

About the project

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 needs of individuals living with SCI.

Assessment activities included:

- Demographic and socio-economic data analysis
- Analysis of SCI-related data indicators
- SCI consumer and caregiver input (i.e., focus groups, one-on-one interviews and online surveys).

Findings from this assessment will be used in the development of Florida's first five-year strategic plan for SCI, which will be completed by June 2010.

For more information, please contact FSCIRC:

800-955-8544
info@flspinalcord.us



Spinal Cord Injury in Florida

A Needs and Resources Assessment



Spinal Cord Injury— What Does it Mean to Survivors?

“Everything has changed since the accident...

I can't do what I want or go where I want. I have to depend on others, where before the accident I was completely independent.” **“I think of my family. I think it hurts them more than it hurts me. I just keep on going.”** **“Disability never even occurred to me until I got injured.”** **“Spinal cord injury depends on what you make of it. It all depends on your attitude and how you decide to move on from your injury.”** **“It redefines your life.”**

Responses from the Spinal Cord Injury (SCI) Community

Biggest Issues for SCI in Florida

- 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
- Access to information and education
- Lack of opportunities to promote healthy living
- Lack of transition support services (e.g., transitional living facilities)

Most Needed Services for SCI in Florida

- Rehabilitation
- Personal Care Assistance
- Accessible, Affordable Housing
- Transportation
- Employment or Vocational Services
- Family/Caregiver Support Services
- Peer Support

Issues Impacting Employment Post Injury

- 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 issues: UTIs, 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 for SCI survivors

WellFlorida asked...

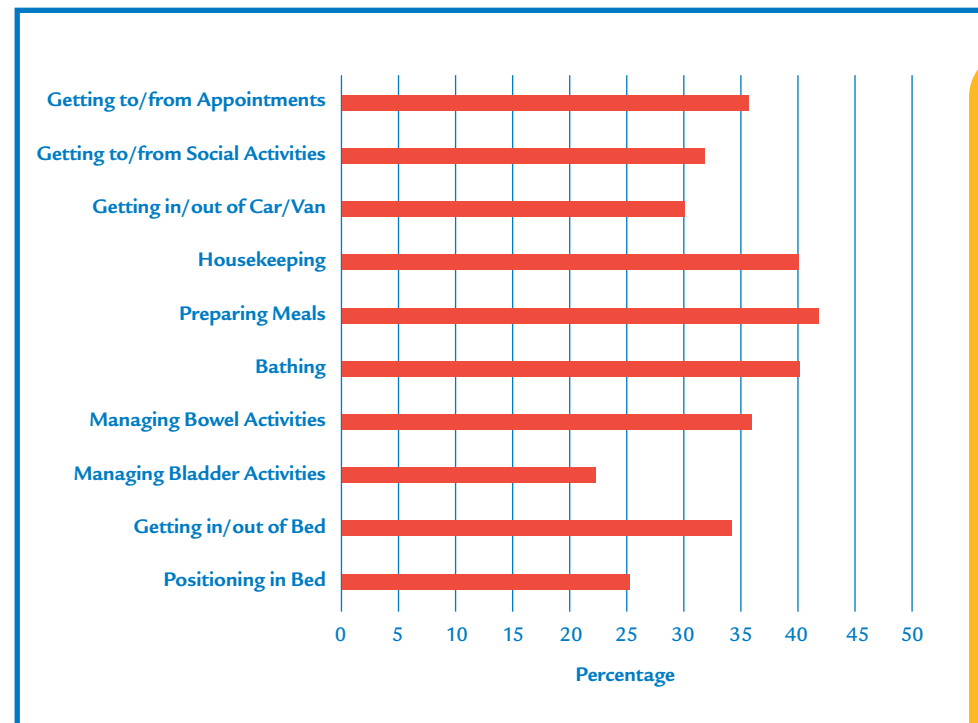
10 SCI Survivor Focus Groups:

- 71 survivors of SCI
- 72% male
- 66.2% white
- More than 25% Hispanic
- Average age nearly 45 years old
- Average of 12.7 years post injury

