



Traumatic Brain Injury in Florida

A Needs and Resource Assessment

EXECUTIVE SUMMARY April 2007

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**Project ACTION
Oversight Committee**

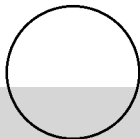
Casey Haddix, PhD
 Marcia Hill
 Tom Kerkhoff, PhD
 Grace Peay
 Martina Schmid
 Barry Shalinsky
 Andrea Slapion
 Phil E. Williams

**Project ACTION
Executive Committee**

Valerie Breen
 Pat Colvin
 Bruce Menchetti, PhD
 Pat Price
 Kris Shields

**Contributing Staff—
WellFlorida Council**

Shane Bailey
 Sandra Carroll
 Jill Dygert
 Jeff Feller
 Lindsey Michaels
 Doug Monroe
 Celia Paynter



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WellFlorida Council
 1785 NW 80th Blvd.
 Gainesville, FL 32606
 Tel: (352) 313-6500
 Fax: (352) 313-6515
 Web: www.wellflorida.org

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Executive Summary

Introduction

Traumatic brain injury (TBI) is recognized as a significant public health problem in the United States and Florida. By Florida Statute, a TBI is defined as an insult to the skull, brain, or its covering that results from external trauma and that produces an altered state of consciousness or anatomic, motor, sensory, cognitive, or behavioral deficit.¹ The severity of the injury may range from mild to severe, based on the classification of the change in mental status or consciousness after the injury. Often called the “invisible” epidemic because the disability is often not apparent to the public, the long-term consequences can be quite enormous. Consequences can include: memory loss, difficulty with judgment and recognition of limitations, anxiety and/or depression, loss of social networking, feelings of isolation, slowness or difficulty with speech, decreased physical coordination, decreased anger management, decreased safety awareness and difficulty initiating, planning and completing tasks.

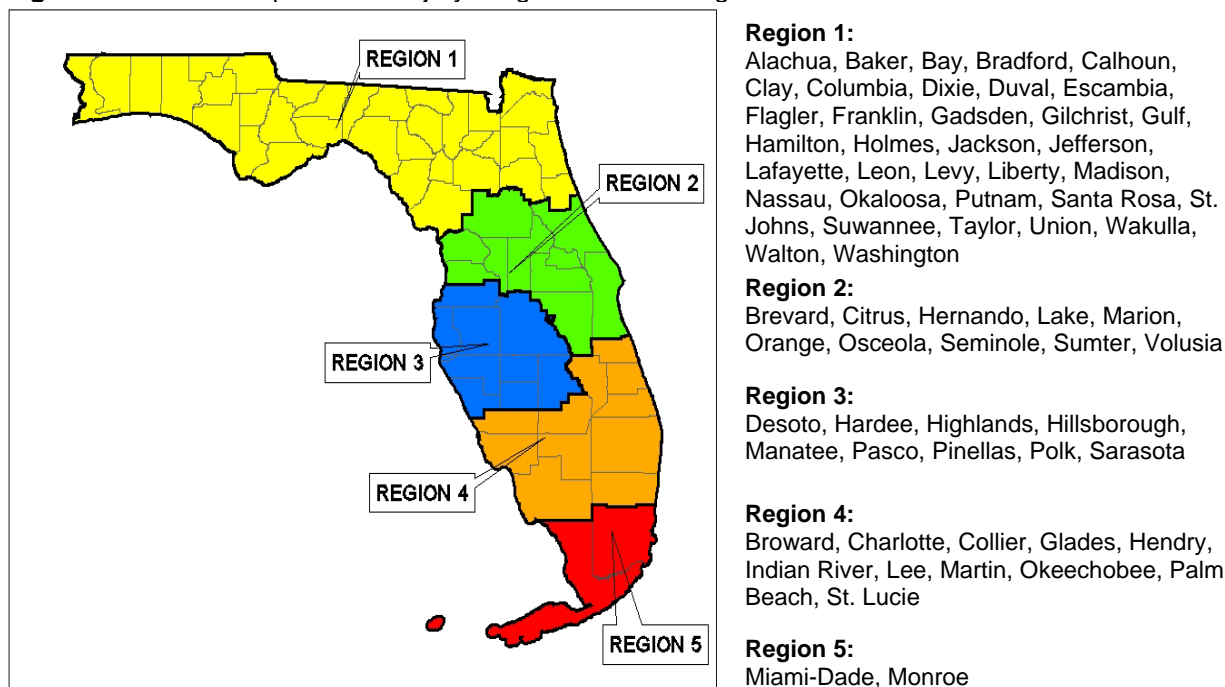
The most recent estimate suggests that approximately 1.4 million TBIs occur in the United States each year resulting in approximately 50,000 deaths, 235,000 hospitalizations and 1.1 million treated and released from emergency departments.² This estimate does not include the unknown number of injuries that are not seen in emergency departments or receive no medical care. Additionally, it does not take into account injury severity. The Centers for Disease Control and Prevention (CDC) estimate that at least 5.3 million Americans, approximately 2 percent of the population, are living with long-term or lifelong disabilities resulting from a TBI.³

- To date, approximately 370,000 Floridians (2 percent of the population) are living with long-term disabilities resulting from a TBI. It is estimated that by 2015 over 435,000 people in Florida will be living with TBI-related disabilities.
- Approximately 93,000 TBIs occurred in Florida during 2005, which resulted in 3900 deaths, 17,600 hospitalizations and 71,500 treated and released from emergency departments (ED).
- Age-adjusted rates for TBIs, TBI-related deaths and ED visits were higher in Florida compared to their respective national rates, while Florida’s rate for TBI-related hospitalizations is lower than the national rate.

Florida is often recognized for its system of identifying and serving individuals with moderate-to-severe TBIs. Mandated by the Florida legislature (Florida Statute 381), the Florida Department of Health, Brain and Spinal Cord Injury Program (BSCIP) is charged with assisting individuals with moderate-to-severe TBI, from time of injury through community reintegration, in accessing federal, state, third party and community resources.¹ BSCIP is supported by the Brain and Spinal Cord Injury Trust Fund, which receives money from traffic-related fines, surcharges for driving or boating under the influence, temporary license fees and a percentage of funds from the motorcycle specialty tag. These funds are used as a payor of last resort for individuals with moderate-to-severe brain injuries to access services including case management, acute care, inpatient and outpatient rehabilitation, transitional living, assistive technology, home and vehicular modification and long-term community-based supports funded under contract with

specific not-for-profit agencies. BSCIP divides its case management and other client-related activities as well as public awareness and outreach activities among five regions. Figure 1 identifies the counties within each BSCIP region. Each region varies in terms of number of counties and geographic area. BSCIP also manages the Central Registry, which by state mandate collects information on all individuals with new moderate-to-severe brain or spinal cord injuries. Data are collected from all public and private health agencies, attending physicians and public and private social agencies.

Figure 1: Brain and Spinal Cord Injury Program Service Regions.



Source: Florida Department of Health, Brain and Spinal Cord Injury Program.
Prepared by: WellFlorida Council Inc., 2007.

Though impressive, its ability to meet the needs of ALL individuals with TBI regardless of level of severity in Florida is unknown. Florida has not conducted a needs assessment for individuals with TBI in over ten years, and the state’s brain injury Action Plan is over five years old. Additionally, Florida recognizes that previous needs assessments did not target underrepresented or underserved populations. In response, Florida’s Department of Health, Brain and Spinal Cord Injury Program (BSCIP), was awarded a Health Resources and Services Administration (HRSA) Traumatic Brain Injury State Implementation Grant (HRSA-06-083) in 2006 to conduct Project ACTION.

Project Description

Project ACTION, “Assessing Communities to Identify Ongoing Needs,” is charged with developing an evolving and dynamic system of services for individuals with 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. This three-year project was designed by the Project ACTION Executive Committee, which consists of staff from BSCIP and Brain

Injury Association of Florida (BIAF), the primary TBI entities in the state. The primary project activities include:

- Establishment of a Oversight Committee (OC);
- Development and implementation of a comprehensive needs and resource assessment for individuals with TBI across a broad spectrum of injuries and in culturally distinct populations;
- Creation of a five-year strategic plan to guide the provision, development and management of TBI services;
- Development and implementation of community-based, culturally sensitive resources based on the strategic plan.

Contracted by BSCIP, BIAF is administering the objectives and activities for Project ACTION. WellFlorida Council (formerly the North Central Florida Health Planning Council), contracted by BIAF, was tasked with the development and implementation of the comprehensive needs and resource assessment for individuals with TBI in Florida under the guidance of the OC.

The findings from *Traumatic Brain Injury in Florida: A Needs and Resource Assessment*, presented in this summary identify the needs of a continuum of individuals with TBI including mild, moderate and severe brain injury across all age groups and in culturally distinct populations. The assessment includes the following sections:

- Demographic and Socioeconomic Profile;
- Traumatic Brain Injury Profile;
- Traumatic Brain Injury Systems Profile;
- Consumer and Community Input;
- Resource Summary;
- Conclusion.

Demographic and Socioeconomic Profile

Demographic and socioeconomic characteristics are often strong predictors of healthcare access and health outcome. Indicators presented in this section are some of the most influential in determining the extent of a community's overall health and will help by creating a profile for the people of Florida, which includes individuals with TBI, to identify the demographic and socioeconomic barriers and opportunities to improve health.

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 TBI or increased morbidity and mortality from TBI. The CDC reports: males are about twice as likely as females to sustain a TBI; individuals ages 0-4 years and ages 15-19 years are at highest risk for TBI; adults age 75 years or older have the highest rates of TBI-related hospitalization and death; blacks have the highest death rate from TBI-related causes²; and TBI-related hospitalization rates are highest among blacks and American Indians/Alaska Natives.⁴ Reviewing Florida's population characteristics by age, race and gender 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 TBI population in Florida.

