

# Spinal Cord Injury in Florida



STRATEGIC PLAN 2010-2015

# Introduction

I recognize and sincerely thank the staff of WellFlorida Council for their professionalism and hard work in conducting statewide surveys on the current state of spinal cord injury (SCI) programs, services and initiatives. WellFlorida has been meticulous in their efforts to compile and analyze survey results and tireless in their efforts to conduct comprehensive in-person needs and resource assessments with SCI stakeholders across the state. This data, along with comments from key SCI stakeholders, are crucial elements in developing the building blocks necessary in the advancement of recommendations for the SCI long-term strategic plan.

The FFAST Spinal Cord Injury Resource Center Advisory Committee fulfilled a critical role as well by serving as advisors, in conjunction with administrators with the Brain and Spinal Cord Injury Program and key stakeholders. This group came together as partners to collaborate on the development of recommendations for a statewide strategic plan to address the long-term needs of individuals with SCI.

Florida has one of the highest proportions of individuals with disabilities inclusive of individuals with SCI, and that demographic trend is expected to continue into the future. These population factors make it imperative for

officials with the Florida Department of Health, Brain and Spinal Cord Injury Program to plan so that our state is adequately prepared to meet the needs of individuals with SCI in the future. The adoption of recommendations contained within this report will assist Florida in addressing some of the most pressing needs affecting individuals with SCI and their families, both now and for decades to come. In addition to a responsible, long-term strategic plan, sufficient funding and the collaboration of key stakeholders are necessary to accomplish the objectives set forth in this report.

I trust that this report—which is based on verifiable data and statistical analyses—and the recommended goals, objectives, and action steps will help guide the Governor, the Legislature, state officials and SCI partners as they join forces to realize the vision of well-coordinated services for individuals with SCI and their families who reside in the great State of Florida.

**Steve Howells**  
Executive Director  
Florida Alliance for Assistive Services and Technology, Inc.

## About the project

The Florida Department of Health Brain and Spinal Cord Injury Program (BSCIP) and its partners, the Florida Alliance for Assistive Services and Technology, Inc. (FAAST), and the FFAST Spinal Cord Injury Resource Center (FSCIRC) and its Advisory Committee have come together to conduct Florida's first comprehensive needs and resources assessment of individuals with spinal cord injury (SCI) and to develop a five-year strategic plan for SCI in Florida.

For more information, please contact FFAST:  
888-788-9216  
[www.FAAST.org](http://www.FAAST.org)



# 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...

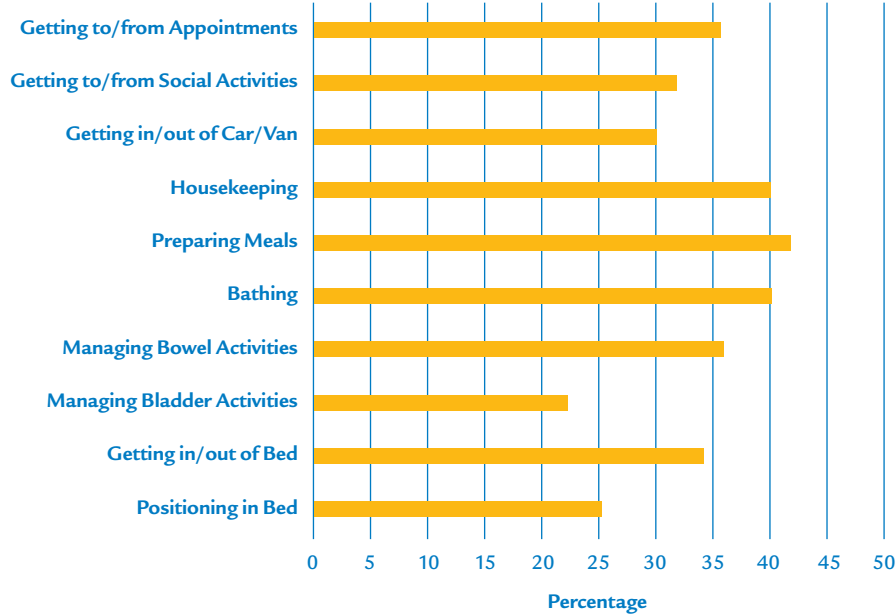
#### 10 SCI Survivor Focus Groups:

- 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

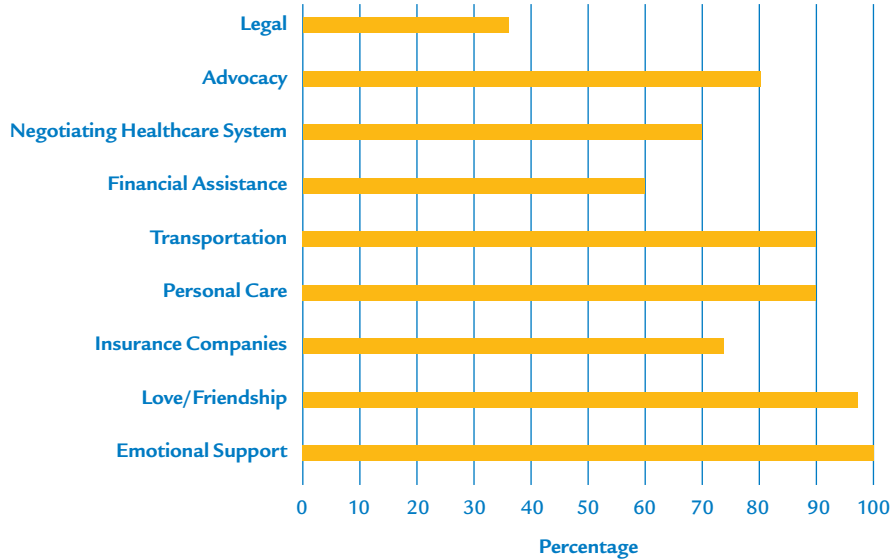
# SCI Consumer and Caregiver Online Survey Findings



## 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.

# Strategic Issue 1: Statewide advocacy initiatives are needed to enhance access to and increase funding for SCI services and supports.

## Strategy 1.1 Explore funding options for Transitional Living Facilities (TLF) in the state of Florida.

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
1. Review best practices. 2. Explore possible expansion of Medicaid Waiver Program to include transitional living services. 3. Promote collaboration and partnerships with existing institutions such as universities and hospitals. (Emphasize benefits for collaboration—cost/benefit analysis, hospitals vs. TLF, quality-of-life survey.) 4. Explore opportunities to support funding for existing programs. 5. Advocate for expansion of insurance policies to cover TLF.	BSCIP Advisory Councils Taskforce; executives from TLF	Qualified experts; staff; time; access to data; research on other states' resources and practices	Medium Term: 1–2 years

### Guide to chart headings and acronyms

#### Chart Headings

**Strategy:** The overarching method/approach that will address the priority issue. There will be one strategy for each priority issue.

**Action Step/Activity:** The critical steps or activities needed to achieve the identified strategy.

**Resources Needed:** Financial, organizational, individual, etc. resources that will be needed to complete the desired strategy.

**Responsible Parties:** Agencies, organizations, individuals, etc. that will be responsible for or participate as key contributors to the completion of the desired strategy.

