cord Injury Program, RIMS, accessed November 2009.

BSCIP Home and Community-Based Medicaid Waiver

Home and community-based waivers are used by states to obtain Federal matching funds to provide long-term care to patients to help maintain their ability to live outside of institutional settings. Eligibility for the BSCIP Home and Community-Based Medicaid Waiver includes: permanent Florida residency, being 18 years of age or older, referral to CR, meeting the state definition for TBI or spinal cord injury or both, being medically stable, meeting at least Level II nursing home level of care, and being financially eligible to receive Florida Medicaid.

Waiver Population

From 2005 through 2008, the Waiver program served 256 SCI consumers (Table 7).

Nearly 76 percent of all the SCI Medicaid Waiver clients served from 2005 through 2008 were male. Waiver participants were most likely to be between the ages of 45-64 years (46.9 percent). Over 80 percent of Waiver participants were white and only 6.2 percent were identified as being of Hispanic ethnicity.

Over 93 percent of participants were identified as having quadriplegia, based on the location of their injury (C1-C8). Nearly 99 percent of all Waiver participants have more than two areas of dysfunction or deficits including sensory, motor, and bowel/bladder issues.

Table 7: Selected SCI-Related BSCIP Medicaid Waiver Client Characteristics, Florida 2005-2008.

Characteristics	Number	Percent
Waiver Participants	256	100.0
Gender		
Female	62	24.2
Male	194	75.8
Age Group		
0-14 years	0	0.0
15-24 years	10	3.9
25-34 years	61	23.8
35-44 years	62	24.2
45-64 years	120	46.9
65 years +	3	1.2
Race		
White	206	80.4
Black	48	18.8
Other	1	0.4
Ethnicity		
Hispanic	16	6.2
Non-Hispanic	239	93.4
Current Level of Injury		
C1-C4	72	28.1
C5-C8	168	65.5
L1-S3	1	0.4
T1-T12	15	5.9
Area of Dysfunction/ Deficit		
Sensory	248	96.9
Motor	248	96.9
Bowel/Bladder	242	94.5

Notes: Numbers may not sum due to rounding; Unknown values are not presented in this table, but are included in the totals.
Sources: Florida Department of Health, Brain and Spinal Cord Injury Program, RIMS, accessed October 2009.

Waiver Services

From 2005 through 2008, participants in the Waiver received approximately 38,500 service units comprised of 25 different services types (Table 8). The most frequently utilized service types were personal care (26.1 percent), companion services (23.8 percent) and community support coordination (20.1 percent).

The total cost of the services received by Waiver participants during this time frame was over $25 million. Personal care services (43.6 percent) and companion services (27.2 percent) accounted for the majority of the dollars, nearly 71 percent, distributed to participants in the Waiver program. Community support coordination, which represented just over 20 percent of all services used by Waiver participants, represented only 4.0 percent of service costs from 2005 through 2008.

Table 8: Service Units and Service Cost by Service Type for BSCIP Home and Community-Based Medicaid Waiver, 2005-2008.

Service Type	Service Units		Service Cost	
	Total Units	Percent	Total Dollars	Percent
Housing	17	<0.1	$14,004	<0.1
Transportation	69	0.2	$26,819	0.1
Personal Care	10,027	26.1	$11,001,363	43.6
Companion Services	9,144	23.8	$6,871,318	27.2
Attendant Care	3,466	9.0	$3,456,732	13.7
Life Skills Training	185	0.5	$97,294	0.4
Personal Adjustment	106	0.3	$31,445	0.1
Community Support Coordination	7,750	20.1	$1,005,463	4.0
Behavioral Programming	25	0.1	$11,838	<0.1
Assistive Technologies	1,313	3.4	$683,562	2.7
Rehabilitation Engineer Evaluation	80	0.2	$26,188	0.1
Environmental Access Adaptation	122	0.3	$396,110	1.6
Consumable Medical Supplies	5,204	13.5	$637,953	2.5
Consulting Services	300	0.8	$42,111	0.2
Comprehensive Inpatient Rehabilitation	37	0.1	$91,515	0.4
Occupational Therapy	81	0.2	$44,470	0.2
Physical Therapy	72	0.2	$32,642	0.1
Psychological/ Neuropsychological Evaluation	12	<0.1	$1,835	<0.1
Assistive Devices	205	0.5	$340,102	1.3
Home Modifications	70	0.2	$283,168	1.1
Medical Follow-Up	18	<0.1	$6,181	<0.1
Medications/ Medical Supplies	86	0.2	$28,660	0.1
Moving Costs	14	<0.1	$4,663	<0.1
Transition Coordination	1	<0.1	$85	<0.1
Other	87	0.2	4118,795	0.5
Total	38,491	100.0	$25,254,317	100.0

Service cost is rounded to the nearest dollar.
Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, accessed October 2009.

Florida State Trauma Registry

The Florida Trauma Registry collects patient-level data from the state's verified trauma centers, as authorized by Florida Statutes Section 395.404(1). The Florida Trauma Registry is a comprehensive database of those injured and treated patients seen in Florida's trauma centers.

The Florida Department of Health, Office of Trauma provided registry data, including age, gender and external cause of injury, for those individuals reported to the registry who were identified with a SCI as their principal diagnosis code for calendar years 2006 and 2007. Additionally, the Office of Trauma provided a total number of individuals with SCI as a principal diagnosis for calendar year 2008.

From 2006 through 2008, a total of 126,509 discharges were reported to Florida's Trauma Registry, which included 1,833 discharges (1.4 percent) that identified SCI as their primary diagnosis.[5]

During calendar years 2006 and 2007, 1,233 SCI-related discharges were reported to Florida's Trauma Registry (Table 9). SCI-related discharges reported to the registry were most likely to be adults between the age of 45-64 years and male. Nearly 45 percent of all SCI-related discharges reported during this time frame were caused by motor vehicle related accidents.

Table 9: SCI-Related Discharges from Florida's Trauma Registry, 2006-2007.

Characteristics	2006		2007		Total	
	Number	Percent	Number	Percent	Number	Percent
SCI-Related Discharges	561	100.0	672	100.0	1,233	100.0
Age Group						
0-14 years	23	4.1	27	4.0	50	4.1
15-24 years	114	20.3	152	22.6	266	21.6
25-34 years	103	18.4	96	14.3	199	16.1
35-44 years	89	15.9	105	15.6	194	15.7
45-64 years	143	25.5	198	29.5	341	27.7
65 years +	87	15.5	94	14.0	181	14.7
Gender						
Male	447	79.7	515	76.6	962	78.0
Female	114	20.3	157	23.4	271	22.0
Causes						
Motor Vehicle	262	46.7	292	43.5	554	44.9
Assault	43	7.7	62	9.2	105	8.5
Falls	162	28.9	196	29.2	358	29.0
Other Accidents	85	15.2	109	16.2	194	15.7
Other	8	1.4	12	1.8	20	1.6
Unknown	1	0.2	1	0.1	2	0.2

Source: Florida Department of Health, Florida Trauma Registry, accessed December 2009.

[1] National Spinal Cord Injury Statistical Center. Spinal Cord Injury Facts and Figures at a Glance. April 2009.
[2] Cahill, A., et al. National Prevalence Survey of Paralysis and Spinal Cord Injury in the United States, 2008. http://cdd.unm.edu/dhpd/prevalsurvey.asp.
[3] Marr, Angela and Coronado, Victor. Central Nervous System Injury Surveillance Data Submission Standards. Department of Health and Human Services. Centers for Disease Control and Prevention. National Center for Injury Prevention and Control, 2002.
[4] Florida Statute 381.74. Title XXIX, Public Health Chapter 381 Public Health: General Provisions; 2006.
[5] Florida Department of Health, Office of Trauma, 2008 Florida Trauma System Annual Report. http://www.doh.state.fl.us/demo/Trauma/registry.htm,

THIS PAGE WAS INTENTIONALLY LEFT BLANK

Spinal Cord Injury Community Input

The perspective and voices of individuals, family members, caregivers, providers, key leaders and decision makers (i.e., community input) are critical when assessing the health and service needs of any population. This section summarizes the findings from the three critical areas of public perspective conducted during this assessment including: 10 SCI survivor focus groups, interviews with 25 key leaders within Florida's SCI community, and an online consumer and caregiver needs survey.