Population

Florida’s current population is nearly 18.5 million, with the largest percentage of the population located in BSCIP Region 4 (26.0 percent) (Table 1). The population of Florida is projected to increase approximately 21.5 percent by 2015, with the largest increase projected in BSCIP Region 2 (27.0 percent).

Table 1: Total Population by BSCIP Region and Florida, 2006 and 2015.

Area	2006 Population		2015 Population	
	Number	Percent	Number	Percent
BSCIP Region 1	3,380,488	18.3	3,970,134	18.2
BSCIP Region 2	3,780,193	20.5	4,626,558	21.3
BSCIP Region 3	3,971,460	21.5	4,561,812	21.0
BSCIP Region 4	4,799,835	26.0	5,751,702	26.4
BSCIP Region 5	2,546,333	13.8	2,857,297	13.1
Florida	18,478,309	100.0	21,767,503	100.0

Please note that due to rounding the sum of the individual groups may not equal the state total.
 Source: ESRI Business Solutions, 2006; 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, 2005-2030.
 Prepared by: WellFlorida Council Inc., 2007.

Age, Race, Ethnicity and Gender

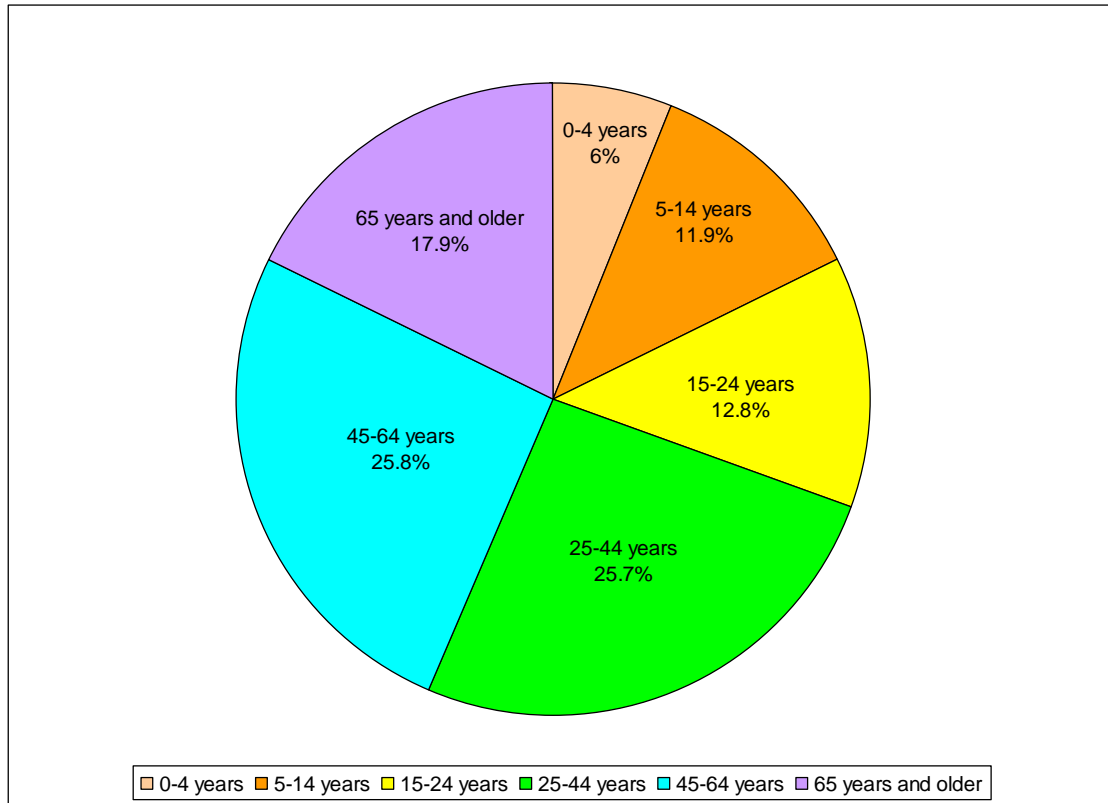
Figure 2 displays the age distribution for the population of Florida in 2006. Individuals 24-44 years of age and 45-64 years of age represent the largest proportion of the population, 26 percent in each group. The age group 0-4 years, which has the highest risk for TBI, currently represents the smallest proportion of Florida’s population (6 percent), but is expected to grow to 17.6 percent by 2015. The elderly population in Florida, ages 65 years or more, currently represents approximately 18 percent of the population and is expecting the greatest amount of growth of all age groups, 36.1 percent, by 2015.

Differences in the age distributions of the population for BSCIP regions exist when compared to the state.

- BSCIP Region 1 contains a larger percentage of individuals under the age of 65 years than the state and has the greatest percentage of individuals 15-24 years of age in the state.
- The age distribution in BSCIP Region 2 is the most similar to the age distribution of the state.
- BSCIP Regions 3 and 4 have a larger percentage of people in age groups 45-64 years and 65 years and older than the state.

- BSCIP Region 5 has a larger percentage of the population under the age of 44 years compared to the state and houses the greatest percentage of age groups 0-4 years, 5-14 years and 25-44 years in the state.

Figure 2: Age Distribution of Florida, 2006.



Source: ESRI Business Solutions, 2006.
Prepared by: WellFlorida Inc., 2007.

As stated above, in the United States, blacks have the highest death rate from TBI²; and TBI-related hospitalization rates are highest among blacks and American Indians/Alaska Natives.⁴ Currently, Florida’s population is 75.7 percent white and 15.5 percent black compared to 73.0 percent white and 12.6 percent black, nationally. The percentage of the population in Florida that identifies their race as Asian or all “other” races is 8.8 percent. The population of Florida is anticipating a 12.7 percent increase in the number of whites, a 28.9 percent increase in the number of blacks and a 41.9 percent increase in the number of all other races by 2015. BSCIP Region 5 is the only region that is expecting a decrease in the percentage of white residents (18.8 percent) by 2015.

- BSCIP Region 3 has the largest percentage of white residents (80.3 percent) and BSCIP Region 5 has the smallest percentage of white residents (70.9 percent).
- BSCIP Region 1 has the greatest percentage of black residents, representing 21.4 percent of its total population.

Health disparities exist between individuals who are non-Hispanic and those of Hispanic descent. The Office of Minority Health, in the United States Department of Health and Human Services,

Hispanic/Latino profile notes that the health of Hispanics is often shaped by language/cultural barriers, lack of access to preventive care and lack of health insurance.⁵ Nationally, 14.8 percent of the population identifies themselves as Hispanic compared to 20 percent of Florida's population. The number of individuals who identify as being of Hispanic ethnicity is projected to increase by 41.8 percent in Florida by 2015.

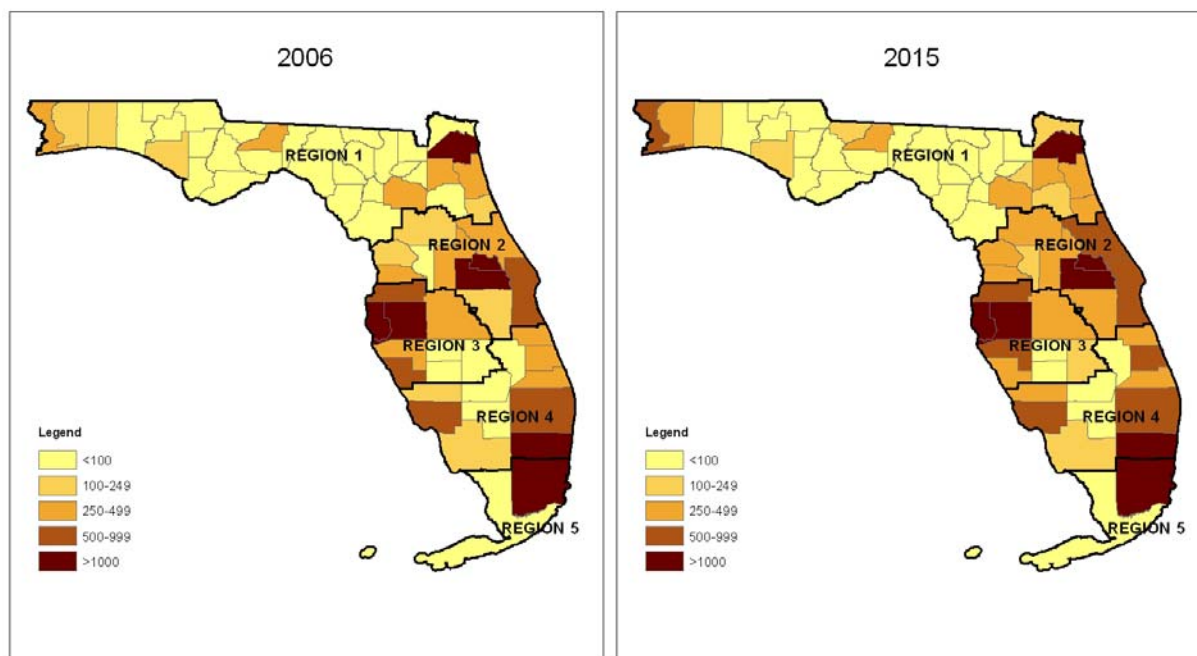
- Currently, Region 5 has a substantially higher percentage (62.1 percent) of individuals of Hispanic background compared to the state and other BSCIP regions.
- Regions 1 through 4 are projecting between 49 percent and 63 percent growth in the size of their Hispanic population by 2015.
- Only BSCIP Region 5 is not expecting an increase in the percentage of non-Hispanic residents by 2015.

Males are approximately two times more likely to experience a TBI than females.² 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. The projected population increase in Florida and each BSCIP region is not impacted by gender, as the population growth is consistent across genders through 2015.

