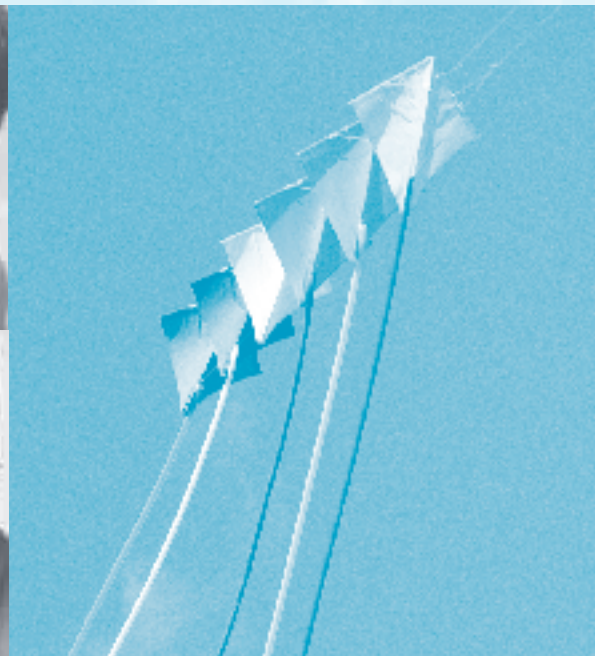


Enhancing the Traumatic Brain Injury System of Care



Florida's Five-Year Strategic Plan

FY 2009-2010—FY 2013-2014

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Acknowledgments

Florida Department of Health Brain and Spinal Cord Injury Program, Brain Injury Association of Florida, and the WellFlorida Council, Inc. would like to acknowledge the many individuals, agencies, and organizations that helped us to develop this five-year strategic plan for the traumatic brain injury system of care in the state of Florida. Sincere thanks to the more than 30 attendees of the Strategic Planning Summit, the 11 members of the Strategic Planning Workgroup and the seven member Needs and Resources Assessment Oversight Committee, listed in Appendix A, who are responsible for generating the content of the plan. These individuals contributed much time and effort to this endeavor, while keeping the identified needs of our survivors and families as their first priority.

A special thanks to the survivors of traumatic brain injury and your families. Your voice was essential to the development of this plan. It is our goal to make your voice heard throughout Florida by carrying out the activities set forth in this plan to ultimately improve your quality of life and the service delivery system.

Florida’s Five-Year Strategic Plan: Enhancing the Traumatic Brain Injury System of Care and corresponding action plan are not intended to replace or criticize the many outstanding traumatic brain injury programs, services, and prevention efforts currently underway in our state, but rather to complement, enhance, and strengthen the service delivery system and help to meet the unmet needs identified by our consumers and their families

Project Partners

Brain Injury Association of Florida strives to improve the quality of life for persons with brain injury and their families by creating a better future through brain injury prevention, research, education, support services and advocacy. **Contact:** Valerie Breen, Executive Director, vbreen@biaf.org

Florida Department of Health, Brain and Spinal Cord Injury Program assists individuals with moderate-to-severe traumatic brain injury, from time of injury through rehabilitation, in accessing federal, state, third party and community resources. **Contact:** Kris Shields, TBI Coordinator, kris_shields@doh.state.fl.us

WellFlorida Council partners with government agencies, health departments, community-based organizations and nonprofits to build healthy communities through research, grants, program development and strategic planning. **Contact:** Jeff Feller, Chief Operations Officer, jfeller@wellflorida.org

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“Traumatic brain injury is life changing for the survivors and those close to them. We describe our life as before the accident and after the accident. People who have never been through it or never experienced it with a family member or friend; they don’t really understand or appreciate the impact that it has on your lives. Living with a brain injury is...it’s real, it’s very real.”

About the project

Project ACTION, “Assessing Communities to Identify Ongoing Needs,” is a three-year project charged with developing a system of services for individuals with traumatic brain injury (TBI) through the creation and implementation of a comprehensive, consumer-directed strategic plan that addresses the needs of Florida's TBI population and their families.

The goal of the project is to improve the lives of all Floridians with TBI and their families by:

- Addressing identified needs
- Establishing goals and priorities
- Increasing system-wide partnerships and collaborations

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Florida’s Five-Year Strategic Plan: Enhancing the Traumatic Brain Injury System of Care was developed in response to the identified needs shared by TBI survivors, their families, service providers, and other key stakeholders in the TBI community during the completion of *Traumatic Brain Injury in Florida: A Needs and Resources Assessment*. The project partners, the Florida Department of Health, Brain and Spinal Cord Injury Program, the Brain Injury Association of Florida and WellFlorida Council, convened consumers, family members, and key stakeholders to develop priority issues, goals, objectives, strategies, and action steps based upon these identified needs. This plan is the building block to move Florida towards its vision of ensuring that all of Florida’s survivors of TBI and their families have access to and are served by a dynamic and comprehensive system of services and supports based on their identified needs.

YEAR 1	YEAR 2	YEAR 3
Formation of Needs Assessment Oversight Committee July 2006	Release of <i>Traumatic Brain Injury in Florida: A Needs and Resources Assessment</i> April 2007	Formation of Strategic Planning Workgroup April 2008
Needs and Resources Assessment July 2006–March 2007	Traumatic Brain Injury Strategic Planning Summit October 2007	Release of Five-Year Strategic Plan February 2009



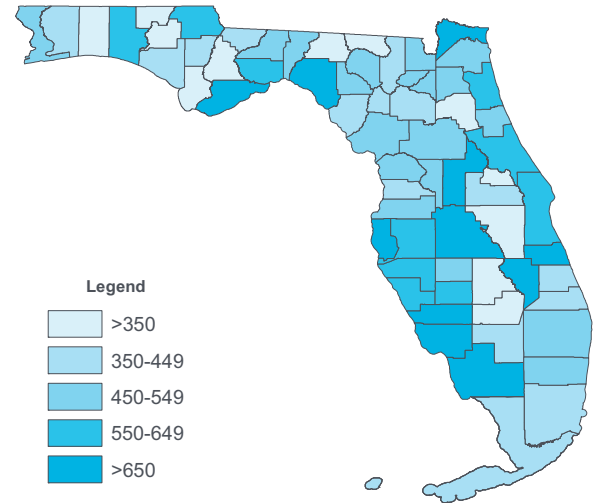
“It is critical for us to offer hope and support for families of individuals who sustain a TBI. Families are in such a state of panic that it is very important for them to realize they are not alone. Learning that they are not alone is an opportunity for hope.”