Focus Groups

WellFlorida Council conducted 10 focus groups, two in each BSCIP Region based on time post injury, with individuals with SCI to learn about their service and support needs. Please see the Technical Appendix for a detailed description of the protocols and questions developed by WellFlorida Council. The specific goals of the focus groups included:

- To identify the most helpful services for individuals with SCI
- To identify service needs for individuals with SCI
- To identify the biggest issues currently facing individuals with SCI
- To identify services that could have the greatest impact for individuals with SCI
- To identify issue impacting employment after SCI
- To understand secondary health-related complications as a result of the SCI
- To examine how service and support needs for individuals with SCI may change over time

Over 70 survivors of SCI participated in the focus groups. The composition of the groups were 72 percent male, 66.2 percent white, with over 25 percent of participants identifying themselves as being of Hispanic ethnicity. The average age of the focus group participants was nearly 45 years old with an average of 12.7 years post injury. Nearly 54 percent of participants identified themselves as sustaining an injury between C1 and C8, while the remaining 46 percent of participants sustained injuries between T1 and S3.

Most Helpful Services for Individuals with SCI

Participants in the focus groups were asked to identify services or supports that were most helpful for individuals with SCI. Four services or supports were heard most frequently among participants including: quality rehabilitation services, access to peer mentors or peer support, access to the needed support services (e.g. transitional living services, personal care assistance, and appropriate assistive devices), and quality organizational support. Other themes that were mentioned across groups include: the need for strong family support and the importance of having opportunities for recreation, healthy living, and socialization.

Organizations or programs that were identified as helpful by participants include: BSCIP, FSCIRC, Vocational Rehabilitation, Centers for Independent Living, SCI support groups, peer mentor programs and selected hospitals and rehabilitation facilities.

Comparing the perception of helpful services across time post injury, focus group participants who sustained their injuries more than five years ago stressed the difference in access to the needed long-term rehabilitation services. They emphasized how the change in length of rehabilitation stays has increased the need for other long-term support services. Additionally, they mentioned more frequently the importance of peer support and the opportunities to engage in healthy living activities. The focus group participants who were injured less than

five years ago often commented on the helpfulness of ongoing quality rehabilitation as well as having access to needed information and education.

Notable Quotes

- "I have someone helping me out in my house. I have found, of course, that I have to go to work, other than that you don't have a way to pay your mortgage or my basic needs. I don't know what I would do without it. It is really essential in my life to have someone help me."
- "It is very important to get in contact with people like you. Those are the real ones that know what's going on."
- "There was a place [transitional living facility] where I went to have rehabilitation. I went and lived there and they taught me how to do everything, dress myself, get in the shower and take a shower. I learned how to do everything on my own, so I could live independently."
- "In the beginning you depend on a lot from physical therapy. Then after that it becomes more about personal care at home."

Service Needs for Individuals with SCI

Focus group participants were asked to identify the services and supports they currently need. The following were identified most frequently among focus group participants: access to rehabilitation services, access to services or resources that promote independence, and access to information and resources for SCI.

Participants shared that access to needed rehabilitation was limited due to insurance restrictions as well as limited availability of qualified SCI rehabilitation providers, particularly in less populated areas of the state. Participants also shared that transitional living facilities and long-term rehabilitation was virtually nonexistent.

Focus group members also shared the need for increased opportunities to access services or support to promote independence. These activities included transportation services, updated equipment, accessible and affordable housing, personal care assistance and opportunities for maintaining healthy living including exercise facilities and socialization activities.

Participants recognized that many of the identified needs may be available, but the financial cost limited their access to needed supports and services, particularly in the areas of rehabilitation, updated equipment, and personal care assistance.

For those participants who were injured more than five years ago, access to opportunities for maintaining healthy living and access to services or supports that promote independence were discussed most frequently. Participants who were injured less than five years ago stressed the need for ongoing quality rehabilitation services and basic services or supports that promote independence such as transportation and accessible, affordable housing. They also shared a continued need for information and education.

Notable Quotes

- "They will fund a client to live in a nursing home, but they won't fund a client to live in a facility that teaches them how to be independent and live on their own."
- "There is no central clearinghouse, whatever your question might be. Whether it is where can I find a wheelchair, where can I find a rugby league, where can I get help finding medications. There is no central place I can go to."

- "To get anything done is a major ordeal. If you need new tires or a new back for your wheelchair is such a fight. It is almost like they are doing you favor by giving you a chair that is two or three years old."

Biggest Issues Currently Facing Individuals with SCI Who Live in Florida

Survivors of SCI were asked to identify the biggest issues they face because of their injury. The most frequently reported issues identified by participants were the lack of opportunities for maintaining a healthy lifestyle, the lack of qualified, knowledgeable providers, and the limited access to long-term needed rehabilitation. Individuals also mentioned their personal financial strain as well as organizational funding issues, employment, transportation, and parking as the biggest issues currently facing individuals with SCI in Florida.

As stated above, the limited opportunities to engage in healthy living activities such as exercise, socialization, and general health was the greatest issue for many focus group participants. Participants also continued to stress the need for long-term access to the appropriate rehabilitation and therapies to promote independence.

Identifying qualified SCI providers including home health, primary care physicians, and rehabilitation specialists continues to be a significant issue facing SCI survivors. Participants commented on having to educate and train providers on how to best meet their needs.

Participants identified that their personal financial strain as well as the increasing organizational funding issues have significantly impacted their ability to access needed services that were previously available. These services include vehicular modifications, housing modifications, and personal care assistance. Survivors of SCI noted substantial increases in program waitlists.

Access to disability parking was a critical issue among participants injured more than five years ago. They discussed the need for additional parking spots, increased regulations on number of disability permits distributed, as well as the need for parking spots reserved for individuals with vehicular ramps. Additionally, individuals injured more than five years ago continued to emphasize how changes in program and insurance regulations (e.g. access to rehabilitation or durable medical equipment) has increased challenges for them over time.

Notable Quotes

- "I have insurance and I still can't find a place to go [rehabilitation]."
- "If you were talking about three years ago, I believe those services [BSCIP] were actually the best. Today unfortunately, because of the budget there are too many waiting lists."
- "Let's say you want to join a gym. You can't even join a public gym because their facilities don't allow access to the equipment. So it becomes even harder for someone to stay healthy."

Services that Could Have the Greatest Impact on the Lives of Individuals with SCI in Florida

The most frequently identified service/support thought to have the greatest impact on the lives of individuals with SCI was increasing access to peer mentoring or peer support. Other services or supports that were identified included: increased access to personal care assistance, family and/or caregiver support services, and advocacy initiatives to raise awareness about SCI.

Regardless of when an individual's injury occurred, having access to peer mentors or peer support was identified frequently as the service that could have the greatest impact on the lives of individuals with SCI. Advocacy

initiatives to raise awareness about SCI, including increasing accessibility, was more common among individuals injured more than five years ago.

Notable Quotes

- "My parents are on a limited income, they are getting older. What I am supposed to do when they can't take care of me?"
- "My sisters need respite care, they need a break."
- "If 200 people turns into 5,000, then we can speak out about certain things like education and transportation. They don't really look at us yet. They don't really know we have a voice."
- "I feel more comfortable when I am around other people in chairs. I actually feel happy inside. I don't feel like a stranger. So having more of a chance to do that would be helpful."