**Time Horizon:** Immediate (0-6 Months); Short Term (6 Months-1 Year); Medium Term (1-2 Years); Long Term (>2 Years)

#### Acronyms

**ADA** Americans with Disabilities Act

**AHCA** Florida Agency for Health Care Administration

**AT** Assistive Technology

**ATE** Assistive Technology and Education

**BSCIP** Brain and Spinal Cord Injury Program administered by the Florida Department of Health

**CIL** Centers for Independent Living

**DME** Durable Medical Equipment

**DOH** Florida Department of Health

**DOH/CMS** Florida Department of Health Children's Medical Services

**FAAST** Florida Alliance for Assistive Services and Technology, Inc.

**FACIL** Florida Association of Centers for Independent Living

**FDOA** Florida Disabled Outdoors Association

**FLORIDAARF** Florida Association of Rehabilitation Facilities

**FSCIRC** Florida Spinal Cord Injury Resource Center

**HUD** U.S. Department of Housing and Urban Development

**NSCIA** National Spinal Cord Injury Association

**OT** Occupational Therapy

**PT** Physical Therapy

**PVA** Paralyzed Veterans of America

**TAC** Technical Advisory Committee

**VA** U.S. Department of Veterans Affairs

## Strategy 1.2

### Advocate for enhanced access to and funding for the appropriate rehabilitation services for individuals with SCI.

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>1. Increase the amount of upfront service and inpatient days.</li> <li>2. Eliminate the 24-month wait for Medicare. Educate and collaborate for public policy change for Medicare wait period.</li> <li>3. Increase number of Medicaid outpatient days and pay for OT services.</li> <li>4. Promote system of care to private insurance companies.</li> </ol>	BSCIP; Florida Insurance Commission representatives; Florida Hospital Association; Medicaid; SCI providers; SCI survivors; key insurance company representatives; Advocacy Center for Persons with Disabilities; BSCIP Advisory Councils	Time; data; money; experts; legislative champion(s)	Long Term: More than 2 years  Action Steps 2–4 are systems change issues and will take resources, time and effort to fulfill these goals.

## Strategy 1.3

### Advocate for regulation change to address SCI appropriate durable medical equipment (DME) supplies, assistive technology (AT) and support services to be covered by all payor sources.

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>1. Identify appropriate legislators to support decision makers.</li> <li>2. Investigate DME, AT and support services in other states.</li> <li>3. Create a position paper of rationale for appropriate equipment supplies, which emphasize the cost benefit of DME and supplies.</li> <li>4. Explore Medicaid paying for durable medical refurbished equipment. (Research what other states are doing).</li> <li>5. Ensure accountability for compliance of existing regulations for DME to be covered under Medicaid.</li> <li>6. Develop cooperative agreement between AHCA and DOH/BSCIP.</li> </ol>	BSCIP; FFAST; VA/PVA; community partners; CILs; medical professionals who write prescriptions; BSCIP Advisory Councils	Case studies; document denials; testimony from SCI caregivers, families and physicians; National Health Law Project; Advocacy Center for Persons with Disabilities; DME providers	Long Term: 3–5 years

## Strategy 1.4

### Identify key policy advocates to garner support among legislators for SCI funding.

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>1. Find champions, for example, officers injured in the line of duty, veterans with SCI, police officers with SCI, and other survivors and their families to tell their stories and advocate to local representatives.</li> <li>2. Create local coalitions to address and advocate for BSCIP funding.</li> <li>3. Identify/recognize champions in the legislature who have worked toward SCI causes.</li> <li>4. Educate clerks of circuit courts and law enforcement agencies about the use of funds from fines and fees associated with the SCI trust fund.</li> </ol>	BSCIP Advisory Councils; FFAST; SCI support groups; law enforcement	VA/PVA; CILs; BSCIP; other interested and affected parties	Medium Term: 1–2 years

## Strategy 1.5

### Implement an advocacy plan to address SCI accessibility issues.

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>1. Create a statewide taskforce to address accessibility.</li> <li>2. Create local accessibility taskforces.</li> <li>3. Create and disseminate media campaigns to address accessibility and educate the public.</li> <li>4. Conduct a needs assessment focusing only on access.</li> <li>5. Market accessibility tools for individuals with SCI and other disabilities.</li> </ol>	BSCIP; FFAST/FSCIRC; CILs; Advocacy Center for Persons with Disabilities; city/county disability coordinators; Division of Vocational Rehabilitation; BSCIP Advisory Councils	Offices of Codes and Standards; ADA; Advocacy Center for Persons with Disabilities; FSCIRC; Ombudsman; CILs; universities; BSCIP; BSCIP Advisory Councils; SCI support groups; disability advisory boards; other interested and affected parties	Medium Term: 1–2 years

## Strategic Issue 2:

**There is a need for enhanced training, education and awareness initiatives designed for specific audiences based on identified needs.**

### Strategy 2.1

**Develop a multifaceted and diverse mass media campaign.**

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>Engage DOH/BSCIP/FSCIRC Advisory Committee to provide oversight and approval of advertising materials.</li> <li>Hold an annual activity day.</li> <li>Proclamation for SCI by the governor and legislature.</li> <li>Identify and engage media.</li> <li>Develop campaign to include the following: PSAs, TV telethon, web site links and advertising, newsletters, social networking and posters.</li> </ol>	State legislators; VA; DOH/BSCIP; Division of Vocational Rehabilitation; FFAST; BSCIP Designated Facilities; Peer Mentors; vendors; NSCIA; Christopher Reeve Foundation; Darrel Gwynn Foundation; Medicaid; community partners; Regional Demonstration Centers; CILs	Designated funding for media coverage; BSCIP funding through contractual partners; financial support with other foundations; volunteers; time; marketing experts	Long Term: More than 2 years Ongoing