Over 210,000 people in Florida are living with a TBI-related disability. By 2020, this number is expected to increase to nearly 260,000.

More than 8,200 Floridians will experience long-term disabilities as a result of their TBI each year.

In 2005, 93,000 TBIs occurred in Florida.

Age-Adjusted Rates (per 100,000) for TBI in Florida by County, 2005



Responses from the TBI community:

Most Needed Services

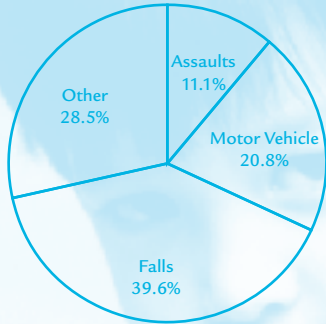
- Financial assistance
- Transportation services
- Employment services
- Accessible, affordable and safe housing
- Recreation activities
- Alcohol and drug addiction services

Biggest Issues for TBI in Florida

- Public and professional brain injury awareness
- Access to qualified providers and specialized services
- Access to appropriate rehabilitation and therapies
- Access to information and education
- Access to long-term services and supports
- Coordination of services and organizations
- Program restrictions and eligibility requirements

Responses from the TBI Community include summary findings from focus groups, interviews, and surveys conducted during *Traumatic Brain Injury in Florida: A Needs and Resources Assessment* in 2007 including 142 consumers and caregivers, 26 key informants, and 58 service providers.

Total TBIs in Florida by Cause, 2005*

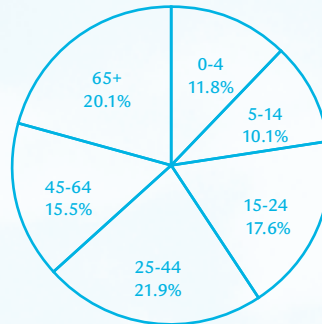


Causes

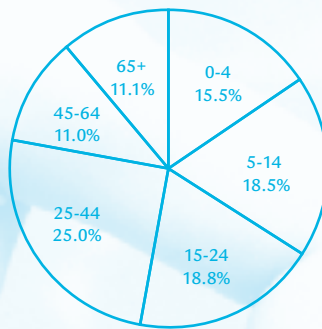
Falls were the leading cause of TBI in Florida. They were most common in the youngest and oldest age groups.

Motor vehicle accidents were the leading cause of TBI-related deaths in Florida.

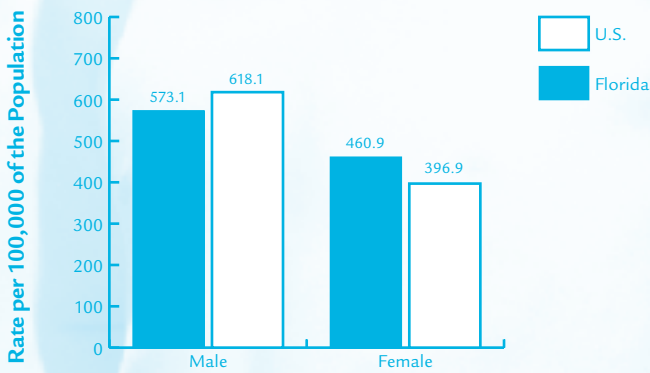
Total TBIs in Florida by Age Group, 2005**



Total TBIs in the U.S. by Age Group, 2005**



TBI Rates for Florida and the U.S. by Gender**



Gender

Males were 1.3 times more likely than females to experience a TBI in Florida.

Age

Children 0-4 years, young adults 15-24 years, and adults 65 years and older were at greatest risk for TBI.

Note the impact of Florida's large elderly population on the distribution of TBI compared to that of the U.S.

The 2005 rate for TBI in Florida (511.5 per 100,000) was higher than the national rate (504.8 per 100,000).**

Of the TBIs that occurred in Florida in 2005, 76.8% resulted in hospital emergency department visits, 19% resulted in hospitalizations and 4.2% resulted in death.*

*Source: State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 2005; State of Florida, AHCA, Detailed Discharge Data, 2005; State of Florida, AHCA, Emergency Department Data, 2005; State of Florida, Department of Health, CHARTS, accessed Feb 2007. **Source: State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 2005; State of Florida, AHCA, Detailed Discharge Data, 2005; State of Florida, AHCA, Emergency Department Data, 2005; Traumatic Brain Injury In the United States: ED Visits, Hospitalizations and Deaths, 2006; State of Florida, Department of Health, CHARTS, accessed Feb 2007.

Strategic Issues and Goals

Issue 1: Statewide System for Information, Referral, Planning and Advocacy

A widely recognized and known statewide system for information, referral, planning and advocacy is needed for the creation, dissemination and linkage of resources, programs, and education.

Rationale: Consumers and stakeholders in *Traumatic Brain Injury In Florida: A Needs and Resources Assessment* indicated that there is limited access to information and education, and a lack of connectivity between resources and services. FDOH-BSCIP, through a contractual partnership with BIAF, funds a statewide information and resource center, toll-free helpline for survivors of TBI and their families, outreach activities, public awareness and prevention activities, community education, capacity building of provider service organizations, and consumer/family education and support to survivors of TBI and their families. Although a design and infrastructure has been created, Florida lacks the legislative mandate and appropriations for a comprehensive, centralized system of information, referral and support in order to successfully address the sheer number of individuals living with long-term disabilities as a result of a TBI in Florida and the number of Floridians who sustain a TBI each year. This expanded infrastructure will create and formalize a central point of entry for information, referral, planning, and advocacy for the TBI community.