Issues Impacting Employment After SCI

Focus group participants were asked to share their thoughts regarding the issues impacting employment following a SCI. The survivors identified four primary issues that may impact an individual's decision to return to or seek out employment after a SCI including: personal factors such as motivation level, perception of ability, fear, and health issues; the impact on benefits or health insurance status; the need to acquire new skills or vocational training; and workplace accessibility.

While most participants agreed that accessibility in the workplace has improved, many barriers still exist that may impact a person's decision to return to work. The barriers include architectural issues, discrimination, employer's lack of knowledge of SCI, lack of flexibility among employers to accommodate personal needs of SCI individuals, and perceived liability associated with hiring a disabled person.

Focus group participants injured less than five years ago were more likely to discuss the need to acquire new skills or vocational training as well as personal factors as the major issues impacting employment after sustaining a SCI. Participants who were injured more than five years ago were more likely to discuss workplace accessibility issues as well as health-related barriers as a major issue impacting employment after sustaining a SCI.

Notable Quotes

- "You have to find a job, then when you get to the interview you have to find out if you can even get into the building, once you get into the building you have to find out if you can even get into the bathroom. If you can't get into the bathroom you can't take the job. Then you have to go in for your interview. So basically to get a job, you have to go through all this. It's just not worth your time."
- "With me, there is a concern. I don't know how much I can make. They give you a grace period, but say I go to this school and then I try this job and it doesn't work out. I don't want to lose my benefits."
- "There are a lot of employers that are scared we might hurt ourselves so that makes them really skeptical about hiring us."
- "I didn't go back; I think I was self-conscious. I could have gone back, I just didn't see myself. I was there just a year ago and then this happened. I didn't want people feeling sorry for me all the time."
- "I think I would also be concerned because some days we feel 100 percent other days we feel 50 percent and it is difficult to get out of bed. You can't be skipping your job every other day because you have a disability."

- "For me, I worked at the power company for 28 years before I got hurt…I wasn't able to do that anymore. Where does a person like me go?"

Understanding Health-Related or Secondary Complications as a Result of SCI

Survivors of SCI identified urinary tract infections, pressure sores, muscle spasms, chronic pain, autonomic dysreflexia, and issues with bowel or bladder function as the most frequent health-related or secondary complications as a result of SCI, while stressing the importance of overall health and engaging in preventative measures to decrease the likelihood of the identified complications.

Members of the focus groups did share that the majority of healthcare providers are not equipped to deal with the issues that SCI survivors face and stressed the importance of finding educated, qualified providers. Many shared that they rely heavily on their rehabilitation medicine physician or therapists for their medical care. Additionally, focus group participants stressed the importance of being a strong advocate for your health and healthcare.

Many focus group participants expressed frustration with the inaccessibility of healthcare facilities. The survivors shared that many facilities do not have accessible exam tables, scales, and other equipment.

The primary difference that was observed among participants in the focus groups that had been injured for a longer duration was their knowledge about their health-related issues and experience with navigating the healthcare system to improve their health. Those that were injured more recently expressed more frustration with finding qualified, knowledgeable providers.

Notable Quotes

- "It doesn't just stop with the spinal cord. You have to take care of your body. You have to workout what you have. You have to watch what you do, what you eat. You have to check your body constantly for bed sores."
- "They usually give me an exam in my chair. I have never been able to go a gynecologist since the accident because none of them have facilities that will work for me."
- "My primary care doctor, he doesn't know anything about spinal cord injury. I have to teach them. They are receptive to that though."
- "You get more knowledgeable, you get smarter about your injury, and how to deal with your body. But then you get into more issues because your health is not what it used to be."

Focus Group Summary

Over 70 survivors of SCI throughout the state of Florida participated in the focus groups. The key findings from the focus groups include:

- Most helpful services included: quality rehabilitation, access to peer mentors or peer support, access to needed support services (e.g., transitional living services, personal care assistance, and assistive devices), and quality organizational support.

- Most needed services or supports included: access to rehabilitation services, access to services that promote independence (e.g., transportation, equipment, housing, personal care assistance, and healthy living opportunities), and access to information and resources for SCI.

- Biggest issues facing individuals with SCI include: lack of opportunities for maintaining a healthy lifestyle, lack of qualified, knowledgeable providers, and limited access to long-term rehabilitation needs.

- The services that could have the greatest impact include: increasing access to peer mentors or peer support, increasing access to personal care assistance, family or caregiver support services, and implementing advocacy activities to raise awareness about SCI issues.

- Issues impacting returning to or engaging employment include: personal factors, impact on benefits or health insurance status, the need to develop new skills or vocational training, and workplace accessibility.

- Most frequently identified SCI-related health issues include: urinary tract infections, pressure sores, muscle spasms, autonomic dysreflexia, and issues with bowel or bladder function. Focus group participants shared an opinion that the majority of healthcare providers are not equipped or trained to deal with SCI-related health issues and that accessibility in healthcare facilities is a significant issue.

- Differences in service and support needs and key issues exist based on time post injury. In general, those injured more recently have an increased need for services such as rehabilitation, transportation, accessible, affordable housing, and personal care. Those who were injured more than five years ago identified an increased need for opportunities to maintain personal health and wellness as well as issues related to increased accessibility such as parking and environmental barriers.

Interviews with Spinal Cord Injury Leaders

From October 2009 through January 2010, 25 key informant interviews were conducted to understand perspectives of key leaders on the service needs of individuals with SCI in the state of Florida. A subset of interviewees were selected to gain additional insights into special populations identified by the FSCIRC Advisory Group. Those interviewed included healthcare providers, state agency administrators, community-based organization representatives, as well as survivors of SCI and their caregivers. The interview guide is included in the Technical Appendix of this report.

Community leaders provided comments on the following issues:

- Most helpful services immediately following a SCI
- Most helpful services for long-term consequences of SCI
- Identification of existing service needs for individuals with SCI
- Identification of issues impacting employment for individuals with SCI
- Identification of issues impacting health or secondary complications as a result of SCI
- Identification of the greatest issue facing individuals with SCI and their families
- Identification of services that can impact the lives of individuals with SCI
- Strengths and weaknesses in the current system of care for individuals with SCI in Florida

Please note that the order in which findings are presented does not indicate ranking of importance.

Services That Are Most Helpful Immediately Following a SCI

Participants shared their thoughts and opinions as to the most helpful services for individuals immediately following their injury. Common opinions included:

- Access to information and education, especially for family members and caregivers
- Quality comprehensive rehabilitation including mental health or adjustment counseling services
- Access to peer mentors and/or peer support
- Identification and access to appropriate equipment and accessibility needs (e.g., housing modifications)

A participant said, “Counseling and peer support, if people have not had a disability before, they do not know what is going on in their life, how they are going to cope. Access to counseling and peer support is essential.”

A survivor of SCI shared, “I went from the ICU right into inpatient, live-in rehabilitation. It was nine months. It was extremely intensive. You had physical therapy, occupational therapy, and recreational therapy…it needs to be a team effort.”

Services That Are Most Helpful for Individuals with SCI Long-Term

Interviewees provided many insights into the service needs for individuals with SCI over time. Most agreed that like the injury, needs are individualistic and change over time. They stressed that continued access to care and resources is essential.

Participants shared that the following services or supports are most helpful:

- Access to peer mentors and/or peer support
- Long-term access to comprehensive rehabilitation services
- Opportunities for healthy living (e.g., strength training, recreation, and exercise)
- Long-term support services (e.g., personal care assistance and transportation services)
- Transition support services (e.g., accessible housing and vocational training or resources)
- Access to financial resources or funding sources (e.g., insurance)

A large proportion of leaders within the SCI community commented on the shortening of inpatient rehabilitation stays and therefore emphasized the increased importance of providing access to long-term outpatient rehabilitation services as well as increasing opportunities to maintain or improve health. As stated by one participant, "really it is a health issue and keeping their bodies strong."