Rural Population

Living in a rural area is a health risk factor because of many associated factors that can negatively impact health and access to healthcare. The Florida Department of Health, Office of Rural Health, has identified issues that impact the rural residents in Florida: disproportionately high mortality rates for selected diseases and population groups; large populations of uninsured/underinsured persons; recruitment/retention problems for emergency medical services; shortage of health personnel; limited physical and/or financial access to services; and significant financial hardships typically suffered by hospitals.⁶ These issues exaggerate barriers for accessing healthcare. The definition of "rural" used in this assessment is from the Florida Department of Health, Office of Rural Health: "An area with a population density of less than 100 individuals per square mile or an area defined by the most recent United States Census as rural."⁷ Currently, 33 of 67 counties in Florida are rural, but by 2015 only 28 of 67 counties will be classified as rural (Figure 3). Though the populations in urban and rural areas are both increasing, the population in urban areas is increasing at a slightly faster pace than in rural areas. Region 1 contains 71.4 percent of the rural counties in the state. These rural counties in Region 1 contain 22 percent of the population in this region.

Figure 3: Population Density (Individuals per Square Mile) by County in Florida, 2006 and 2015.



Source: ESRI Business Solutions, 2006; 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, 2005-2030. Florida Statistical Abstract 2006, accessed March 2007.
Prepared by: WellFlorida Council Inc., 2007.

Economic Characteristics

Lower poverty and better employment have all been shown to impact favorably health access and health outcome. Conversely, higher poverty and poorer employment are definite predictors of a lack of access to healthcare and adverse health outcomes.

Increased income is associated with increased access to healthcare and related services. Per capita income is the total income for a given population divided by the number of people within the population. Florida's income is \$26,399 per capita.

- BSCIP Regions 3 and 4 have per capita income levels higher than the state per capita income level. BSCIP Region 5 has the lowest per capita income (\$22,706).

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 18.6 percent of residents are estimated to be between 100 percent and 200 percent of the federal poverty level.

- 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 percentage of residents at or below 200 percent of the federal poverty level.

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. Unemployed individuals are thus vastly less likely to have private health insurance coverage. Current unemployment rates in Florida, from the Florida Research and Economic Database, are 3.2 percent of the number of people in the labor force. BSCIP Region 5 has the highest percentage of unemployment (3.8 percent) compared to the other regions.

Educational Attainment

Today's complex healthcare systems and treatment guidelines are often difficult to navigate and understand. Generally, persons with higher educational levels utilize healthcare systems somewhat more effectively and efficiently than their counterparts without higher levels of educational attainment. In addition, research has suggested that educational level also has a bearing on health outcome.

Approximately 20 percent of Florida residents (age 25 and over) have no high school diploma and just over 50 percent have earned a high school diploma as their highest level of educational attainment. In Florida, 29.4 percent of the population have earned a college degree or higher.

- BSCIP Region 5 has the greatest percentage of residents without a high school diploma and the smallest percentage who earned a high school diploma as their highest level of educational attainment.

Traumatic Brain Injury Profile

The traumatic brain injury profile describes individuals with TBIs in Florida, including the prevalence and incidence of TBI in Florida and each BSCIP region. The CDC published report, "Traumatic Brain Injury In the United States: Emergency Department Visits, Hospitalizations and Deaths," presents the most comprehensive measures of the incidence of TBI in the United States to date because it incorporates emergency department visits.² Emergency department visits account for approximately 80 percent of all TBIs and a large percentage of mild TBIs. The TBI incidence rates for Florida were calculated using the methodology presented in this report. The methodology used in this report does not take into account injury severity which would help to identify the most severely injured.

The TBI incidence rates for Florida were calculated using the methodology presented in this report including vital statistics, hospital discharge and emergency department (ED) visit data for the state of Florida. Data on TBIs in Florida and each BSCIP region are presented, including analyses by age, gender, race, ethnicity and common causes. The national data included in this report is based on the aforementioned CDC report; therefore, all data is from 1995 through 2001.

Prevalence of Traumatic Brain Injury-Related Disability

From most recent TBI-related disability estimates, established in 1996, at least 5.3 million people in the United States, approximately two percent of the population, currently present long-term or lifelong need for help to perform activities of daily living as a result of a TBI.³ This model incorporates estimates on the incidence of TBI, injury severity levels and the likelihood of TBI-related disability for given levels of severity reflecting the proportion of the population who had ever been hospitalized for a TBI that resulted in prolonged disability. This figure does not take into account individuals who visited emergency departments or outpatient clinics and those whose injuries have gone undetected. Although, underestimating the prevalence of TBI-related disability it remains the best model to date.

Table 2 shows the prevalence of TBI-related disability in Florida and each BSCIP region based on the 2006 population and 2015 population projections. Prevalence is the proportion of persons with a particular disease or condition within a given population at a given time. Currently, 369,566 people (2 percent) are living with a TBI-related disability in Florida. By 2015, this is expected to increase to approximately 435,350 people. The prevalence of TBI-related disabilities mirrors the population distribution.

- Like the general population, the greatest number of people with TBI-related disabilities live in BSCIP Region 4 (95,997 people) and the fewest in BSCIP Region 5 (50,927 people).
- Through 2015, BSCIP Region 2 is anticipating the greatest increase in the percentage of individuals living with TBI-related disabilities and BSCIP Region 5 is expecting the smallest increase.

Table 2: TBI-Related Disability Prevalence Estimates for Florida and BSCIP Regions, 2006 and 2015.

Area	2006 TBI-Related Disability Prevalence		2015 TBI-Related Disability Prevalence	
	Number	Percent	Number	Percent
BSCIP Region 1	67,610	18.3	79,403	18.2
BSCIP Region 2	75,604	20.5	92,531	21.3
BSCIP Region 3	79,429	21.5	91,236	21.0
BSCIP Region 4	95,997	26.0	115,034	26.4
BSCIP Region 5	50,927	13.8	57,146	13.1
Florida	369,566	100.0	435,350	100.0

Please note that due to rounding the sum of the individual groups may not equal the state total.

Source: ESRI Business Solutions, 2006; 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, 2005-2030; Thurman, et al., 1999. Prepared by: WellFlorida Council Inc., 2007.

Incidence of Traumatic Brain Injury

Incidence of TBI is defined as the proportion of new brain injuries within a selected population during a given time period. Incidence data are presented in two ways, crude and age-adjusted rates. Crude rates show the number of TBIs in a given population during a defined time-frame. Age-adjusted rates are used to compare TBI rates between different geographic areas. Age-adjusted rates are those rates that would have been observed if the age distribution of the compared areas were the same as that of the standard population. The standard population used in this study is the 2000 United States population.

In 2005, there were approximately 93,000 TBIs in Florida, which included 71,400 ED visits (76.8 percent), 17,700 hospitalizations (19.0 percent) and 3,900 deaths (4.2 percent). Nationally, an average of 1.4 million TBIs occur each year, which includes 1.1 million ED visits (79.6 percent), 235,000 hospitalizations (16.8 percent) and 50,000 deaths (3.6 percent). The rate of TBI in Florida during 2005 (515.8) is greater than the national average annual TBI rate (506.4). When adjusting for differences in age, the rate for TBI in Florida (511.5) remains higher than the national rate for TBI (504.8).

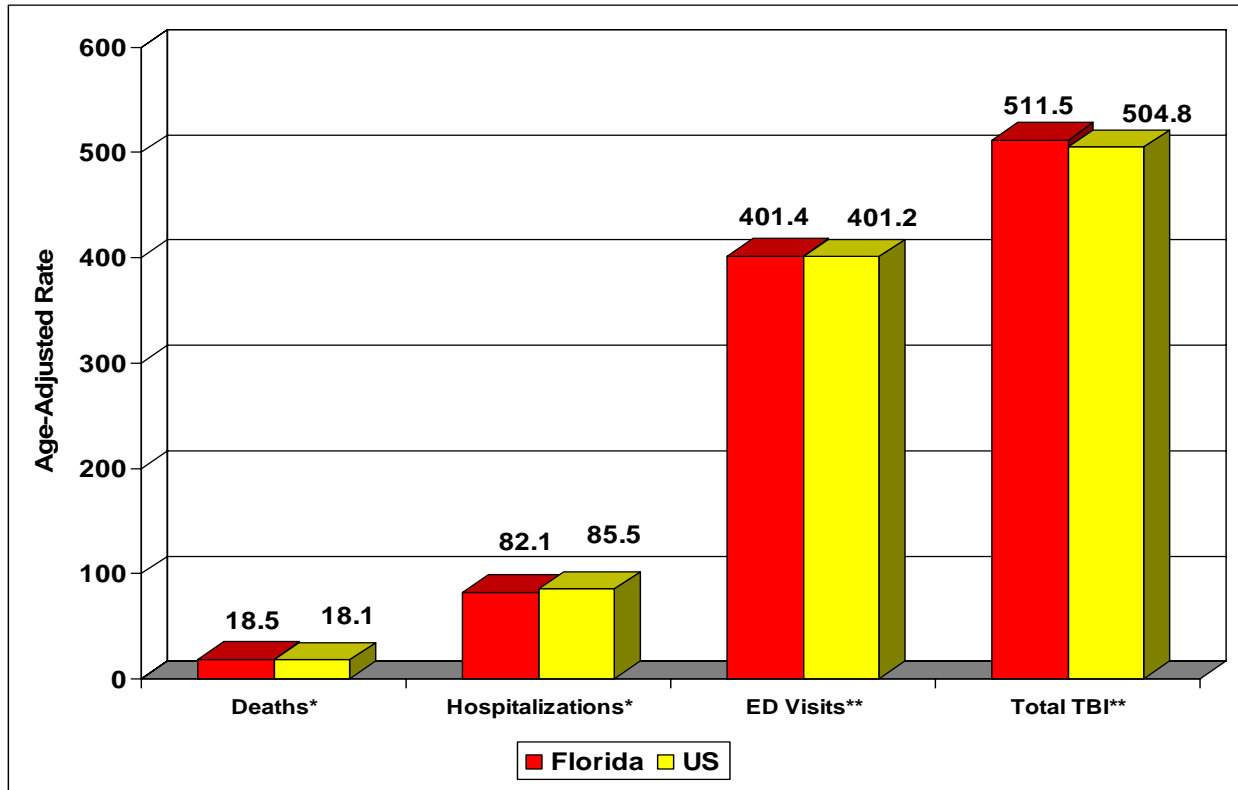
- In 2005, the greatest number of TBIs occurred in BSCIP Region 4 (26,887) compared to BSCIP Region 5 with the fewest (10,148), which corresponds with the population distribution of the state.
- Compared to the percentage of the population that lived in BSCIP Regions 3 and 4 during 2005, there were a greater percentage of total TBIs that occurred within these regions. The opposite trend was true in BSCIP Region 5, where a smaller percentage of total TBIs occurred compared to the percentage of the total population that lived in the region.
- Four of the five counties with the largest populations in Florida had the greatest number of TBIs in 2005: Miami-Dade (9,866), Broward (9,125), Hillsborough (6,874) and Palm Beach (6,338). Orange County has the fifth greatest population in the state, but ranked seventh in total TBIs reported in 2005.