Goal 1: Identify or create a state entity for TBI that has the responsibility to: review existing statutes including advisory board membership; conduct surveillance and data management; promote interagency coordination; oversee financial administration of federal, state, and private grant funding; create formal linkages with community-based organizations; and conduct legislative planning activities.

Goal 2: Establish or identify the information, referral, planning, and advocacy capacity to achieve the following: information and referral; outreach; public awareness; community education; capacity building of provider service organizations; consumer/family education and support; interagency coordination while interfacing with

systems of care; creating a formal linkage with the state agency and providing system entry and navigation; and incorporating TBI prevention messages into these activities.

Issue 2: Traumatic Brain Injury Awareness

Effective and uniform messages for traumatic brain injury are needed to increase awareness and promote advocacy.

Rationale: Findings from *Traumatic Brain Injury in Florida: A Needs and Resources Assessment* highlighted that Floridians are not aware of TBI. In fact, consumers often used the term “invisible” when discussing the lack of awareness surrounding TBI. This long-standing issue has been addressed in a limited capacity through a partnership between BIAF and FDOH-BSCIP by the creation of public service announcements, public awareness campaigns and educational materials distributed throughout Florida. Further commitment among community partners is needed to raise awareness of TBI through fully funded statewide campaigns. These culturally competent messages should increase the knowledge of the signs and symptoms of TBI, reduce stigma associated with TBI, as well as increase knowledge of advocacy activities to support policies and legislation for children, teenagers and seniors. To do this effectively, the survivors of TBI and their families must be empowered, through education and training, to participate in TBI awareness and advocacy activities.

Goal 1: Create an ongoing, sustainable marketing campaign for TBI.

Goal 2: Identify, recruit, and nurture champions throughout the state on TBI including survivors, families, advocates, legislators, funders, and policy makers.

Issue 3: Traumatic Brain Injury Provider and Professional Education

Providers and professionals in the healthcare and support spectrum need education, including competency-based standards and training.

Rationale: Through ongoing contracts with BIAF, the FDOH-BSCIP has continued to fund basic education and training on TBI for community-based organizations providing needed services to survivors of TBI and their families. Through these efforts awareness of TBI has increased, but more education and training is needed for specific provider and professional groups as noted in *Traumatic Brain Injury in Florida: A Needs and Resources Assessment*. Training and education needs were identified in both the healthcare and other support fields, specifically in the area of identification of signs and symptoms of TBI and appropriate referrals and linkages.

Goal 1: Determine, create, and/or modify educational programs for community partners to identify and recognize symptoms of TBI and make appropriate referrals and linkages.

Goal 2: Establish training for providers who serve individuals with TBI, but whose primary function is not to work exclusively with individuals with TBI.

Goal 3: Integrate TBI training and education into professional curricula, licensures, and ongoing continuing education.

Issue 4: Lifelong/ Long-Term System of Care
A comprehensive lifelong/long-term system of care and supporting infrastructure that supports transitions through life stages is needed for persons with traumatic brain injury.

Rationale: *Traumatic Brain Injury in Florida: A Needs and Resources Assessment* emphasized the need for the development and implementation, including financial support, of a model of service delivery and array of services to provide a continuum of services and supports for individuals with TBI at each life stage. Survivors of TBI and their families expressed that the recovery from their injury lasts a lifetime and as they progress through life's stages, their needs for services and supports change by type, frequency, and/or intensity. Although a traumatic brain and spinal cord injury Medicaid waiver through FDOH-BSCIP and a Family/Community Support Program through BIAF are in place, there is

limited funding and access to services throughout the continuum of care to address the long-term, dynamic nature of recovery from TBI. FDOH-BSCIP has begun to address this issue through the formation of taskforces within the Advisory Council, including Neurobehavioral and School Re-Integration Taskforces, though more needs to be done. Key stakeholders in the strategic planning process recognized that this comprehensive model must include culturally competent neurobehavioral services; community supports; housing and residential treatment services; caregiver respite services and supports; employment services; day treatment and day activities; adaptive technology; transition planning and case management; transportation; alcohol and other drug addiction services; and mental health services; while focusing on furthering the development of key partnerships and collaborations among state and local agencies and organizations.

Goal 1: Implement a model of service delivery and array of services for individuals with TBI to include: neurobehavioral services; community supports; housing and residential treatment services; caregiver respite care; employment; day treatment and day activities; adaptive technology; transition planning and case management; transportation; alcohol and other drug treatment services; and mental health services.

Goal 2: Increase access to intermediate and long-term funding to support the service delivery system for persons with TBI.

Strategic Plan Acronym List

BIAF: Brain Injury Association of Florida

FDOH: Florida Department of Health

FDOH-BSCIP: Florida Department of Health
Brain and Spinal Cord Injury Program

FDOH-DEMO: Florida Department of Health
Division of Emergency Medical Operations

TBI: Traumatic Brain Injury



“We have to do a better job in linking resources for families. We need to create a mechanism to identify, follow, and support our survivors and their families by providing access to and awareness of needed supports and services.”

Issue 1: Statewide System for Information, Referral, Planning, and Advocacy

Goal 1: Identify or create a state entity for TBI.

- Objective 1:** The statewide advisory board will be established no later than July 2011.
- Objective 2:** Research and review national best practices for TBI services administration and management and create model for Florida by July 2010.
- Objective 3:** State entity for TBI will be fully functional by June 2012.

Strategies	Timeframe	Partners	Resources Needed
1. Establish a statewide TBI Advisory Board.	2009-2011	Strategic Planning Workgroup; Ad Hoc TBI Advisory Committee comprised of key agencies, organizations, and individuals.	Volunteer time; additional financial support for meeting expenses.
2. Create a conceptual model for effective practices of TBI services administration and management.	2010	TBI Advisory Board; BIAF; statewide advocates.	Volunteer time; BIAF personnel; travel and electronic meeting expenses.
3. Elevate the focus of TBI within FDOH and FDOH-DEMO.	2009-2014	TBI Advisory Board; FDOH and FDOH-DEMO.	Volunteer time; travel and electronic meeting expenses.