Participants commented that access to transition support services and activities including education, employment, active leisure and social experiences were helpful. "We need supports to promote independence. I waited a longtime to drive. I shouldn't have waited so long. It has made a world of difference in my life."

Identification of Existing Service Needs for Individuals with SCI

Leaders were asked their perception of the existing service needs for individuals with SCI and why these services are not being received. The following were mentioned by participants:

- Community reintegration and transitional services
- Rehabilitation services
- Personal care assistant services
- Accessible and affordable housing
- Transportation services
- Access to qualified, trained providers

The participants shared the following reasons that individuals are not receiving the identified services including: cost of services, decrease in programmatic funding, limited service/resource availability, limited knowledge of available services or resources, and programmatic restrictions.

Leaders shared that the distribution of available resources is not equitable throughout the state of Florida, especially for those individuals with SCI who live in rural areas. "There is a big disparity in services, especially support for family caregivers and those that live in rural areas…There are not as many services available. Addressing the disparity in rural and urban care options is critical."

Some notable quotes from interviewees included:

- "Community reintegration component is huge. We are seeing people who have been injured two and three years and are not reintegrating back into the community and to work. Clinically, I know these individuals should be capable of participating in life independently. Many of them don't have insurance, so they don't have access to services."
- "You only have a certain amount of time to respond after you are injured. If you send people home in six to eight weeks you haven't even begun to deal with the physical issues as well as the psychological issues."

- "The lack of personal care attendants. The one resource that is available requires folks to be employed or seeking employment. Those are not the folks that are the most severely disabled or have the most financial need."
- "There are not enough providers in the community that understand spinal cord injury…It is not only a funding issue, it is also a true resource issue. If they are in a location that does have some local resources they tend to do better versus if they live in rural areas without any services."
- "The services are not really out there and the systems themselves are terribly difficult to navigate. There is also not a lot of information out there. You have to know about the services that are out there and then you have to be able to navigate the system."

Issues Impacting Employment for Individuals with SCI

Gaining additional insights into the issues impacting employment and whether or not an individual who sustains a SCI will enter or return to the workforce was identified as an area of focus for this assessment. Key leaders shared:

- The fear of losing or losing benefits is one critical factor that individuals with SCI consider when contemplating returning to employment after their injury.
- Many survivors of SCI have a need for skill or vocational retraining after their injury.
- Personal motivation level as well as an individual's personality contribute to the likelihood of an individual securing gainful employment after a SCI.

The participants shared barriers for returning to the force including: workforce accessibility (environmental and architectural), employer discrimination, health-related issues (e.g., urinary tract infections, need for more flexible scheduling) and lack of employer education. One leader stated, "There are not a lot of disability friendly companies. There is a lot of discrimination out there. There is a lot of fear on the part of the employers. It falls upon the applicant to educate the employer about their disability."

Though barriers to employment exist and have actually decreased over time according to the leaders interviewed, one participant stressed: "The majority of people with disabilities are unemployed and the majority of people with disabilities live in poverty. These things are related. The best way to empower somebody, or give them the means to improve themselves, give them a paycheck."

Identification of Health-Related or Secondary Complications as a Result of SCI

The most frequent health-related or secondary complications discussed by leaders included: urinary tract infections, pressure sores, pain management, mental health issues, undiagnosed traumatic brain injuries, and limited opportunities to engage in healthy lifestyle maintenance behaviors such as exercise.

Participants commented that for the most part, medical offices are not accessible to individuals with SCI. A participant shared, "Access to care is a huge issue. I went to a brand new facility and there is not one accessible table in the entire facility…If you have trouble getting transportation and then you have get to the doctor's office and have trouble getting into the door, how likely are you to get the care that you need?"

The following areas were mentioned as having limited accessibility: exam tables, dentist offices, mammography facilities, gynecological tables, and scales. One participant suggested implementing an incentive program for doctors to purchase accessible equipment for their offices.

The interviewees also discussed the limited number of trained, qualified SCI providers. They stressed the importance of educating primary care providers as well as increasing the number of SCI specialists. The limited number of qualified providers requires individuals with SCI to be strong self-advocates to receive the most appropriate care for their health issues.

Identification of Greatest Issue Facing Individuals with SCI

Participants identified the following as the greatest issues currently facing individuals who sustained SCI and their families:

- Financial burden
- Need for additional rehabilitation or longer rehabilitation stays
- Access to long-term support services (e.g., personal care assistance, transportation, housing, and employment)
- Lack of transition services (e.g., transitional living facilities)
- Limited knowledge of available services or supports
- Access to opportunities for healthy living (e.g., exercise, recreation, and socialization).

Some notable quotes shared by interview participants included:

- "The overall lifestyle change. The ability to adapt to this catastrophic event. A spinal cord injury affects the entire family…A mixture of education and support from both professionals and non-professionals is needed to help family accept the injury and maintain hope for the future."
- "For quadriplegics with personal care needs, it is the lack of attendant care programs and resources and the weight the personal care places on families."
- "The knowledge. I learn every day. People don't have access to the knowledge that is out there. Resources are a big thing. Not knowing where to go or who to contact."
- "Access to rehabilitation. Now you only get six to eight weeks of rehabilitation versus nine months. That is not enough time to develop independence."
- "The cost of doing things to improve or enhance your quality of life. There is some basic equipment that is funded, but a lot of these things are too expensive…There are many technological advances, but the cost of these things hinders access."

Identification of Services That Could Impact the Lives of Individuals with SCI

The participants provided their thoughts as to what services could have the greatest impact on the lives of individuals with SCI. These services or supports include:

- Enhanced peer support or mentor programs
- Increased opportunities for recreation and socialization activities
- Enhanced opportunities for upfront services including rehabilitation
- Expanded personal care assistant and caregiver support services
- Increased knowledge of available resources, services, and information

Strengths and Weaknesses in the Current System of Care For individuals with SCI in Florida

Perceptions of the strengths of the current system of care for individuals with SCI in Florida were varied. Strengths include:

- Trauma system and acute medical services including rehabilitation services
- The Central Registry and the BSCIP

The trauma system and acute medical services in Florida were regarded as the greatest strength in the current system of care by a large proportion of participants. As one leader stated, "We have some very outstanding areas of the state with very high quality systems."

Other participants described the Central Registry and BSCIP as the greatest strength in the current system. Participants noted:

- "We have a statewide coordinated system. We have great public and private collaboration. We have the infrastructure to do a dynamite job."
- "The Central Registry. That is wonderful. That is a strength of Florida, it doesn't happen everywhere. There is information being collected and that can stimulate change."

The perceptions of the greatest weakness of the current system of care for individuals with SCI in Florida were also varied. The weaknesses include:

- Lack of funding
- Limited number of qualified SCI providers
- Limited number of personal care assistance programs
- Lack of awareness of services and resources
- Geographic variability of available services

The majority of participants identified the lack of funding for programs and services as the greatest weakness of the current system of care.

Limited coverage for inpatient rehabilitation was also viewed as a weakness in the state of Florida. "The Medicaid coverage here is very limited for acute inpatient rehabilitation. I think we are shooting ourselves in the foot for making this short upfront. We are ending up with re-hospitalizations. We are costing ourselves a lot in the future."

Finally, when addressing the issue of the geographic availability of services, one participant stated, "If you are in a place with better health services you will have better outcomes, especially if you live in rural areas of the state."