### Strategy 2.2

**Identify resources and partners to research, develop and disseminate educational materials and information to include community-based rehabilitation, wellness, safety, employment and community reintegration.**

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>Research and develop curriculum (e.g., SCI 101).</li> <li>Research and develop ADA web site survey tools.               <ol style="list-style-type: none"> <li>Disseminate information on accessibility issues and universal design for SCI to targeted audiences.</li> </ol> </li> <li>Identify and access available resources for healthcare providers.               <ol style="list-style-type: none"> <li>Identify wellness and fitness needs of persons with SCI from point of injury throughout lifetime.</li> <li>Advocate for providers to have best practices for SCI care and rehabilitation.</li> </ol> </li> <li>Provide regional trainings.</li> <li>Incorporate disability sensitivity training to new employees along the lines of “diversity trainings” offered by many companies.</li> </ol>	FFAST/FSCIRC; DOH/BSCIP; healthcare professionals/educators and other experts as needed; Florida Housing Finance Corporation; CILs; Advocacy Center for Persons with Disabilities; PVA; Division of Vocational Rehabilitation; universities (teaching medical/nursing, planning, architecture, interior design); FDOA; BSCIP Designated Facilities; Florida Medical Association	Researcher (to draft proposal); media coordinator; funding; review of other states; Accessibility TAC (Building Codes and Standards); universities; existing studies/research; U.S. Access Board	Long Term: 3+ years Ongoing



## Strategy 2.3

### Maintain a state-of-the-art centralized clearinghouse for SCI.

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>1. Maintain toll-free phone lines for SCI Resource Center.</li> <li>2. Conduct a membership campaign.</li> <li>3. Enhance promotion and marketing efforts.</li> <li>4. Partner with libraries and existing educational publication houses to identify and disseminate materials (e.g., Lash Associates, United Spinal, etc.).</li> <li>5. Provide resources for all aspects of SCI (e.g., personal care, etc.).</li> <li>6. Provide prevention and education for the K-12 schools and post-secondary schools.</li> <li>7. Provide web-based materials and enhance current online services.</li> <li>8. Ensure that materials are multi-lingual and accessible.</li> <li>9. Update needs assessment every 3-5 years.</li> </ol>	<p>Collaborative effort must include survivors and families, agencies and organizations; community partners; FFAST; DOH/BSCIP; SCI Resource Center</p>	<p>Researcher; funding; existing staff</p>	<p>Medium Term: 1-2 years</p> <p>Some Activities: Ongoing</p>

## Strategy 2.4

### Increase awareness and utilization of the Peer Mentor program.

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>1. Enhance visibility of Peer Mentors in existing support groups.</li> <li>2. Establish Peer Mentor coordinators in rehabilitation units.</li> <li>3. Collaborate with DOH/BSCIP, community partners, CILs and FSCIRC.</li> <li>4. Increase opportunities for sharing information in a timely, cost-effective manner.</li> <li>5. Increase outreach at SCI facilities.</li> <li>6. Develop updated materials and information to display in rehabilitation facilities, CILs, etc.</li> <li>7. Increase advertising in organization newsletters, publications, web sites, etc.</li> <li>8. Enhance Peer Mentor program to assist parents and caregivers for pediatric SCI.</li> </ol>	<p>Support group leaders; FSCIRC; mentors; CILs; hospitals; rehabilitation staff, including psychiatric; OT; PT; Recreation Therapists; parents and caregivers; DOH/CMS; BSCIP case managers</p>	<p>Time; money; access to technology, including video conferencing; manpower</p>	<p>Medium Term: 1–2 years</p> <p>Some Actions: Ongoing</p>

## Strategy 2.5

### Enhance and maximize independence of SCI survivors through the use of assistive technology and education (ATE).

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>1. Utilize Peer Mentor program as a vehicle for information dissemination.</li> <li>2. Increase educational in-services, enhance ATE web site/database, and provide trainings on ATE services.</li> <li>3. Assist with access to state and national conferences for SCI survivors and caregivers on ATE.</li> <li>4. Provide device loan and refurbishing.</li> <li>5. Provide demonstrations and individualized training for AT devices.</li> </ol>	<p>AT vendors; FSCIRC; DOH/BSCIP; role models; hospitals; rehabilitation centers; Regional Demonstration Centers; CILs; BSCIP case managers</p>	<p>Technology; experts; time; money; individuals with SCI</p>	<p>Medium: 1–2 years</p>

## Strategic Issue 3:

# Initiatives and activities are needed to promote physical and programmatic accessibility for individuals living with SCI.