Measures of Success:

The state entity for TBI should have the responsibility to: review existing statutes including advisory board membership; conduct surveillance and data management; promote interagency coordination; oversee financial administration of federal, state, and private grant funding; create formal linkages with community-based organizations; and conduct legislative planning activities.

Measures of success include:

- The completion of a comprehensive historical and statutory review of TBI activities and legislation in Florida.
- The creation of an ad hoc TBI Advisory Committee to oversee the development and implementation of a statewide TBI Advisory Board within FDOH.
- The implementation of a statewide TBI Advisory Board within FDOH.
- The development of a model for TBI services administration and management for Florida.
- The collaboration between the statewide TBI Advisory Board and FDOH-DEMO to promote the integration of the developed model.

Issue 1: Statewide System for Information, Referral, Planning, and Advocacy

Goal 2: Establish or identify the information, referral, planning, and advocacy capacity needed to create, disseminate, and link resources, programs, and education.

Objective 1: Create a statewide information and referral and outreach system plan by July 2012.

Objective 2: The statewide information and referral and outreach system plan will be operational by October 2013.

Strategies	Timeframe	Partners	Resources Needed
1. Determine the characteristics of organization(s) to provide the identified services and supports.	2010	BIAF; FDOH and appropriate FDOH advisory boards; consumer organizations.	Volunteer time; additional funding including grant funds and FDOH contract funds.
2. Determine the organization(s) in Florida with the capacity or characteristics determined in Strategy 1.	2010	BIAF; FDOH and appropriate FDOH advisory boards; consumer organizations.	Volunteer time; additional funding including grant funds and FDOH contract funds.
3. Develop an operational plan on how organization(s) will be selected, how work will be coordinated, and how services will be funded.	2010-2012	BIAF; FDOH and appropriate FDOH advisory boards; consumer organizations.	Volunteer time; additional funding including grant funds and FDOH contract funds.
4. Analyze types of additional resources needed to build identified capacity.	2010-2012	BIAF; FDOH and appropriate FDOH advisory boards; consumer organizations.	Volunteer time; additional funding including grant funds and FDOH contract funds.

Measures of Success:

The information, referral, planning, and advocacy capacity must include the ability to provide the following services: information and referral; outreach; public awareness; community education; capacity building of provider service organizations; consumer/family education and support; interagency coordination while interfacing with the systems of care; creating a formal linkage with the state agency and providing system entry and navigation; and incorporating TBI prevention messages into these activities. The evidence of success will include:

- Organizations are operational statewide to address the services described.
- An increase in the number of persons appropriately referred into the system of care.
- Improved referral linkages.



“We need a major educational campaign about brain injury. Unless it happens to somebody that you know or your family, people don’t have an understanding about brain injury.”

Issue 2: Traumatic Brain Injury Awareness

Goal 1: Create an ongoing, sustainable marketing campaign for TBI.

- Objective 1:** Develop shared messages with partners that enhance awareness of and reduce stigma associated with TBI by March 2011.
- Objective 2:** Implement a marketing campaign that increases access to referrals and services, and supports efforts to create legislation and change public policy to enhance services for individuals with TBI and their families by January 2013.
- Objective 3:** Implement a marketing campaign that secures more public and private funding across the continuum of care for TBI and the lifespan of an individual with TBI by June 2013.

Strategies	Timeframe	Partners	Resources Needed
1. Seek vested community, private sector, and governmental partners who have a stake in raising awareness of TBI, with the understanding of the need for recurring annual awareness efforts.	2009-2011	BIAF; FDOH-BSCIP.	Staff time of BIAF and FDOH-BSCIP.
2. Define target populations, determine key messages, and identify the most effective delivery methods and timing for each population.	2010-2013	Consortium of community partners or designated TBI Advisory Board Subcommittee.	Time, funds, and expertise contributed by each consortium member.

Measures of Success:

- Extensive and engaged participation in the consortium of community partners.
- Completed marketing plan.
- Signed memorandum of understanding by partners reflecting commitment to joint messaging efforts.
- Ongoing presence of messaging in various communications media.
- Raised level of awareness among community leaders and the public regarding the impact of TBI and the issues in the delivery of services to persons with TBI.
- Decreased stigma and increased empowerment among survivors of TBI and their families.

Issue 2: Traumatic Brain Injury Awareness

Goal 2: Identify, recruit, and nurture champions throughout the state on TBI including survivors, families, advocates, legislators, funders, and policy makers.

- Objective 1:** Develop a network of TBI advocates that focuses on both TBI public policy and community- and family-level issues by December 2010.
- Objective 2:** Make a positive impact on TBI public policy in Florida that ultimately improves quality of life for TBI survivors and their families by June 2014.
- Objective 3:** Empower TBI survivors and families to take a more active role in issues that affect them by June 2014.

Strategies	Timeframe	Partners	Resources Needed
1. Expose potential champions to survivors with TBI and their families.	2009-2014	BIAF; consumer organizations; consortium of community partners or designated TBI Advisory Board Subcommittee.	Staff time of BIAF and consumer organizations; time, funds, and expertise contributed by each consortium member.
2. Use existing TBI groups, events, and programs as opportunities to organize, educate and inspire family members and survivors to be effective messengers.	2010-2014	BIAF; consumer organizations; consortium of community partners or designated TBI Advisory Board Subcommittee.	Staff time of BIAF and consumer organizations; time, funds, and expertise contributed by each consortium member.



“The more information people have the better they are able to advocate for their loved ones. We don’t have the type of grassroots advocacy that we need to make change. I think people have become complacent; there is too much reliance on someone else solving the problem. We need to come together and solve the problem.”

Measures of Success:

- Consortium will have secured at least one champion on TBI issues in the Florida Legislature.
- A network of survivors and family members will be in place to mobilize for community outreach and advocacy.
- The legislative champion will have a positive impact on TBI legislation and appropriation decisions.
- Survivors and family members will take a more active role in personal and public policy advocacy.
- Raised level of awareness among community leaders and the public regarding the impact of TBI and issues in the delivery of services to persons with TBI.
- Decreased stigma and increased empowerment among survivors of TBI and their families.