Issues for Special Populations

Women

Leaders with in-depth understanding of women's issues were asked to comment about unique barriers or issues that are encountered after sustaining a SCI. Many issues surrounded reproductive health and healthcare accessibility, including menstrual cycles, pregnancy, and children.

Our leaders shared some of the following comments:

- "For females you have many more issues including menstrual cycles, children, sexuality. I had sexuality counseling as part of my rehabilitation. That is not done here."
- "When I was pregnant, I had to seek out mentors on my own, which was extremely hard to do. I would call around for a doctor and even the high-risk clinics wouldn't treat me. There was no help available."
- "Mammograms is another major issue, it was very painful and very frustrating."

Caregivers of Individuals with SCI

Participants with expertise in caregiving for individuals with SCI were asked to comment on specific needs or issues encountered by caregivers of individuals with SCI. Most frequently noted was the need for respite care or assistance with personal care. Noteworthy comments include:

- "Caregivers come out ready to do what they need to do from a technical point of view. But so much depends upon the family structure and the family support systems. One person doing 24-7 care is virtually impossible. They are going to get burned out eventually. They need respite care."
- "We were not prepared to bring our son home. When my son came home, I had a 6 foot 4 inch, 190 pound infant dropped into our laps."

Additionally, participants shared that finding a qualified, trustworthy caregiver to provide personal care is very difficult. Participants suggested working with local colleges or nursing programs as possible avenues for training caregivers and educating future health professionals about individuals with disabilities.

Veterans with SCI

Experts who work with Florida's veterans with SCI provided insights into the service and support needs for this population. All of the experts emphasized the high quality medical and rehabilitation care that the veterans receive after their injuries through their healthcare system. The experts also noted that there is considerable need for partnership with state agencies and community-based organizations to strengthen the needed long-term community-based supports for Florida's veterans. One participant said, "After healthcare, because of limited resources and staffing, it [Veterans Administration] cannot provide all of things individuals with SCI need, such as peer mentoring, job placement, and recreation. That is why our partnership with the Florida Department of Health is so important."

Experts also shared that there are similar service and support needs for the civilian and veteran population. Similarities include the need for age-appropriate transitional living facilities as well as the limited service availability in Florida's rural areas. They also emphasized that these needs are increased due in part to the shortening of inpatient acute rehabilitation stays.

Pediatrics with SCI

Participants with expertise in working with children with SCI were asked to share needs or issues encountered by this population. Participants provided insight into three main areas: the importance of working with local schools to promote successful reintegration; the need for pediatric SCI specialists; and the need for ongoing rehabilitation as children mature over time.

- All experts viewed the schools as a vital partner in promoting successful reintegration of children back into the community after their injury, but acknowledged that limited funding has made this transition more difficult.
- Experts identified needing pediatric specialists in both urology and neuropsychology. They suggested training pediatric primary care providers in issues related to SCI as a way to decrease the gap in knowledge.
- In regards to the need for ongoing rehabilitation over time, one expert stated, "They need services as they reach their development milestones. They need to be able to access those needed services. If they are hurt very young, their parents are taught everything. So they need to be taught their own independence. Kids grow up."

Also of note, the experts stressed how important technology has become to children who sustain a SCI. Access to technology provides information as well as opportunities for socialization and peer support.

Minorities with SCI

Minorities with SCI were asked to share barriers to care during the interview process. Identified issues included the need to provide bilingual staff at training and education sessions as well as the additional difficulties minorities face when trying to navigate the healthcare system, particularly if they are non-English speaking. A participant shared, "Spanish-speaking people have trouble navigating the healthcare system, especially when the need to file a complaint to communicate their issues or needs to them. There are not people available to listen or translate."

Key Leader Interview Summary

- Most helpful services immediately following a SCI include: access to information and education; quality comprehensive rehabilitation; access to peer mentors and/or peer support; and the identification of or access to appropriate equipment and accessibility needs.

- The following long-term services were identified as the most helpful: access to peer mentors and/or peer supports; access to needed rehabilitation services; opportunities to engage in healthy living; support services (e.g., personal care assistance and transportation); transition support services (e.g., housing and vocational training); and access to financial resources or funding supports.

- Issues impacting employment include: the fear of losing benefits; the need for vocational re-training; and personal motivation factors.

- The most frequently mentioned health-related issues or secondary complications as a result of SCI include UTIs, pressure sores, pain management, mental health issues, undiagnosed traumatic brain injuries, and limited opportunities to engage in healthy lifestyle behaviors.

- Leaders stressed the lack of accessibility in medical providers' offices.

- Most frequently mentioned service needs for individuals with SCI include: community reintegration or transition services, rehabilitation, personal care services, accessible and affordable housing, transportation, and access to qualified trained providers.

- Biggest issues facing individuals with SCIs and their families include: financial burden, need for additional rehabilitation services, access to long-term support services (e.g., personal care, transportation, housing, and employment), need for transitional services, limited knowledge of available services and supports, and limited opportunities to access healthy living behaviors.

- The following services could impact the lives of individuals who sustain SCI and their families: enhanced peer support or mentor programs, increased opportunities for recreation and socialization, enhanced opportunities for upfront services (e.g., rehabilitation), expanded personal care assistant and caregiver support programs, and increased knowledge of available resources, services, and information.

- Strengths of the current system of care for individuals with SCI include: the trauma and acute medical services, the BSCIP, and the CR. The weaknesses identified were: lack of funding, limited number of SCI providers, limited number of personal care assistance programs, lack of awareness of services and resources, and geographic variability of service availability.

- Issues for special populations include:

    - Women: reproductive health and healthcare accessibility
    - Caregivers: need for respite care and personal care assistance
    - Veterans: need for partnership with community-based organizations and state agencies for additional services and supports, outside of the healthcare arena
    - Pediatrics: transition back to school is essential and there is a need for ongoing rehabilitation as children mature
    - Minorities: individuals with limited or no ability to speak English have difficulty navigating the healthcare system, particularly in times of crisis

Spinal Cord Injury Consumer and Caregiver Online Survey

To gain additional insights into the needs and issues impacting Florida's survivors of SCI and their caregivers, an online needs assessment survey was conducted. The survey, based on the Virginia Spinal Cord Injury Needs Assessment, was available through WellFlorida Council's website during the months of October and November 2009. Please see the Technical Appendix of this report for detailed data tables.

One hundred and nineteen individuals, 98 SCI survivors and 21 caregivers, participated in the online survey.

SCI Consumer Survey Findings

SCI Consumer Demographics

Ninety-eight SCI consumers participated in the survey, representing 27 (40 percent) of Florida's 67 counties. Of the participants who provided demographic information:

- 64.6 percent were male
- 72.6 percent were between 35 and 64 years of age
- 71.4 percent were white
- 9.8 percent were of Hispanic ethnicity
- 60.9 percent completed at least some college