Figure 4 compares the age-adjusted rates for TBI-related deaths, hospitalizations, ED visits and total TBIs for Florida to the United States.

- From 1999 through 2005, Florida's average annual TBI-related crude death rate (19.8) was greater than the national average annual TBI-related crude death rate (18.1). Like the crude rates, the average annual age-adjusted rate for TBI-related deaths in Florida (18.5) was higher than the average annual age-adjusted TBI-related death rate (18.1) for the United States.
- From 1999 through 2005, Florida's average annual crude TBI-related hospitalization rate (88.1) was higher than the national rate (85.2). But, when adjusting for differences in age, the average annual rate for TBI-related hospitalizations in Florida (82.1) was lower than the average annual national TBI-related hospitalization rate (85.5).
- In 2005, Florida's crude TBI-related ED visit rate (396.2) was lower than the national TBI-related ED visit rate (403.1). When adjusted for differences in age, the 2005

age-adjusted rate for TBI-related ED visits in Florida (401.4) was slightly higher than the age-adjusted average annual national rate (401.2) for TBI-related ED visits.

Figure 4: Age-Adjusted TBI-Related Deaths, Hospitalizations, Emergency Department Visits and Total TBIs Rates (per 100,000) for Florida and the United States.

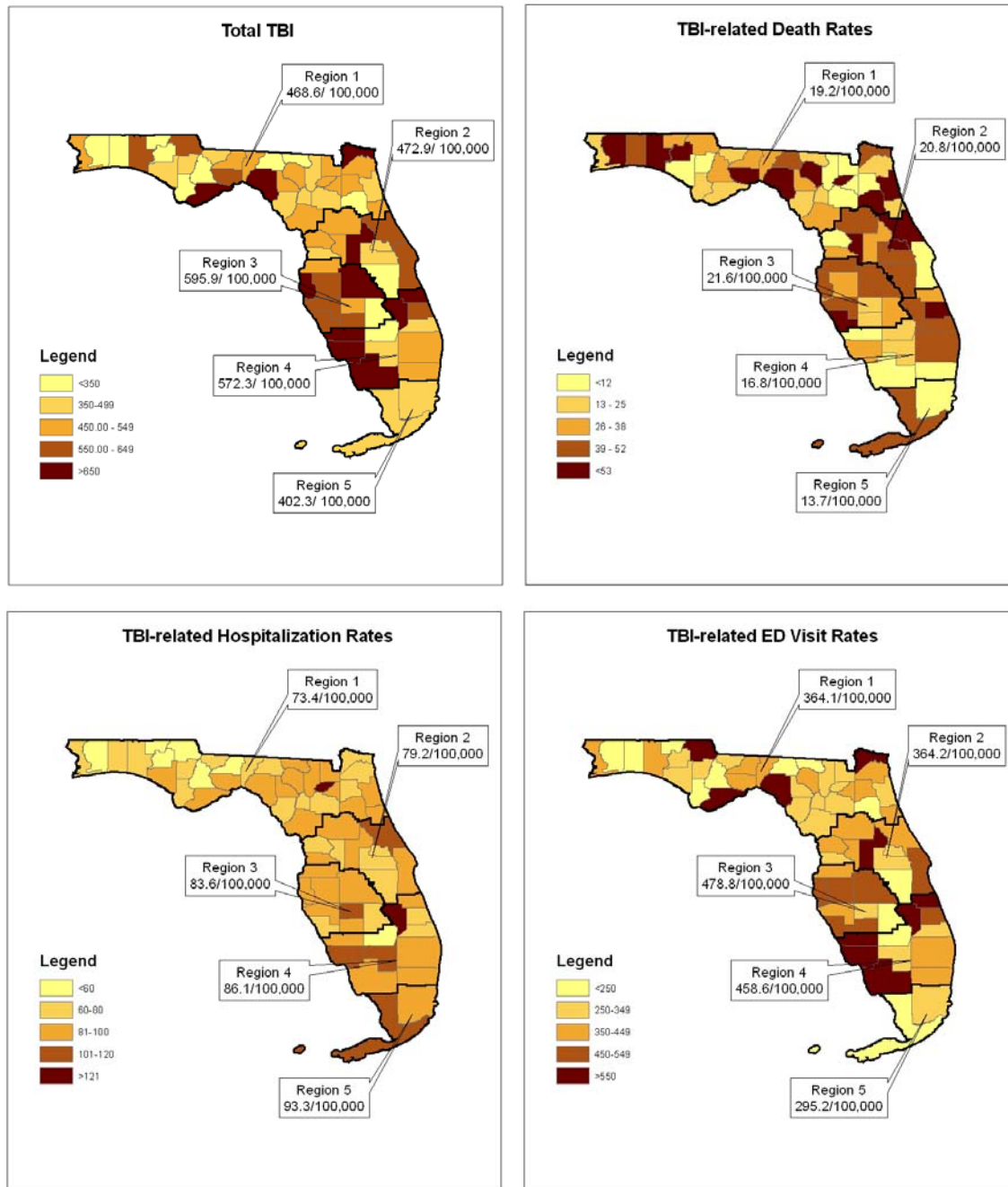


Source: *State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 1999-2005; *State of Florida, AHCA, Detailed Discharge Data, 1999-2005; **State of Florida, AHCA, Emergency Department Data, 2005; **State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 2005; **State of Florida, AHCA, Detailed Discharge 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.
Prepared by: WellFlorida Council Inc., 2007.

In Florida from 1999 through 2005, an average of 3,331 TBI-related deaths occurred each year, with the most in BSCIP Region 3 (852) compared to BSCIP Region 5 with the fewest (338) and an average of 14,810 TBI-related hospitalizations occurred each year, with the most occurring in BSCIP Region 4 (4,177) compared to BSCIP Region 1 with the fewest (2,253). Statewide, 71,382 TBI-related ED visits occurred during 2005, with the most in BSCIP Region 4 (20,862) compared to BSCIP Region 5 with the fewest (7,375). Figure 5 shows the age-adjusted TBI rates including deaths, hospitalizations and ED visits per 100,000 of the population for each BSCIP region and county.

- Total TBI age-adjusted rates in BSCIP Regions 3 and 4 were higher than the state rate and BSCIP Region 5 had lowest total TBI age-adjusted rate in the state during 2005.
- BSCIP Region 5 had the lowest TBI-related death rate and TBI-related ED visit rate in the state.
- BSCIP Region 1 had the lowest average annual age-adjusted rate for TBI-related hospitalizations in the state.

Figure 5: Age-Adjusted TBI Rates per 100,000 for Florida Counties and BSCIP Regions, 1999-2005.



* Total TBI and TBI-related ED visit rates for 2005 only.

** TBI-related deaths and hospitalization rates average from 1999-2005.

*** Age-adjusted to the US Standard Population, 2000.

Source: State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 1999- 2005; State of Florida, AHCA, Detailed Discharge Data, 2005; State of Florida, AHCA, Emergency Department Data, 1999- 2005; Traumatic Brain Injury in the United States: ED Visits, Hospitalizations and Deaths, 2006; State of Florida, Department of Health, CHARTS, accessed Feb 2007.