“More education is needed for service providers. They need to know what traumatic brain injury is, how to work with our population, what to expect when working with us.”

Issue 3: Traumatic Brain Injury Provider and Professional Education

Goal 1: Determine, create, and/or modify educational programs for community partners to identify and recognize symptoms of TBI and make appropriate referrals and linkages.

- Objective 1:** Create an easily accessible and useable education program by July 2013.
- Objective 2:** Develop multiple formats for delivery of the educational program (i.e. self-instruction, guided instruction) by July 2013.
- Objective 3:** Incentivize the target population to adopt and use training program by June 2014.

Strategies	Timeframe	Partners	Resources Needed
1. Integrate the knowledge of TBI and TBI awareness into existing educational programs at state and private community agencies that provide services to survivors of TBI and their families.	2011-2014	TBI Advisory Board; BIAF.	Time and expertise of TBI Advisory Board and BIAF staff.
2. Develop education materials to present methods of identifying persons with TBI and how to serve them.	2011-2013	TBI Advisory Board; BIAF.	Time and expertise of TBI Advisory Board and BIAF staff; additional funding needed for the development of materials (FDOH-BSCIP, additional legislative appropriations, or legislative budget requests).
3. Incentivize the target population to adopt and utilize the training program.	2013-2014	TBI Advisory Board; BIAF.	Time and expertise of TBI Advisory Board and BIAF staff; additional funding needed for incentives (FDOH-BSCIP, additional legislative appropriations, or legislative budget requests).

Measures of Success:

- Fully implemented competency-based instructional system is in place for community partners.
- The majority of targeted community partners are utilizing instructional system within five years.
- Community partners will report an increase in their ability and confidence in serving individuals with TBI and their families.
- Individuals with TBI and their families will report higher levels of satisfaction with services obtained from community partners.

Issue 3: Traumatic Brain Injury Provider and Professional Education

Goal 2: Establish training for providers who serve individuals with TBI, but whose primary function is not to work exclusively with individuals with TBI.

- Objective 1:** Develop multiple formats for the delivery of the educational program (i.e. self instructional, guided instruction) by July 2012.
- Objective 2:** Widespread utilization of training materials/modules among identified professionals by July 2013.
- Objective 3:** The utilization of training materials/modules among identified professionals will improve the quality of life and services received by persons with TBI by June 2014.
- Objective 4:** The utilization of training materials/modules among identified professionals will improve the professional development of the persons providing services by June 2014.

Strategies	Timeframe	Partners	Resources Needed
1. Develop a set of training materials/modules geared to specific needs of identified professionals.	2011-2012	TBI Advisory Board.	Time and expertise of TBI Advisory Board.
2. Create multiple formats for delivery of training materials.	2011-2012	TBI Advisory Board.	Time and expertise of TBI Advisory Board.
3. Incentivize the target population to adopt and utilize the training program.	2012-2013	TBI Advisory Board; FDOH-BSCIP; BIAF.	Time and expertise of TBI Advisory Board; FDOH-BSCIP; BIAF.

Measures of Success:

- Fully developed training materials/modules are available for providers.
- Providers will utilize training materials.
- Individuals with TBI and their families report higher levels of satisfaction with services and higher levels of satisfaction with service delivery integration.



“The people who work with survivors of TBI are not qualified. Most of us receive our services from a nurse, social worker, or psychologist who have virtually no training in TBI. They need to be trained.”

Issue 3: Traumatic Brain Injury Provider and Professional Education

Goal 3: Integrate TBI training and education into professional curricula, licensures, and ongoing continuing education.

- Objective 1:** Ensure the availability and use of comprehensive and current materials by academic, pre-service, and continuing education programs by June 2012.
- Objective 2:** Establish legislative requirements for TBI licensure, certification, and/or endorsement in key professional training areas by December 2012.
- Objective 3:** More professionals are licensed, certified, and/or endorsed in TBI by June 2014.

Strategies	Timeframe	Partners	Resources Needed
1. Work with major educational institutions in key academic areas to determine the current scope of TBI within existing curricula.	2011	TBI Advisory Board; BIAF.	Time and expertise of TBI Advisory Board; volunteer experts in TBI educational materials.
2. Encourage the use of comprehensive and current materials related to TBI in key professional training programs including academic, pre-service, and continuing education programs.	2011-2012	TBI Advisory Board, with appropriate state and official support.	Time and expertise of TBI Advisory Board; time of a team of negotiators with appropriate influence to achieve implementation.
3. Advocate for statutory mandates and mechanisms requiring licensure, endorsements, and/or certification for key professionals in the area of TBI.	2012	TBI Advisory Board, with appropriate state and official support.	Time and expertise of TBI Advisory Board; time of a team of negotiators with appropriate influence to achieve implementation.

Measures of Success:

- TBI education content is incorporated into relevant curricula through the state educational institutions.
- License boards will adopt mandatory continuing education requirements for TBI content.
- Private continuing education corporations will adopt TBI education to meet licensure mandates.





“We need a continuum of long-term lifetime care for overseeing medical, behavioral, and community level supports. You can take a newly injured person and provide them all the best care, but if you don’t have the continuum of needed, specialized services for people to rely on as time goes on, these individuals will and do decompensate.”

Issue 4: Lifelong/Long-Term System of Care

Goal 1: Implement a model of service delivery and array of services for individuals with TBI.

Objective 1: By June 2014, initiate implementation of the new service delivery model and processes.

Strategies	Timeframe	Partners	Resources Needed
1. Identify the critical list (array) of services needed to provide a continuum of care for persons with TBI at each life stage.	2010-2011	TBI Advisory Board; state entity.	Volunteer time; stakeholders including other governmental entities; state entity staff time.
2. Redesign the eligibility and order of selection determination criteria and process to be more sensitive to the nature and course of recovery of TBI.	2011-2012	TBI Advisory Board; state entity.	Volunteer time; stakeholders including other governmental entities; state entity staff time.
3. Develop a bio-psycho-social model and an ongoing person-centered planning process that supports community and vocational reintegration.	2011-2012	TBI Advisory Board; state entity.	Volunteer time; stakeholders including other governmental entities; state entity staff time.
4. Develop a phase-in plan for implementation of the model.	2013-2014	TBI Advisory Board; state entity; national experts/academic centers.	Funds to pay for academic center or national expert; existing operational funds; additional legislative funding appropriations; private funding sources.