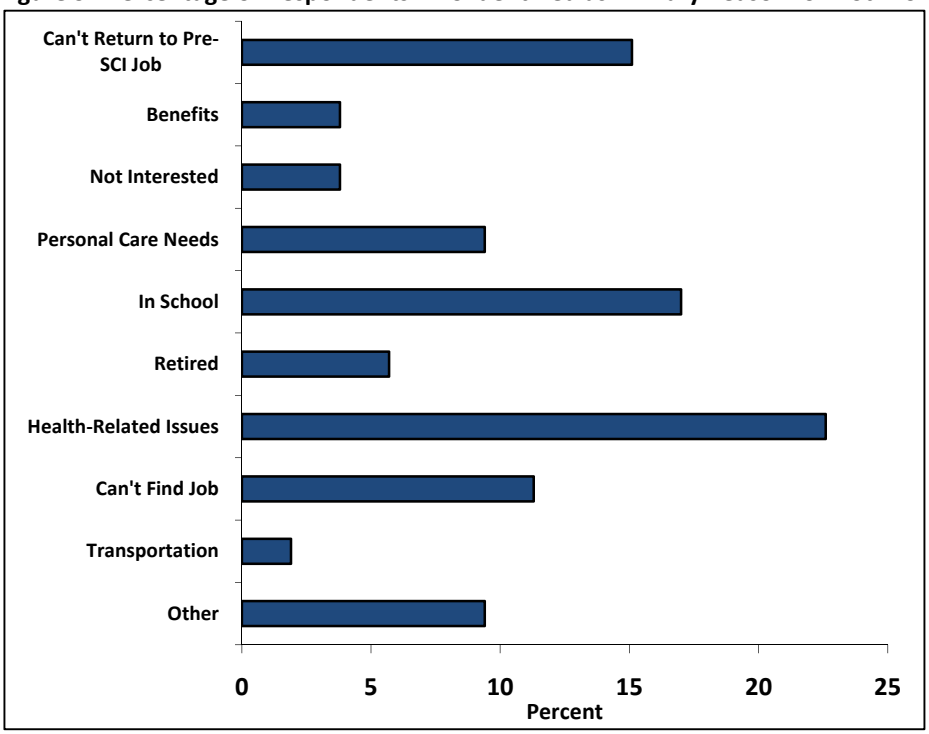
Over 61 percent of survey respondents reported that their SCI occurred in Florida, with 64.5 percent of injuries occurring more than 5 years ago. Just over 63 percent of respondents reported their highest level of injury to be between C1-C8.

SCI Consumers and Employment

Over 79 percent of SCI consumers reported working prior to their injury and nearly 44 percent reported currently working at a job in which they receive pay. Of those currently working, approximately 50 percent reported currently working full-time (40 hours per week).

For SCI consumers that are currently not working, health-related issues were identified most frequently as the reason for not currently working (Figure 9).

Figure 9: Percentage of Respondents who Identified as Primary Reason for Not Working after Sustaining SCI



Source: SCI Consumer Caregiver Online Survey, 2009.

SCI Consumers and Health

Over 85 percent of SCI consumers reported that in general their health was good, very good, or excellent.

Over 87 percent reported currently having health insurance, with the majority reporting Medicare, employer health plans, and Medicaid as their current kind of insurance. More than 58 percent of respondents reported seeing either a family practice or internal medicine doctor for the majority their medical issues. An additional 29 percent reported seeing a rehabilitation medicine doctor/physiatrist for their routine medical issues.

In the past 12 months, over nine percent of respondents reported a time when they were not able to receive needed medical care, citing the cost of care as the most common reason for not receiving care.

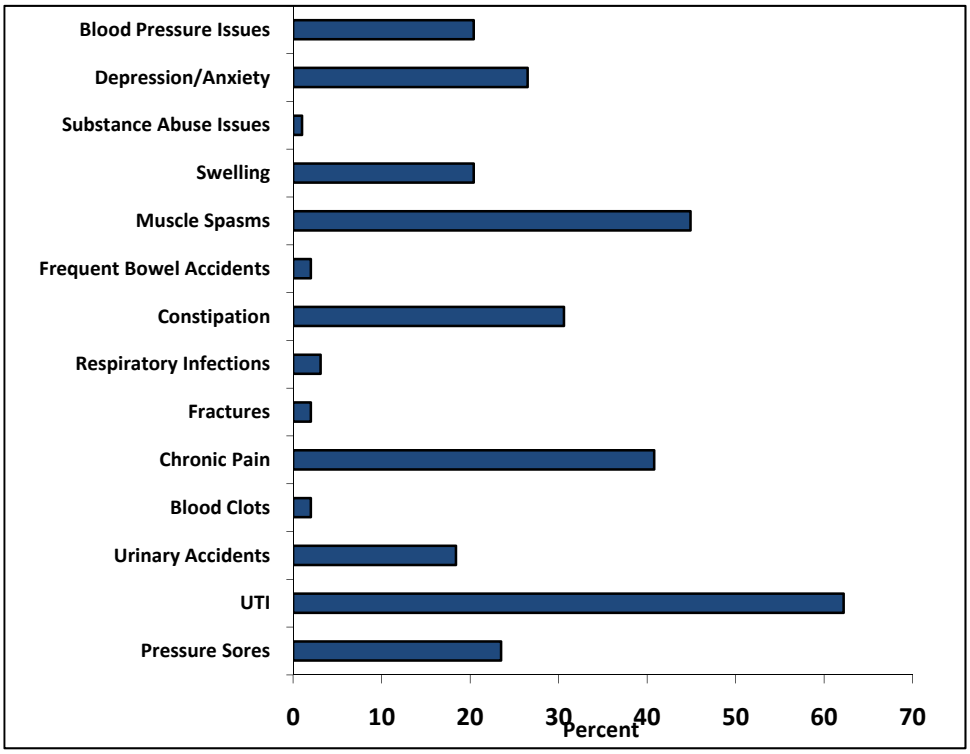
Over 53 percent of SCI survivors reported having a bad experience when receiving or attempting to receive medical care since sustaining their injury. Nearly 39 percent of those reported that the bad experience was related to their provider not understanding SCI needs. Other comments included:

- "Durable medical equipment is not well understood or supported in the healthcare system."
- "Doctors on four occasions in the emergency room did not know what autonomic dysreflexia was."
- "Inaccessible facilities."
- "Insurance did not cover the services I needed."

When asked in general how satisfied you are with the medical care you receive, 76.6 percent of respondents reported being satisfied or very satisfied.

SCI survivors were asked to share if they had experienced any of the following problems within the past 12 months (Figure 10). Of the issues listed, urinary tract infections, muscle spasms/uncontrolled spasticity, and chronic pain were the most frequently reported issues.

Figure 10: Percentage Reporting Experiencing Health Problem within Past 12 Months.



Source: SCI Consumer Caregiver Online Survey, 2009.

SCI Consumers and Level of Assistance Needed for Activities

SCI consumers were asked to share the level of assistance they required for identified activities of daily living (Table 10). At least 20 percent of respondents reported requiring assistance for the following activities: positioning in bed, getting in/out of bed, managing bladder activities, managing bowel activities, getting dressed/undressed, bathing/showering, preparing meals, housekeeping, getting in/out of a car or van, and getting to social activities and appointments. Housekeeping, managing bowel activities, and preparing meals had the highest percentage of respondents reporting that they are currently not able to do these activities, but they would like to.

For the activities that consumers reported needing assistance with, their spouse or significant other was identified most frequently (48.1 percent) as providing the most help. Over 15 percent of respondents reported using personal assistance services to help with these activities. Nearly 89 percent of respondents rated the quality of the assistance received by their caregiver as very good or excellent.

Table 10: Percentage of Respondents Reporting Level of Assistance Needed for Activities.

Activity	Respondents	Without Help	With Assistance	Not Able to Do	No Need To Do
Positioning in bed	96	63.0	25.0	10.9	1.1
Getting in/out of bed	92	55.4	33.7	9.8	1.1
Getting around in wheelchair	89	84.3	6.7	1.1	7.9
Pressure relief in wheelchair	91	80.2	4.4	2.2	13.2
Managing bladder activities	91	61.5	23.1	12.1	3.3
Managing bowel activities	90	44.4	35.6	17.8	2.2
Getting dressed/undressed	92	50.0	35.9	12.0	2.2
Bathing/showering	92	46.7	40.2	10.9	2.2
Brushing teeth, combing hair	92	83.7	12.0	2.2	2.2
Managing medications	90	73.3	17.8	4.4	4.4
Preparing meals	91	38.5	41.8	15.4	4.4
Eating	92	85.9	8.7	3.3	2.2
Housekeeping	92	26.1	40.2	28.3	5.4
Banking/paying bills	92	77.2	16.3	4.3	2.2
Getting in/out of car/van	92	64.1	30.4	3.3	2.2
Getting to/from work	91	49.5	9.9	11.0	29.7
Getting to/from social activities	92	57.6	32.6	4.3	5.4
Getting to/from appointments	92	58.7	35.9	3.3	2.2
Using the telephone	92	92.4	5.4	0.0	2.2

Source: SCI Consumer Caregiver Online Survey, 2009.