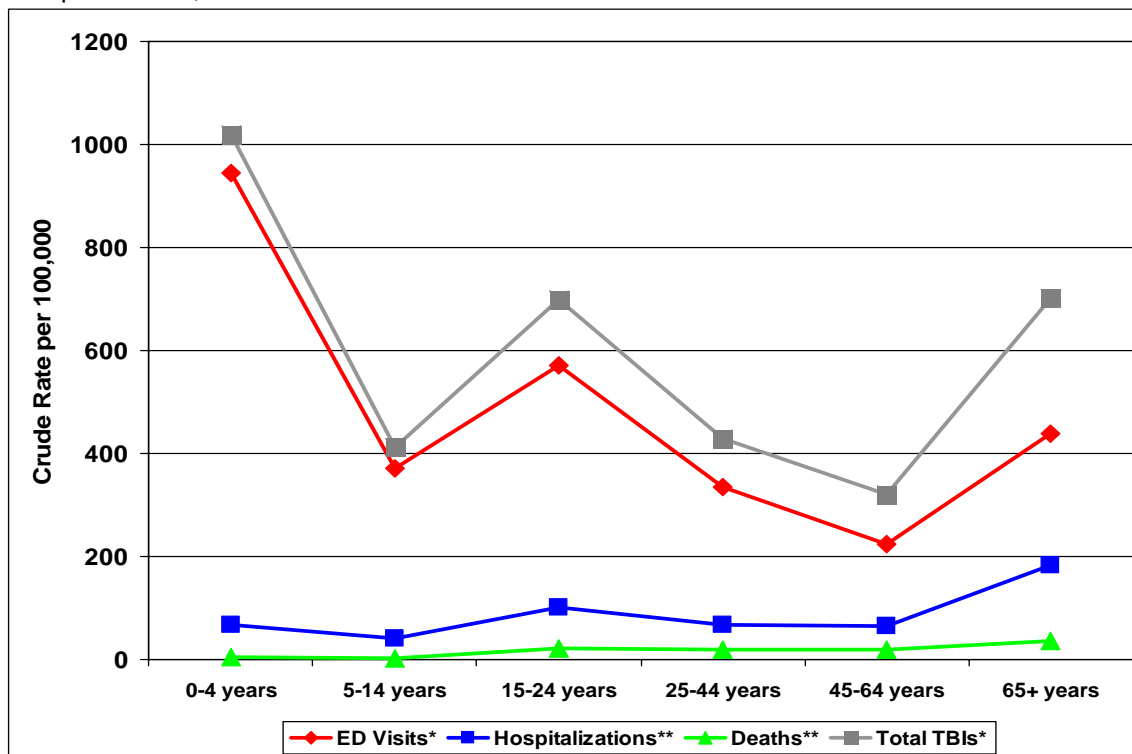
Prepared by: WellFlorida Council Inc., 2007.

TBI Rates by Age

Figure 6 shows the rates for TBI-related deaths, hospitalizations, ED visits and total TBIs by age for 2005 in Florida. The groups at greatest risk for all TBIs include children 0-4 years of age (1020.0), young adults 15-24 years of age (699.4) and adults over the age of 65 (700.7). Figure 7 shows the age distribution for all TBIs that occurred in Florida during 2005.

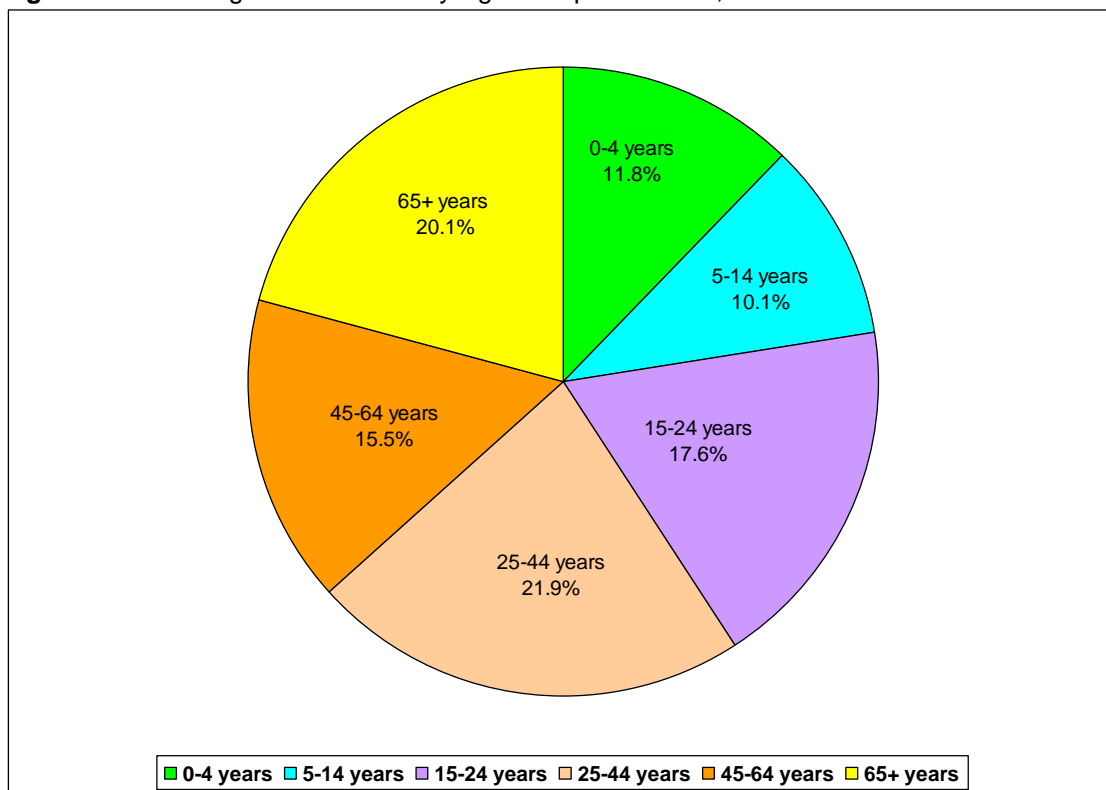
- In 2005, each of the age groups over 15 years of age in Florida was at higher risk for TBI compared to their national counterpart.
- Adults 65 and over were at greatest risk for TBI-related deaths (36.9) and hospitalizations (183.2), which were greater than the national rates for this population (35.5 and 173.5, respectively).
- Individuals 15 to 24 years of age were at second greatest risk for TBI-related deaths (22.5) and hospitalizations (101.3), which was greater than the national rate for TBI-related deaths (25.9) and less than the national rate for TBI-related hospitalizations (112.9).
- Youth 0-4 years of age were at greatest risk for TBI-related ED visits (944.0), which was less than the national rate (1035.0) for this population. Adults 65 years of age and older were at second greatest risk for TBI-related ED visits (439.2), which is 1.8 times greater than the national rate for this population.

Figure 6: Total TBIs, TBI-Related Deaths, Hospitalizations and ED Visits Rates (per 100,000) by Age Group in Florida, 2005.



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, Office of Vital Statistics, Public Health Statistics, 1999-2005; **State of Florida, AHCA, Detailed Discharge Data, 1999-2005; State of Florida, Department of Health, CHARTS, accessed Feb 2007.
Prepared by: WellFlorida Council Inc., 2007.

Figure 7: Percentage of Total TBIs by Age Group for Florida, 2005.



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 Date, 2005; State of Florida, Department of Health, CHARTS, accessed Feb 2007.

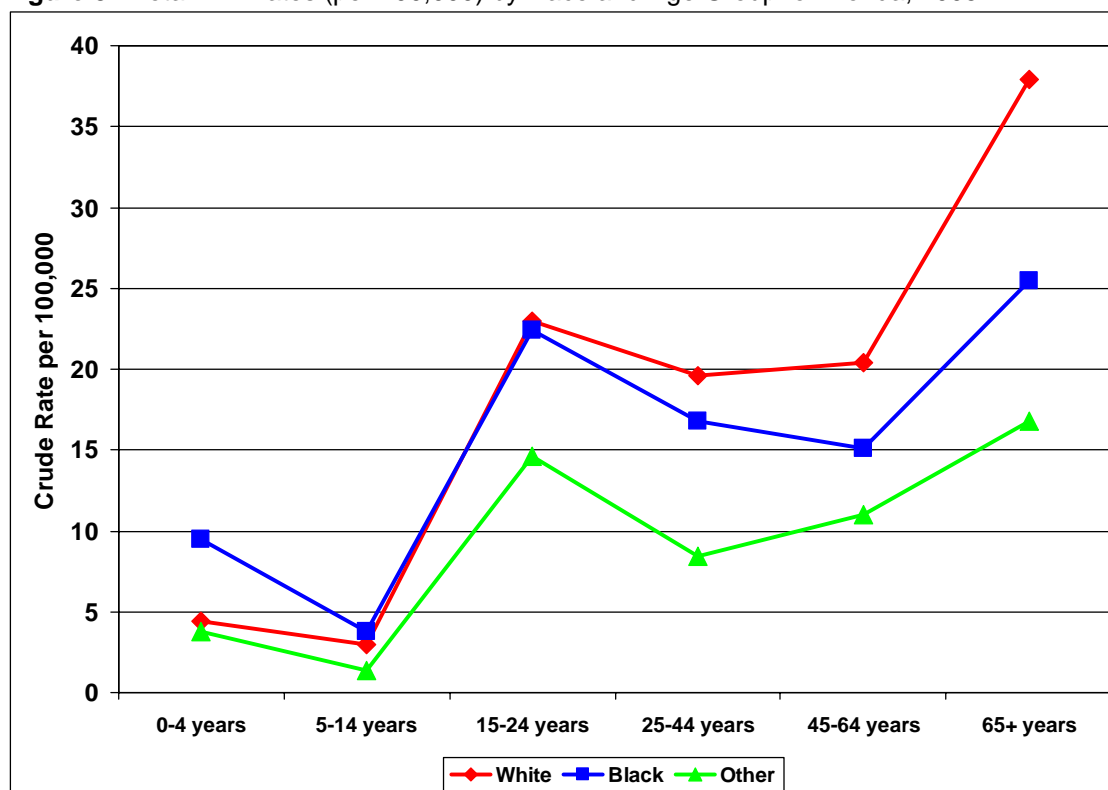
Prepared by: WellFlorida Council Inc., 2007.

TBI Rates by Race and Ethnicity

In Florida, 82.3 percent of all TBIs that occurred in 2005 were to whites, 14.1 percent were to blacks and 2.8 percent were to individuals who were classified as all other races. During 2005, individuals classified as other races had the highest crude rate of total TBIs (525.1) in Florida, followed by whites (524.4). Blacks, who are at greatest risk for TBI hospitalizations and deaths in the United States, were at the lowest risk for all TBIs (445.8) in Florida. Similar to the crude rates, individuals identified as other races had the highest age-adjusted rate for TBI (539.2) compared to whites (522.3) and blacks (440.5) in Florida during 2005. Figure 8 displays the 2005 crude rates for total TBI by race and age groups in Florida.