Measures of Success:

The lifelong/long-term system of care for persons with TBI should include: neurobehavioral services; community supports; housing and residential treatment services; caregiver respite care; employment; day treatment and day activities; adaptive technology; transition planning and case management; transportation; alcohol and other drug treatment services; and mental health services. Measures of success include:

- Complete statutory review and modifications for current service delivery system.
- Create and designate a TBI Coordinator and TBI Medical Director.
- Critical array of services have been identified.
- Standards and protocols are available for each aspect of the service delivery system.
- Develop comprehensive model for service delivery.
- Begin the initiation of model for service delivery.

Issue 4: Lifelong/Long-Term System of Care

Goal 2: Increase access to intermediate and long-term funding to support the service delivery system for persons with TBI.

- Objective 1:** Expanded Medicaid services for TBI will be available by June 2014.
- Objective 2:** Sustain the current trust fund for TBI and expand other state designated sources of TBI funding by June 2014.
- Objective 3:** The Florida Comprehensive Health Association's high-risk insurance pool will be open to persons with TBI by June 2014.

Strategies	Timeframe	Partners	Resources Needed
1. Expand Medicaid services available to persons with TBI through enhanced state plan services, Medicaid waivers, Medicaid buy-in, and services for Medicare dual eligibles.	2010-2014	TBI Advisory Board; state entity.	Volunteer time; state entity staff time.
2. Seek public appropriations for under- and uninsured persons with TBI including designated funding sources.	2010-2014	TBI Advisory Board; state entity; community partners; state legislature.	Volunteer time; state entity staff time.
3. Open enrollment to persons with TBI to the Florida Comprehensive Health Association's high-risk insurance pool.	2010-2014	TBI Advisory Board; state entity; community partners.	Volunteer time; state entity staff time.

Measures of Success:

- Seek and implement TBI-specific Medicaid Waiver.
- Partner with other disability groups to pass Medicaid buy-in.
- Establish allocation formula for TBI.
- Determine other designated funding sources for persons with TBI.
- Obtain General Revenue necessary for Medicaid match.

Strategic Planning Summit Invitees October 2007

Daryl Barowicz, MA
Chief of Program Services
Florida Department of Health
Division of Disability Determination

Lisa Bascot
Executive Director
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Table 1: Total Incidence, Mortality, Hospitalizations, and Emergency Department Visits for TBI by County and Florida

Area	Total TBI Incidence, 2005 ¹			Average Annual TBI-Related Mortality, 1999-2005 ²			Average Annual TBI-Related Hospitalizations, 1999-2005 ³			TBI-Related Emergency Department Visits, 2005 ⁴		
	Number	Crude Rate	Age Adjusted Rates	Number	Crude Rate	Age Adjusted Rates	Number	Crude Rate	Age Adjusted Rates	Number	Crude Rate	Age Adjusted Rates
Alachua	1012	418.4	425.0	30	13.1	14.6	160	69.9	74.5	780	322.5	320.7
Baker	105	437.9	455.2	4	18.6	19.4	21	90.6	95.6	76	316.9	319.0
Bay	687	422.8	432.8	40	25.8	25.6	129	83.6	84.4	480	295.4	306.5
Bradford	137	485.9	485.5	4	14.9	14.4	23	85.2	83.9	111	393.7	398.2
Brevard	3080	576.1	601.1	100	20.0	17.9	463	92.6	87.0	2,416	451.9	487.8
Broward	9125	522.4	514.0	268	16.0	14.8	1,510	90.1	82.1	7,109	407.0	407.6
Calhoun	58	414.0	402.7	3	24.6	23.3	10	74.9	72.7	40	285.5	280.1
Charlotte	979	636.6	716.3	35	23.3	19.9	177	119.2	95.1	723	470.1	571.6
Citrus	593	444.3	521.1	40	32.3	29.9	90	72.8	68.8	420	314.7	403.4
Clay	873	510.2	531.3	27	17.6	18.3	104	68.2	72.9	695	406.2	420.7
Collier	2609	813.1	836.4	53	19.0	17.3	258	91.7	88.4	2,201	686.0	724.3
Columbia	274	443.8	447.8	14	24.2	23.3	50	85.2	86.3	176	285.0	292.3
Desoto	198	611.3	609.8	10	31.7	31.7	30	91.7	89.8	148	456.9	455.5
Dixie	58	374.6	370.0	4	29.6	28.5	9	62.1	62.7	41	264.8	265.8
Duval	4554	525.9	531.0	150	18.4	18.8	624	76.6	79.4	3,649	421.4	423.4
Escambia	1475	486.4	484.4	55	18.4	18.1	213	71.1	70.3	1,144	377.3	377.7
Flagler	360	446.9	489.9	13	21.9	22.7	52	85.8	81.9	253	314.1	366.3
Franklin	90	825.0	849.3	4	34.8	33.5	9	83.4	83.1	77	705.8	740.6
Gadsden	197	411.4	412.4	15	32.8	32.8	28	61.5	62.1	150	313.3	313.1
Gilchrist	70	429.4	421.4	3	19.7	19.0	12	78.0	77.6	46	282.2	280.8
Glades	30	279.3	274.6	4	33.5	33.6	6	60.3	60.0	14	130.3	137.2
Gulf	50	302.2	310.1	4	24.3	22.3	11	73.7	75.3	34	205.5	219.8
Hamilton	40	279.3	281.3	3	18.6	19.2	11	79.6	82.1	22	153.6	148.5
Hardee	128	469.3	458.9	6	21.0	21.0	30	110.2	106.7	81	297.0	290.1
Hendry	166	429.9	426.9	12	33.0	34.5	39	106.0	106.9	102	264.2	256.9
Hernando	546	359.1	400.2	40	28.9	26.1	146	105.1	96.2	334	219.7	273.5
Highlands	331	352.9	333.7	25	27.7	23.8	89	99.3	79.2	173	184.4	200.8
Hillsborough	6874	604.3	606.5	278	26.2	26.4	846	79.8	80.6	5,563	489.0	490.8
Holmes	49	255.4	252.7	4	22.8	22.6	10	54.7	53.0	37	192.8	192.5
Indian River	1156	883.5	908.1	30	24.7	21.4	124	103.6	94.4	951	726.8	773.2
Jackson	303	607.4	618.9	12	24.1	23.6	22	44.9	42.8	274	549.3	561.5
Jefferson	63	441.6	470.2	4	28.5	26.6	9	65.5	64.4	51	357.5	392.2
Lafayette	37	458.8	469.2	1	15.7	16.2	7	90.0	89.5	23	285.2	294.6
Lake	2003	753.8	757.1	66	28.1	26.2	214	91.5	84.0	1,608	605.2	622.3
Lee	4548	818.2	877.0	122	25.2	23.4	526	108.5	107.5	3,686	663.1	727.3
Leon	1222	448.0	453.8	37	14.5	16.2	128	50.6	56.0	1,033	378.7	377.2
Levy	172	451.0	483.4	11	30.1	29.0	35	96.6	98.7	102	267.5	292.4
Liberty	18	236.1	263.3	2	25.7	25.1	4	51.4	51.7	16	209.9	236.2
Madison	64	324.2	305.1	4	21.7	21.7	14	73.3	69.5	40	202.7	196.9
Manatee	1701	554.9	560.1	64	22.8	21.0	268	95.2	86.2	1,280	417.5	444.9
Marion	1613	524.3	541.1	85	30.6	28.5	242	87.3	82.8	1,171	380.6	407.2
Martin	578	407.4	416.3	28	21.4	20.0	124	93.2	78.8	384	270.7	310.5
Miami-Dade	9866	405.6	403.4	315	13.6	13.2	2,205	94.9	92.9	7,197	295.9	296.7
Monroe	282	341.3	355.9	22	27.7	25.3	84	103.7	103.1	178	215.4	234.9