### Strategy 3.1

#### Develop standards of services to promote access to public and private transportation for persons with SCI.

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>1. Identify needs impacting public transportation.</li> <li>2. Identify needs to promote access to private transportation.</li> <li>3. Develop standards and recommendations for public transportation.</li> <li>4. Promote standards to key transportation stakeholders.</li> </ol>	Department of Transportation; BSCIP; SCI providers; SCI consumers; transportation vendors; Florida Highway Patrol; Governor’s Commission on Disabilities; Division of Vocational Rehabilitation; CILs; FFAST; county and city government; Advocacy Center for Persons with Disabilities	Time; data; access to experts	Long Term: More than 2 years

### Strategy 3.2

#### Advocate at state level to achieve visitability\* for Florida Building Codes.

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"> <li>1. Identify and provide data showing housing needs.</li> <li>2. Create position paper to educate and inform public on the housing needs for individuals with SCI and other mobility-impaired persons. Include in the document counties that have visitability ordinances (for new home construction and remodeling).</li> <li>3. Identify funding opportunities for housing needs.</li> <li>4. Collaborate with other organizations to create position paper and educate lawmakers on building codes.</li> <li>5. Create user-friendly educational tool for ADA/Florida Building Code compliance.</li> </ol>	FFAST; housing coordinators; BSCIP; community-based organizations/community partners; BSCIP Advisory Councils; Advocacy Center for Persons with Disabilities; Florida Housing Finance Corp.; Accessibility TAC; CILs	Testimonies of SCI families; UF Shimborg Center for Affordable Housing; FFAST Resource Center; Department of Housing at USF and other universities; Jack Humburg of Boley Centers; Florida Housing Coalition; HUD	Medium Term: 1–2 years

\*Visitability: single-family or owner-occupied housing designed in such a way that it can be lived in or visited by people who have trouble with steps or who use wheelchairs or walkers. A house is visitable when it meets three basic requirements: (1) One zero-step entrance; (2) Doors with 32 inches of clear passage space; (3) One accessible bathroom on the main floor.

## Strategic Issue 4:

**System-wide partnership and collaboration is needed to enhance communication among SCI survivors and their families, providers and other stakeholders.**

### Strategy 4.1

**Use the SCI strategic plan as a platform to promote collaborative partnerships among organizations.**

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"><li>1. Establish a taskforce.</li><li>2. Establish staff liaison.</li><li>3. Utilize technology such as online web conferences (e.g., GoToMeeting), internet, telemeeting, e-mail and blogs.</li><li>4. Combine meetings with existing meetings, events or venues.</li><li>5. Acknowledge contributing partners by introducing partner organizations in the newsletter in a column called "Meet the &lt;organization name&gt;."</li><li>6. Expand FSCIRC committee to include organizations such as Vocational Rehabilitation, CILs, FACIL, etc.</li></ol>	FSCIRC Advisory Committee; BSCIP Advisory Councils	Staff from participating organizations and possible utilization of the following: volunteer organizations, college student interns, retired professionals, seniors and high school students; funding; time; database; manpower	Short Term: 6 months–1 year

### Strategy 4.2

**Explore existing entities to serve as advisers on local accessibility issues for SCI.**

Action Steps/Activities	Responsible Parties	Resources Needed	Time Horizon
<ol style="list-style-type: none"><li>1. Review existing entities, advisory councils (counties, cities, etc.).</li></ol>	CILs; FFAST; Advocacy Center for Persons with Disabilities; support groups; PVA; FSCIRC	PVA; law enforcement; Advocacy Center for Persons with Disabilities; BSCIP; Governors Commission on Disabilities; CILs; FACIL	Short/Medium Term: 12–18 months

## Spinal Cord Injury Long-Term Statewide Strategic Planning Conference Invitees January 2010

**Luis Amaro**  
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Beta Chapter

**Judith Barrett**  
Executive Director  
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**Ramond Bruce**  
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**Jennifer McParland, PT, COMT**  
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**Barb Page**  
Senior Advocate/Investigator  
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