- Individuals identified as other races had the highest rate of TBI in the youngest and oldest age groups, compared to whites and blacks.
- For young adults, 15-24 years of age, whites were at greatest risk for TBI (735.9) compared to all other races.

Figure 8: Total TBI Rates (per 100,000) by Race and Age Group for Florida, 2005.



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.

Prepared by: WellFlorida Council Inc., 2007.

When looking at TBI-related deaths, hospitalizations and ED visits alone:

- From 1999 through 2005, whites (21.1) were at greatest risk for TBI-related deaths, which is unlike the national picture where blacks are at greatest risk for TBI-related deaths (19.3). This trend remains when comparing age-adjusted TBI-related death rates.
- Nationally, blacks (72.4) are more likely to be hospitalized from TBI-related causes than other races. In Florida, from 1999 through 2005, individuals classified as all other races (99.8) were more likely to be hospitalized for TBI-related issues than whites (90.1) or blacks (65.6). The same trend exists for age-adjusted rates.
- Nationally, blacks (485.6) are most likely to have visited the ED from TBI-related causes than other races. During 2005, individuals in Florida who were white (399.1) were most likely to be treated and released from the ED for TBI-related issues than other races (397.6) or blacks (364.1). The same trend exists for age-adjusted rates.

In 2005, 15 percent of all TBIs were sustained by individuals who identify themselves as Hispanic, resulting in a rate of 402.9 per 100,000 of the population. The rate was highest in BSCIP Region 3 (505.4) and lowest in BSCIP Region 1 (276.9).

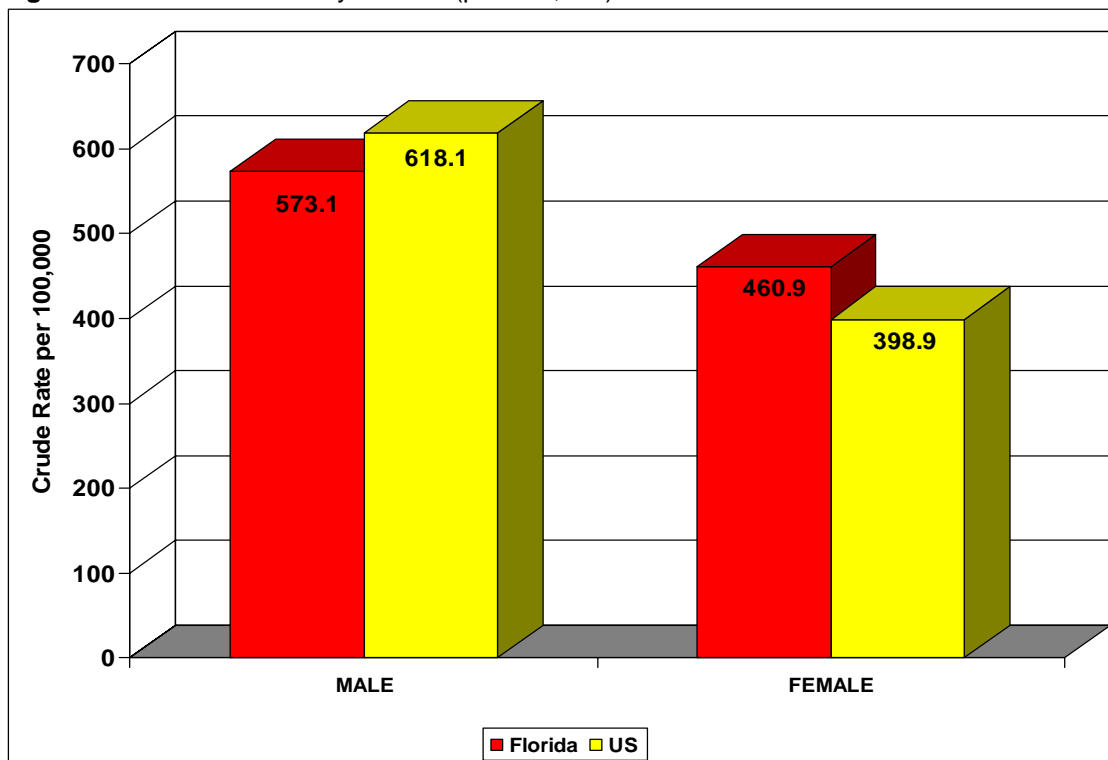
- From 1999 through 2005, the average annual TBI-related death rate for Hispanics in Florida was 13.4 per 100,000 of the population. The average annual TBI-related death rate was highest in BSCIP Region 3 (20.1) and lowest in BSCIP Region 5 (11.6).
- From 1999 through 2005, the average annual hospitalization rate for Hispanics in Florida was 68.5 per 100,000 of the population. BSCIP Region 5 had the highest rate of TBI-related hospitalizations in Florida (81.0) and BSCIP Region 1 had the lowest (34.1).
- The 2005 ED visit rate for Hispanics in Florida was 310.3 per 100,000 of the population. BSCIP Region 4 had the highest rate of TBI-related ED visits in Florida (411.5) compared to BSCIP Region 1 with the lowest (207.5).

TBI Rates by Gender

Males are 1.4 times more likely to have a TBI than females in the United States; in Florida, males were 1.2 times more likely to experience a TBI than females during 2005. The crude rate for TBI for males (573.1) in Florida was higher than the rate for females (460.9) (Figure 9).

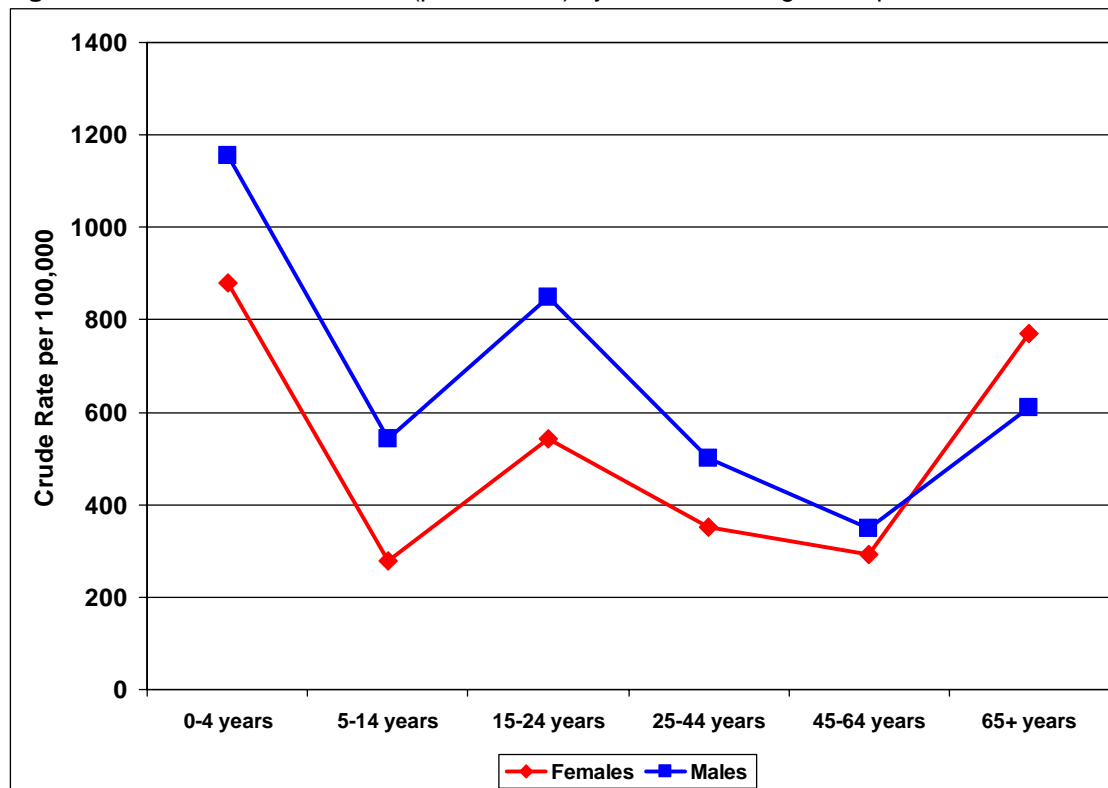
Across all age groups in Florida, except the 65 years of age and older age group, males are more likely to experience a TBI than females (Figure 10). Males 0-4 years of age were at highest risk for TBI in Florida during 2005 (1,154.4) followed by females in the same age group (880.7). The 2005 age-adjusted rate for TBI for males in Florida was 601.0 per 100,000 of the population, which was 1.4 times higher than the rate for females.

Figure 9: Total TBI Rates by Gender (per 100,000) for Florida and the United States.



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. Prepared by: WellFlorida Council Inc., 2007.

Figure 10: Total TBI Crude Rates (per 100,000) by Gender and Age Group for Florida, 2005.



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.
Prepared by: WellFlorida Council Inc., 2007.

When examining TBI-related deaths, hospitalizations and ED visits alone:

- In Florida, males are approximately three times more likely to die from TBI-related causes than females. From 1999 through 2005, the average annual crude death rates were higher for both genders in Florida (30.0 for males and 10.1 for females) than their respective national rates (27.3 for males and 9.2 for females). When adjusting the TBI-related death rates for age, males in Florida (29.0) were slightly more likely than their national counterparts (28.4) to die from a TBI-related cause. Females in Florida were equal to their national counterparts (8.9) in this regard.
- In Florida, males are approximately 1.7 times more likely to be hospitalized from TBI-related causes than females. From 1999 through 2005, TBI-related hospitalization rates were higher for both genders in Florida (110.4 for males and 66.7 for females) compared to the nation (107.8 for males and 63.4 for females). When adjusted for age, the trend reversed and males and females in Florida (107.2 and 55.1, respectively) were less likely to be hospitalized for TBI than their national counterparts (110.4 and 60.7, respectively).
- In Florida, males were approximately 1.2 times more likely to go to the ED for a TBI-related cause than females. Males have higher rates for TBI-related ED visits than females in Florida as well as in the nation. But, compared to the national rate (362.5), the ED visit rates were higher for females (354.7) in Florida. The rates for males (439.4) in

Florida were lower than the national (482.9) rate. This trend remains after adjusting for differences in the age of the population.