Rates represent 100,000 per population
Age adjusted rates are standardized to 2000 population

Continued on next page

Table 1: Total Incidence, Mortality, Hospitalizations, and Emergency Department Visits for TBI by County and Florida, *continued*

Area	Total TBI Incidence, 2005 ¹			Average Annual TBI-Related Mortality, 1999-2005 ²			Average Annual TBI-Related Hospitalizations, 1999-2005 ³			TBI-Related Emergency Department Visits, 2005 ⁴		
	Number	Crude Rate	Age Adjusted Rates	Number	Crude Rate	Age Adjusted Rates	Number	Crude Rate	Age Adjusted Rates	Number	Crude Rate	Age Adjusted Rates
Nassau	417	631.6	667.3	11	18.1	18.3	45	73.9	76.4	344	521.1	553.8
Okaloosa	456	240.3	243.8	31	17.2	17.6	106	59.6	62.1	287	151.2	153.0
Okeechobee	297	786.7	783.4	11	30.3	28.6	52	142.4	137.3	232	614.5	616.9
Orange	4402	418.9	427.1	180	18.7	19.1	704	73.2	76.5	3,386	322.2	323.4
Osceola	742	312.2	319.0	44	22.2	22.6	132	66.2	67.6	539	226.8	230.0
Palm Beach	6338	498.1	478.9	205	17.2	14.9	1,190	99.9	84.6	4,664	366.6	369.9
Pasco	1858	452.3	483.2	94	25.4	23.1	367	99.5	94.2	1,317	320.6	361.9
Pinellas	6229	656.4	663.2	187	20.0	17.3	954	102.1	90.1	4,909	517.3	544.0
Polk	3633	666.5	667.4	109	21.4	20.6	439	86.5	83.0	2,920	535.7	543.4
Putnam	233	315.3	327.9	20	28.1	28.4	72	100.1	99.7	133	180.0	191.2
Santa Rosa	533	388.4	402.0	22	17.4	18.5	100	79.5	85.8	387	282.0	290.2
Sarasota	2049	553.6	612.9	79	23.1	20.2	290	84.4	73.8	1,594	430.7	498.9
Seminole	1152	278.3	293.5	58	15.0	15.4	215	55.4	58.8	847	204.6	215.4
St. Johns	982	617.0	631.7	25	17.9	17.0	107	78.4	75.5	813	510.8	529.5
St. Lucie	1061	436.5	444.3	43	20.2	19.4	170	80.6	75.9	796	327.5	345.2
Sumter	393	519.4	507.1	15	23.9	22.7	39	62.8	62.2	304	401.8	403.9
Suwannee	193	503.7	515.3	6	17.7	17.1	31	84.1	83.3	143	373.2	388.0
Taylor	160	747.8	773.0	6	30.5	30.1	17	82.2	81.6	137	640.3	662.9
Union	67	442.7	481.0	2	13.3	17.2	21	147.0	155.3	36	237.9	250.9
Volusia	2858	574.8	578.6	109	23.3	21.5	529	113.8	107.0	2,099	422.1	440.5
Wakulla	143	525.9	556.9	7	26.8	27.3	20	79.9	84.7	115	422.9	447.6
Walton	291	536.7	552.9	13	27.6	27.5	30	66.0	65.1	230	424.2	440.0
Washington	77	331.1	337.8	5	20.9	20.4	11	51.0	49.7	61	262.3	270.4
Unknown	10	NC	NC	1	NC	NC	3	NC	NC	0	NC	NC
Florida	92948	515.8	511.5	3,331	19.8	18.5	14,810	88.1	82.1	71,382	396.2	401.4

Rates represent 100,000 per population

Numbers in columns may not sum due to rounding

NA= Data Not Available

NC= Not Computed

Rates represent 100,000 per population

Age adjusted rates are standardized to 2000 population

Source: 1) State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 2005 State of Florida, AHCA, Detailed Discharge Data, 2005 State of Florida, AHCA, Emergency Department Data, 2005 State of Florida, Department of Health, CHARTS, accessed Feb 2007. 2) State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 1999-2005 State of Florida, Department of Health, CHARTS, accessed Feb 2007. 3) State of Florida, Agency for Healthcare Administration, Detailed Discharge Data, 1999-2005 State of Florida, Department of Health, CHARTS, accessed Feb 2007. 4) State of Florida, Agency for Healthcare Administration, Emergency Department Data, 2005 State of Florida, Department of Health, CHARTS, accessed Feb 2007.