25 Key Leaders

119 SCI Survivors and Caregivers

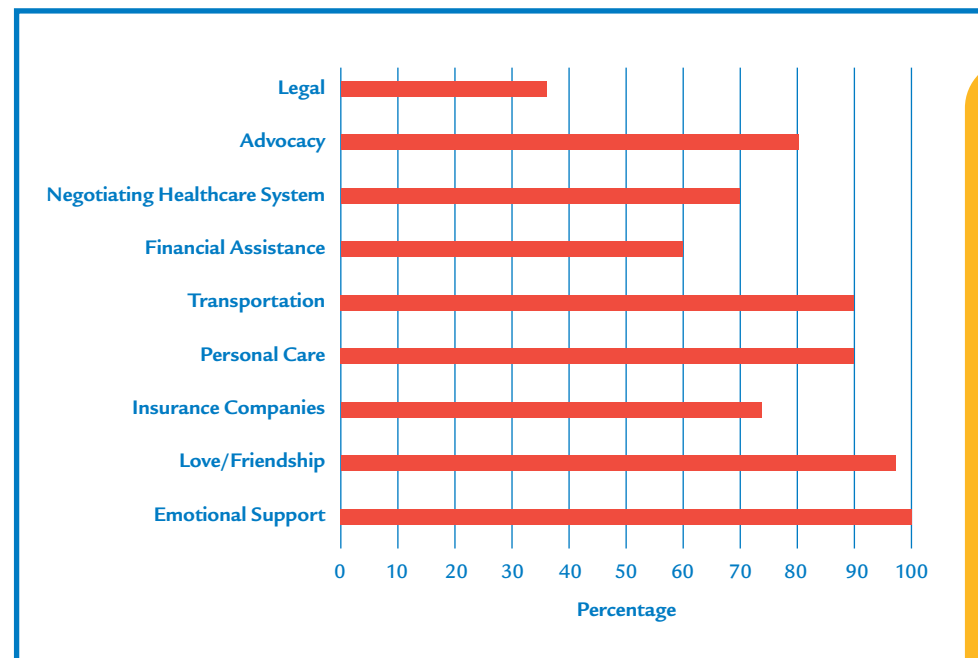
SCI Consumer and Caregiver Online Survey Findings



Percent of SCI Consumers Requiring Assistance to Perform Daily Activities



98 SCI consumers participated in the online survey. More than 60% of consumers reported injuries between C1-C8 that occurred more than 5 years ago. More than 20% of consumers reported needing assistance with the identified activities.



Percent of SCI Caregivers Providing Identified Support



21 caregivers for individuals with SCI participated in the online survey. More than 75% of caregivers reported being a spouse/partner or parent to the individual they cared for. More than 50% reported providing more than 40 hours of personal care per week.

Spinal Cord Injury (SCI)-Related Indicator Data Summary

SCI Incidence in Florida

Estimated Number of New SCIs 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.

The national incidence of SCI is estimated to be approximately 40 cases per million, resulting in 12,000 new cases each. Based on these estimates, approximately 760 new SCIs occurred in Florida during 2009.

SCI Program Information

SCI Program Information, 2005-2008.

Program	Total Number
Central Registry New Injury Referrals	2,730
BSCIP Trust Fund	1,987
BSCIP Home and Community-Based Medicaid Waiver	256

Sources: Florida Department of Health, Brain and Spinal Cord Injury Program, RIMS, Accessed 10-09.

The Florida Department of Health, BSCIP identifies and serves individuals with SCI in the state of Florida. The Central Registry (FS 381.74) collects information on individuals who experience a moderate-to-severe brain or spinal cord injury, such as name, age, residence, and type of disability. The BSCIP Trust Fund works to assist eligible residents who sustain a SCI the opportunity to obtain necessary services enabling them to return to their community. The BSCIP Home and Community-Based Medicaid Waiver provides long-term care to SCI survivors to help maintain their ability to live outside of institutional settings.

SCI-Related Hospitalizations

Average Annual SCI-Related Hospitalization Characteristics, 2006-2008.

Total Hospitalizations	Number	Percent	Rate
	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; Population estimates from Florida Charts 2006-2008.

An average of 807 SCI-related hospitalizations occur in Florida each year with falls and motor vehicle accidents the most likely causes.