TBI Rates by Cause

Nationally, falls (28 percent), motor vehicle-traffic accidents (20 percent), struck by/against (19 percent) and assaults (11.0 percent) are the primary causes of TBI. During 2005, falls caused 39.6 percent of all TBIs in Florida, followed by motor vehicle-traffic accidents (20.8 percent) and assaults (11.1 percent). Figure 11 shows the percentage distribution of TBI causes by total TBIs, TBI-related deaths, hospitalizations and ED visits.

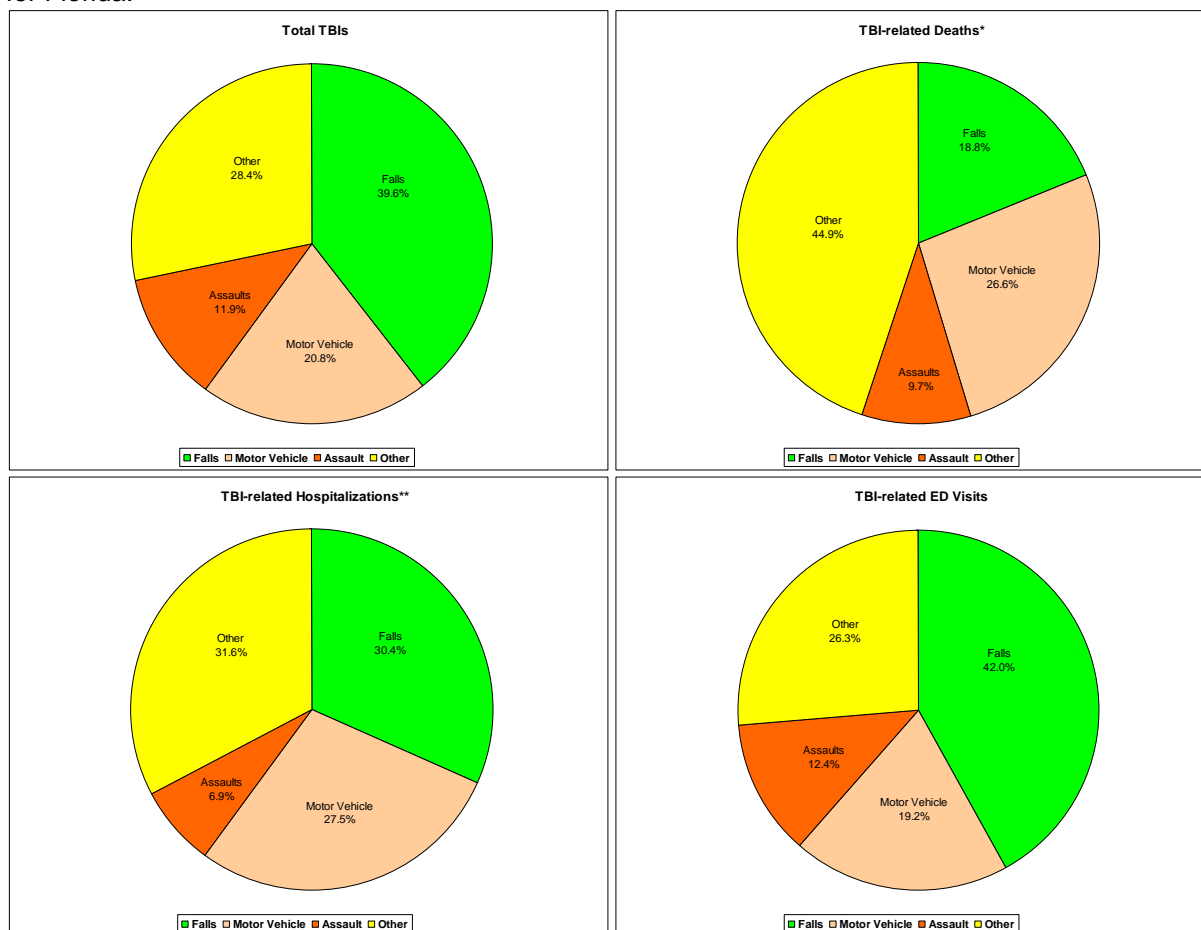
- Compared to the United States, there were a greater percentage of TBI-related deaths that resulted from falls and a smaller percentage that resulted from motor vehicle-traffic accidents and assaults from 1999 through 2005. But the leading cause of TBI-related death in the United States and Florida was motor vehicle-traffic accidents.
- Unlike the nation, falls resulted in the most TBI-related hospitalizations in Florida from 1999 through 2005, followed by motor vehicle-traffic accidents and assaults. Nationally, motor vehicle-traffic accidents (35.3 percent), falls (20.5 percent) and assaults (6.1 percent) are the primary causes of TBI-related hospitalizations.
- Falls were the leading cause of TBI-related ED visits in the state and nation, but the percentage of falls in Florida during 2005 was much higher (42 percent) than the national percentage (30.9 percent).

During 2005, rates for TBI were highest for falls (204.3). Motor vehicle-traffic accidents had the second highest rate for TBI in Florida (107.1), followed by assaults (57.2). These rates were higher than their respective rates nationally. Figure 12 shows the age-adjusted total TBI rates by cause for Florida and the United States. Figure 13 shows the rates for primary causes of TBI by age-group.

In Florida, there were 36,803 falls that resulted in TBIs in 2005, which resulted in a rate of 204.3 per 100,000 of the population. The rate for falls was greater in Florida compared to the national rate (144.4). BSCIP Region 4 has the highest total TBI rate (249.6) from falls in the state. Consistent with national trends, the TBI rates resulting from falls in Florida were highest in the youngest (694.2) and oldest populations (485.8).

- From 1999 through 2005, the average annual crude TBI-related death (3.7) and hospitalizations (26.8) rates from falls were greater than the national rates (2.3 and 17.5, respectively). In 2005 the TBI-related ED rate (166.5) was greater than the average annual national rate (124.4). Consistent with national trends, the average annual crude TBI-related death and hospitalization rates resulting from falls in Florida were highest in the 65 years of age and older category and TBI-related ED visits were highest in the 0-4 years of age group. When adjusting for differences in age, the rates remained higher in Florida but the disparity was decreased.

Figure 11: Percentage of TBI Causes by Total TBIs, TBI-related Deaths, Hospitalizations, and ED Visits for Florida.



Source: *State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 1999-2005; **State of Florida, AHCA, Detailed Discharge Data, 1999-2005; 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.
Prepared by: WellFlorida Council Inc., 2007.

During 2005, in Florida 19,306 motor vehicle-traffic accidents resulted in TBIs, which resulted in a rate of 107.1 per 100,000 of the population. The rate for motor vehicle-traffic related TBIs was the highest in the 15-24 years of age population (263.8). Occupant motor vehicle accidents resulted in 14,696 TBIs (81.6 per 100,000); pedestrian accidents resulted in 1,189 TBIs (6.6 per 100,000); motorcycle accidents resulted in 1,643 TBIs (9.1 per 100,000); and pedalcycle accidents resulted in 622 TBIs (3.5 per 100,000).

- From 1999 through 2005, the average annual crude TBI-related death rate (5.3) from motor vehicle-traffic accidents was less than the national rate (6.1), but the TBI-related hospitalization rate (24.2) from motor vehicle-traffic accidents was greater than the national rate (21.6). In 2005, the TBI-related ED rate (76.1) was greater than the average annual national rate (73.1). Consistent with national trends, the average annual crude TBI-related death and hospitalization rates and the 2005 TBI-related ED visit rate resulting from motor vehicle-traffic accidents in Florida was highest in the 15-24 years of age category. When adjusting for differences in age, the rates for TBI-related

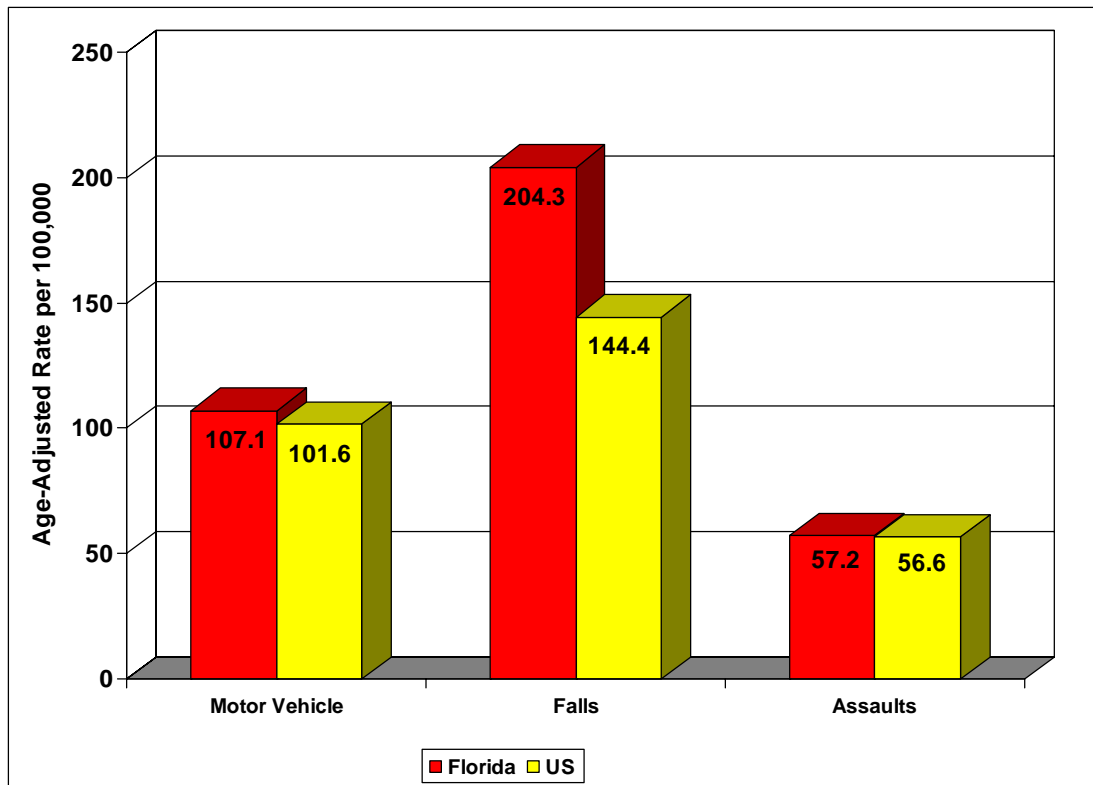
hospitalizations and ED visits were greater in Florida than the nation and the TBI-related death rate was less than the national rate.