SCI Consumers Service or Support Needs

SCI survivors were asked to identify services they would like to receive for a series of categories including counseling/support groups; cancer screenings; reproductive health; dental and vision care; equipment and supplies; education, employment, and finances; and others. Detailed tables summarizing service and support needs are available in the Technical Appendix of this report. Additionally, respondents were asked to share the primary reason they were not receiving the needed services.

Counseling and Support Groups:

- SCI support groups (32.2 percent) and peer support in one-on-one formats (16.7 percent) were identified most frequently as needed services.
- Respondents identified that services not being available in their area as the primary reason they are currently not receiving the identified services.

Cancer Screenings:

- Between 10 and 20 percent of survey respondents reported that they would like to receive either a pap smear, mammography, and/or prostate screenings.
- Over 35 percent of respondents reported that the primary reason they have not received these services is because they are not comfortable seeking desired services. Respondents also shared that accessibility for these services is limited.

Reproductive Health:

- Nearly 18 percent of respondents reported they would like to receive information on having children and 28.8 percent would like information on sexual functioning.
- The most common reason respondents identified as not receiving these services was because they were not comfortable seeking the desired services.

Dental and Vision Care:

- Over 30 percent of respondents would like to receive preventative dental care, restorative dental care, and vision exams.
- The most frequent reason for not seeking these services includes cost and limited insurance coverage.

Equipment and Supplies:

- Respondents would like to receive wheelchair maintenance (27.5 percent), new updated equipment (39 percent), and medical supplies (22.8 percent).
- Cost and insurance coverage was identified most frequently as the reason for not receiving desired services.

Education, Employment, and Finances:

- In regards to employment, over 20 percent of respondents would like to receive services related to each of the following: developing a new job skill, providing workplace modifications or improving workplace accessibility, and assistance with keeping a job.
- Over 31 percent of respondents would like to receive retirement planning services.

Other:

- Over 33 percent of respondents would like to receive services in regards to obtaining and using assistive technology.
- Nearly 44 percent of respondents would like access to a fitness center or gym.
- Transportation services are needed by 21 percent of survey respondents and nearly 18 percent requested accessible, affordable housing.
- Respondents identified services not being available in their area as well as not being able to afford desired services most frequently as the primary reason for not obtaining the desired services.

SCI Caregiver Survey Findings

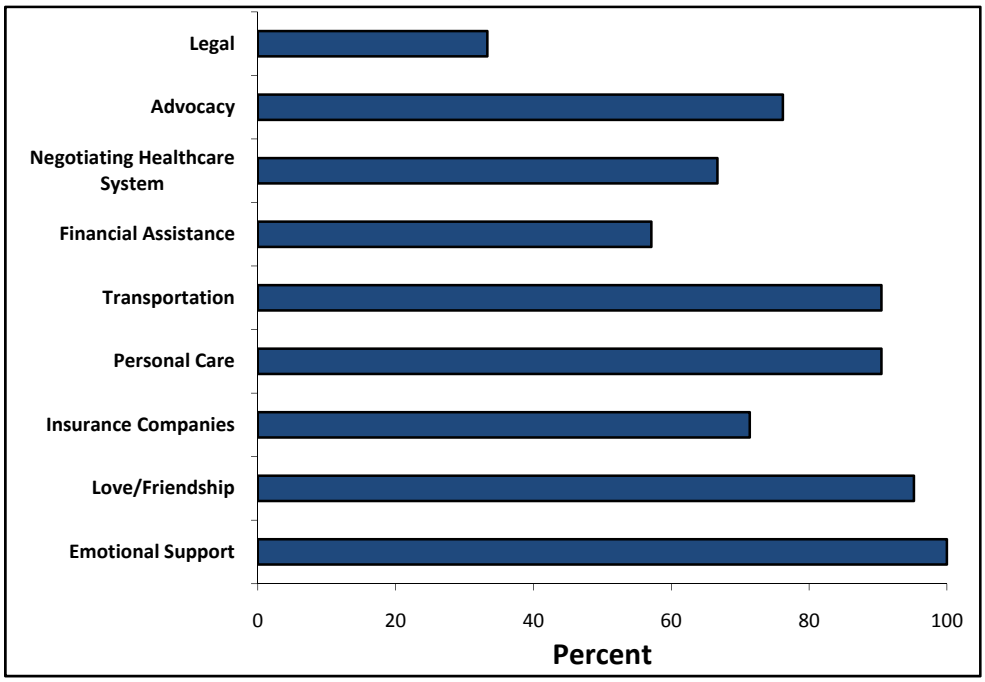
SCI Caregiver Description

Twenty-one caregivers of individuals with SCI participated in the online survey.

- Over 76 percent of the caregivers who completed the survey reported being either a spouse/partner or parent of the individual with SCI for whom they were caring.
- More than 50 percent of respondents reported providing more than 40 hours per week of personal care assistance and 55 percent reported that their personal employment was limited due to the time spent providing personal care assistance to the individual with SCI.

Caregivers were asked to share the type of assistance provided to the individual with SCI (Figure 11). Over 90 percent of respondents reported providing emotional support, love/friendship, personal care, and transportation services to the individual with SCI.

Figure 11: Percentage Reporting Providing Assistance.



Source: SCI Consumer Caregiver Online Survey, 2009.

The caregivers were also asked to identify their primary sources of emotional and physical support (Table 11). Other family members and friends provide the most emotional support for the survey respondents. Other family members and healthcare providers provide the most physical support for caregivers.

Table 11: Percentage of Caregivers who Reported Primary Source of Physical and Emotional Support.

Support Sources	Emotional	Physical
Family Members	66.7	57.1
Healthcare Providers	23.8	38.1
Church	33.3	9.5
Friends	66.7	23.8
Other Community Organizations	14.7	19.0
Other Individuals or Families with SCI	19.0	4.8

Source: Consumer Caregiver Online Survey, 2009.

SCI Caregivers Service or Support Needs

The caregivers of individuals with SCI were asked to identify services they would like to receive including counseling and support group services; care for the individuals with SCI; and others. Detailed data tables summarizing service and support needs are available in the Technical Appendix of this report. Additionally, respondents were asked to share the primary reason they were not receiving the needed services.

Counseling and Support Groups:

- Support groups for families and caregivers (63.2 percent), peer support in one-on-one formats (55.6 percent), family support/family counseling (50.0 percent), and mental health counseling (31.6 percent) were identified most frequently as needed services.
- Respondents identified cost of services as the primary reason they are currently not receiving the identified services.

Care for the Individual with SCI:

- Between 40 and 50 percent of caregiver respondents reported that they would like to receive assistance with dressing and bathing, eating and meal preparation, transferring survivor in and out of bed, and bowel and bladder programs.
- Cost was reported most frequently as the primary reason they have not received these services.

Other:

- Over 70 percent of caregivers reported needing to receive financial assistance and nearly 53 percent of caregivers reported the need for social activities.
- Respondents identified not being able to afford desired services most frequently as the primary reason for not obtaining the desired services.

Caregiver Perception of SCI Consumer Service or Support Needs

Caregivers were asked their perception about the service needs for the individuals they care for in a series of categories including counseling/support groups; cancer screenings; reproductive health; dental and vision care; equipment and supplies; education, employment, and finances; and others. Detailed data tables summarizing service and support needs are available in the Technical Appendix of this report. Additionally, respondents were asked to share the primary reason the individual with SCI was not receiving the needed services.