Table 2: Total Incidence, Mortality, Hospitalizations, and Emergency Department Visits for TBI in Florida by Selected Characteristics

Characteristic	Total TBI Incidence, 2005 ¹				Average Annual TBI-Related Mortality, 1999-2005 ²				Average Annual TBI-Related Hospitalizations, 1999-2005 ³				TBI-Related Emergency Department Visits, 2005 ⁴			
	Number	Percent	Crude Rate	Age Adjusted Rate	Number	Percent	Crude Rate	Age Adjusted Rate	Number	Percent	Crude Rate	Age Adjusted Rate	Number	Percent	Crude Rate	Age Adjusted Rate
Incidence of TBI	92,948	100.0	515.8	511.5	3,331	100.0	19.8	18.5	14,810	100.0	88.1	82.1	71,382	100.0	396.2	401.4
Age Group																
0-4 years	10,984	11.8	1020.0	NC	55	1.7	5.5	NC	680	4.6	67.9	NC	10,166	14.2	944.0	NC
5-14 years	9,403	10.1	413.2	NC	67	2.0	3.1	NC	867	5.9	40.4	NC	8,430	11.8	370.4	NC
15-24 years	16,329	17.6	699.4	NC	475	14.3	22.5	NC	2,133	14.4	101.0	NC	13,311	18.6	570.2	NC
25-44 years	20,328	21.9	427.8	NC	868	26.1	18.8	NC	3,155	21.3	68.4	NC	15,877	22.2	334.1	NC
45-64 years	14,439	15.5	319.7	NC	786	23.6	19.6	NC	2,606	17.6	64.9	NC	10,149	14.2	224.7	NC
65+ years	21,459	23.1	700.7	NC	1,080	32.4	36.9	NC	5,370	36.3	183.2	NC	13,449	18.8	439.2	NC
Unknown	6	0.0	NC	NC	0	0.0	NC	NC	0	0.0	NC	NC	0	0.0	NC	NC
Gender																
Male	52,342	56.3	593.7	601.0	2,461	73.9	30.0	29.0	9,067	61.2	109.1	107.2	38,735	54.3	439.4	451.6
Female	40,598	43.6	441.1	418.4	870	26.1	10.1	8.9	5,742	38.8	64.8	55.1	32,643	45.7	354.7	346.8
Unknown	8	0.0	NC	NC	0	0.0	NC	NC	0	0.0	NC	NC	4	0.0	NC	NC
Race																
White	76,467	82.3	524.4	522.3	2,893	86.9	21.0	19.0	12,397	83.7	90.1	81.6	58,196	81.5	399.1	411.0
Black	13,149	14.1	445.8	440.5	399	12.0	15.1	16.0	1,734	11.7	65.6	71.4	10,741	15.0	364.1	351.7
Others	2,558	2.8	525.1	539.2	37	1.1	8.9	9.6	466	3.1	111.2	128.4	1,937	2.7	197.6	395.3
Unknown	774	0.8	NC	NC	2	0.1	NC	NC	213	1.4	NC	NC	508	0.7	NC	NC
Ethnicity																
Hispanic	13,971	15.0	402.9	NA	410	12.3	2.4	NA	2,099	14.2	12.2	NA	10,760	15.1	310.3	NA
Cause																
Falls	36,803	39.6	204.2	189.5	627	18.8	3.7	2.9	4,503	30.4	26.8	22.5	30,001	42.0	166.5	158.8
Motor Vehicle	19,306	20.8	107.1	111.6	887	26.6	5.3	5.4	4,067	27.5	34.2	24.8	13,715	19.2	76.1	79.9
Assault	10,314	11.1	57.2	61.0	325	9.8	1.9	2.0	1,016	6.9	6.0	6.3	8,878	12.4	49.3	52.7
Other / Unknown	26,525	28.5	149.3	147.2	1,492	44.8	8.9	8.3	5,224	35.3	31.1	28.5	18,788	26.3	104.3	110.0
Motor Vehicle Causes																
Occupant	14,696	76.1	81.6	85.0	545	61.4	3.2	3.3	2,725	67.0	16.2	16.6	11,140	81.2	61.8	64.8
Pedestrian	1,189	6.2	6.6	6.7	167	18.8	1.0	1.0	466	11.5	2.8	2.8	520	3.8	2.9	3.0
Pedalcycle	622	3.2	3.5	3.6	49	5.5	0.3	0.3	204	5.0	1.2	1.3	346	2.5	1.9	2.0
Motorcycle	1,643	8.5	9.1	9.6	126	14.2	0.7	0.8	482	11.9	2.9	3.0	778	5.7	4.3	4.6
Other	1,156	6.0	6.4	6.7	0	0.0	0.0	0.0	190	4.7	1.1	1.1	931	6.8	5.2	5.4
Numbers in columns may not sum due to rounding																
NA= Data Not Available			NC= Not Computed			Rates represent 100,000 per population						Age adjusted rates are standardized to 2000 population				
Source: 1) State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 2005; State of Florida, AHCA, Detailed Discharge Data, 2005; State of Florida, AHCA, Emergency Department Data, 2005; State of Florida, Department of Health, CHARTS, accessed Feb 2007. 2) State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 1999-2005; State of Florida, Department of Health, CHARTS, accessed Feb 2007. 3) State of Florida, Agency for Healthcare Administration, Detailed Discharge Data, 1999-2005; State of Florida, Department of Health, CHARTS, accessed Feb 2007. 4) State of Florida, Agency for Healthcare Administration, Emergency Department Data, 2005; State of Florida, Department of Health, CHARTS, accessed Feb 2007.																

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