Counseling and Support Groups:

- SCI support groups (66.7 percent), peer support in one-on-one formats (66.7 percent), and family support and family counseling (46.7 percent) were identified most frequently as needed services.
- Respondents identified that the cost of services is the primary reason they are currently not receiving the identified services.

Cancer Screenings:

- Between 20 and 30 percent of caregivers reported that the individual with SCI for whom they care need to receive either a pap smear, mammography, and/or prostate screenings.
- Over 35 percent of respondents reported that the primary reason they have not received these services is because of the cost.

Reproductive Health:

- Nearly 29 percent of caregivers reported that the individual they care for would like to receive information on having children and 40.0 percent would like information on sexual functioning.
- The most common reason respondents identified as not receiving these services was because they were not comfortable seeking the desired services.

Dental and Vision Care:

- Over 50 percent of caregivers reported that the individual with SCI they care for would like to receive preventative dental care and restorative dental care.
- The most frequent reason for not seeking these services includes cost and limited insurance coverage.

Equipment and Supplies:

- Caregivers reported that the individuals for whom they care would like to receive wheelchair maintenance (50.0 percent), new updated equipment (64.3 percent), and medical supplies (35.7percent).
- Cost and insurance coverage was identified most frequently as the reason for not receiving desired services.

Education, Employment, and Finances:

- In regards to employment, over 40 percent of respondents would like to receive services related to developing a new job skill, providing workplace modifications or improving workplace accessibility, and assistance with keeping a job.
- Nearly 54 percent would like assistance with budgeting and money management, while just less than 43 percent of respondents would like to receive retirement planning services.

Other:

- Over 61 percent of respondents would like to receive services in regards to obtaining and using assistive technology.
- Half of the caregivers reported the individuals they care for would like access to a fitness center or gym and more than 63 percent reported a need for opportunities for socialization.
- Transportation services are needed by 69.2 percent of survivors of SCI and more than 57 percent requested accessible, affordable housing.
- Respondents identified not being able to afford desired services as the primary reason for not obtaining the desired services.

SCI Consumer and Caregiver Online Survey Summary

Survivors of SCI (98 respondents) in the state of Florida reported the following:

- Of the SCI survivors who reported not working after their injury, health-related issues were cited most frequently as the primary reason for not obtaining employment after their injury.

- Over 85 percent of SCI consumers report their health was good, very good, or excellent.

- Of the SCI survivors that reported having a bad experience when receiving or attempting to receive medical care, nearly 39 percent of respondents reported that the issue was related to their provider not understanding their SCI needs.

- At least 20 percent of respondents reported needing assistance with the following activities: positioning in bed, getting in/out of bed, managing bowel or bladder activities, getting dressed/undressed, bathing/showering, preparing meals, housekeeping, getting in/out of a van/car, and getting to/from social activities or appointments. They noted that these services were most frequently provided by their spouses/partners.

- Survivors stated they would like to receive the following services most frequently: SCI support groups, preventative and restorative dental care, vision exams, wheelchair maintenance, updated equipment, obtaining and using assistive technology and access to fitness facilities. Barriers to these services included cost, limited service availability, and respondents not being comfortable seeking desired services.

Caregivers of SCI survivors (21 respondents) in the state of Florida reported the following:

- Caregivers were most likely to be spouses or partners of the survivor of SCI. The majority of the caregivers reported providing more than 40 hours of care per week.

- Over 90 percent of caregivers reported providing the following supports to persons with SCI: emotional, love/friendship, personal care, and transportation.

- Caregivers reported wanting to receive the following services: support groups for families and caregivers, peer support in one-on-one formats, family support/ counseling, financial assistance, and social activities. Additionally, between 40 and 50 percent of caregivers reported needing assistance with

the following activities: dressing and bathing, eating and preparing meals, transferring survivors in and out of bed, and bowel and bladder programs.

- Caregivers perceived needs of the SCI survivor to include: SCI support groups, peer support in one-on-one formats, preventative and restorative dental care, wheelchair maintenance, updated equipment, transportation services, obtaining and using assistive technology, access to fitness facilities, and opportunities for socialization.

Conclusion

The findings from *Spinal Cord Injury in Florida: A Needs and Resources Assessment,* summarize the needs of individuals with SCI throughout Florida. Please see the Technical Appendix accompanying this assessment that includes all detailed data tables for all the indicators presented in this report as well as research protocols and methodologies.

Summary of Findings

Demographic and socioeconomic characteristics of a region are associated with healthcare access and health outcomes. Key indicators that may be associated with SCI in Florida and its BSCIP Regions include:

- The population of the state of Florida is projected to increase through the year 2030.
- Florida's population tends to be "older" than the population of the country as a whole. Additionally, nearly 25 percent of Florida's population is between the ages of 15 and 34 years, which represents the most frequently injured age group by the NSCISC.
- Differences in the racial and ethnic makeup across BSCIP Regions may be contributing to differences observed in SCI-related indicators.

The prevalence and incidence of SCI in the state of Florida are fairly unreliable based on the lack of recent studies and consistency of research methodologies. Therefore, SCI-related indicators are used as proxy measures to provide insights into the SCI population in the state. Key findings across the SCI-related indicators presented in this report include:

- The national incidence of SCI is 40 cases per million. Based on Florida's population, approximately 761 SCIs occurred in Florida during 2009. As the population of Florida increases through 2030, it is anticipated that the incidence of SCI will increase as well.
- Over 800 SCI-related hospitalizations occur in Florida per year. Floridians between the ages of 45 and 64 years and 15-34 years accounted for over half of all SCI-related hospitalizations and males were more than two and a half times more likely to be hospitalized for SCI than females. Falls and motor vehicle accidents were the leading causes of SCI-related hospitalizations.
- Florida's CR, which collects information on individuals who experience moderate to severe brain and SCI, reported 2,730 new injury referrals, approximately 683 per year, from calendar year 2005 through 2008. Florida's Trauma Registry, which collects patient level data from the state's verified trauma centers, reported more than 1,800 discharges for patients with SCI identified as their primary diagnosis from 2006 through 2008. For both state registries, motor vehicle accidents accounted for largest percentage of SCIs.
- The Florida Department of Health, BSCIP serves individuals with SCI. From 2005 through 2008, the Trust Fund Program served nearly 2,000 individuals with SCI and the Home and Community-Based Waiver provided services to over 250 individuals with SCI.

Members of the SCI community were asked to provide insights into their current service and support needs through participating in focus groups, online surveys, and one-on-one interviews. 215 members of the SCI participated.

The SCI community identified the following as the biggest issues for SCI in the state of Florida (order does not indicate ranking):

- Access to services that promote independence (e.g., personal care and transportation)
- Financial burden
- Lack of qualified, knowledgeable SCI providers
- Decreased access to appropriate rehabilitation services
- Access to information and education
- Lack of opportunities to promote healthy living
- Lack of transition support services (e.g. transitional living facilities)

The SCI community identified the following as the most needed services or supports for SCI in Florida (order does not indicate ranking):

- Rehabilitation
- Personal care assistance
- Accessible, affordable housing
- Transportation
- Employment or vocational services
- Family/caregiver support services
- Peer support

Next Steps

Under the guidance of the FSCIRC Advisory Group, findings from *Spinal Cord Injury in Florida: A Needs and Resources Assessment,* will be used as a critical piece when developing Florida's first five-year strategic plan for SCI. The strategic plan will identify key strategic issues, develop goals and objectives, and determine action steps for achieving the outlined goals and objectives. It is anticipated that the strategic plan will be completed by June 2010.