- From 1999 through 2005, the average annual crude death rates in Florida for all motor vehicle-traffic categories except occupant accidents were higher than national rates. The average annual rates in Florida for hospitalizations were higher than the national rates in all categories. National averages were not available for ED visits.

During 2005, 10,314 people in Florida experienced an assault that resulted in a TBI (57.2 per 100,000), which is higher than the national rate (56.2 per 100,000). The total TBI rate from assaults was highest in the 15-24 years of age population (141.1).

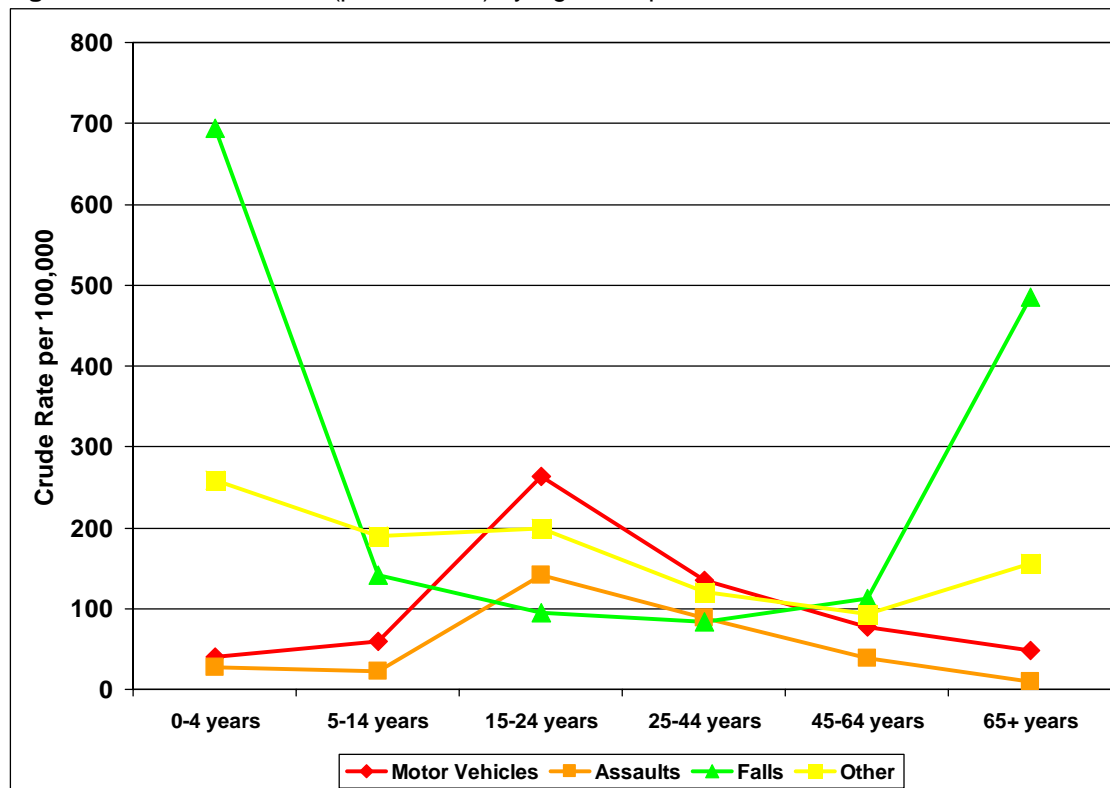
- From 1999 through 2005, the average annual crude TBI-related death and hospitalization rates (1.9 and 6.0, respectively) from assaults were higher than the national rate (1.1 and 5.2, respectively). In 2005, the TBI-related ED rate (49.3) was slightly greater than the average annual national rate (49.1). Consistent with national trends, the average annual crude TBI-related death and hospitalization rates and the 2005 TBI-related ED visit rate resulting from assaults in Florida was highest in the 15-24 years of age category. When adjusting for differences in age, Florida's rates for TBI-related hospitalizations and ED visits remained higher than the respective national rates. TBI-related death rates from assaults were lower than the national rate.

Figure 12: Total TBI Age-Adjusted Rates (per 100,000) by Cause of Injury for Florida and the United States.



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. Prepared by: WellFlorida Council Inc., 2007.

Figure 13: Total TBI Rates (per 100,000) by Age Group and Cause, 2005.



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.
Prepared by: WellFlorida Council Inc., 2007.

TBI Rates by Rural Residency

In Florida, 6.1 percent of the population resides in rural counties. In 2005, the rural population of Florida accounted for 5,191 (5.6 percent) of the total TBIs in the state. The total rate for TBIs in the rural counties of Florida was 461.6, compared to 525.6 in the non-rural counties. BSCIP Region 1, which most closely represents “rural” based on population density, has total TBI rate of 469.8 per 100,000 of the population.

- From 1999 through 2005, the rural population of Florida accounted for an average of 270 TBI-related deaths and 899 TBI-related hospitalizations each year. The average annual crude TBI-related death rate in the rural counties of Florida is 25.5 per 100,000, compared to 19.3 per 100,000 in the non-rural counties and 19.8 per 100,000 for the state. The average annual crude TBI-related hospitalization rate in the rural counties of Florida is 84.4 per 100,000, compared to 87.6 per 100,000 in the non-rural counties and 88.1 per 100,000 for the state. The higher death rates and lower hospitalization rates in rural counties may be due to decreased access to medical care in rural areas including lack of trauma centers and increased response and transport time.
- The 2005 TBI-related ED rate in the rural counties of Florida is 333.2 per 100,000, compared to 407.5 per 100,000 in the non-rural counties and 396.2 per 100,000 for the

state. Therefore, individuals in rural areas utilize emergency department services less frequently for TBI-related causes compared to their non-rural counterparts and the state as a whole. Accurately reporting and diagnosing TBIs in rural emergency departments may be less likely than in more populated areas. This may result in an underreporting of the number of ED TBI-related visits in rural areas.

Traumatic Brain Injury System Profile

The system profile examines some of the primary features in the system of care for individuals with TBI in Florida. The profile includes descriptions of key programs and services as well as various data from these entities. Programs and services included in this analysis are the Florida Department of Health Brain and Spinal Cord Injury Program (BSCIP), Brain Injury Association of Florida (BIAF), Department of Education Division of Vocational Rehabilitation (DVR) and Exceptional Student Education Program (ESE), Florida Alliance for Assistive Services and Technology (FAAST), protection and advocacy and Centers for Independent Living (CIL). This analysis of system components for individuals with TBI will enable the state, stakeholders, consumers and family members to identify current service delivery patterns and ultimately guide decision-making to improve the overall health and access to services for individuals with TBI in Florida.

Brain and Spinal Cord Injury Program

The state of Florida has a government administered program, BSCIP, which is designed to assist individuals and their families who experience a moderate-to-severe traumatic brain injury from time of injury through reintegration back into the community in accessing federal, state, third party and community resources. Since 2000, BSCIP is housed within the Department of Health, Division of Health Access and Tobacco. At this time, the program is funded through the Brain and Spinal Cord Injury Trust Fund, which receives funding from 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 tag. These funds can be used to access services as a payor of last resort including case management, acute care, inpatient and outpatient rehabilitation, transitional living, assistive technology, home and vehicular modification and long-term community-based supports funded under contract with specific not-for-profit agencies. Finally, for those individuals who need lifetime support, BSCIP provides its Home and Community Medicaid Waiver Services, which can provide support for up to 325 individuals (brain and/or spinal cord injuries) annually. BSCIP also houses the Central Registry (CR), mandated by the Florida statute, to collect information about individuals who experience a moderate-to-severe brain or spinal cord injury.

New Brain Injuries

The Central Registry (CR) is mandated (Florida Statute 381.74) to collect information on individuals who sustain a moderate-to-severe brain or spinal cord injury, including the name, age, residence, type of disability of the individual and other information as deemed necessary by the department.¹ Specifically, reporting a moderate-to-severe injury is required if the injury

resulted in external trauma to the skull causing an insult to the brain and resulted in the patient having a Glasgow Coma Scale score of 12 and below or a Rancho Scale score of 8 and below. The law requires that every public health agency, private health agency, public social agency, private social agency, and attending physician report all new traumatic moderate-to-severe brain or spinal cord injuries within five days to the CR. Referral to the Registry may also be initiated by service providers, injury survivors, family members or guardians.

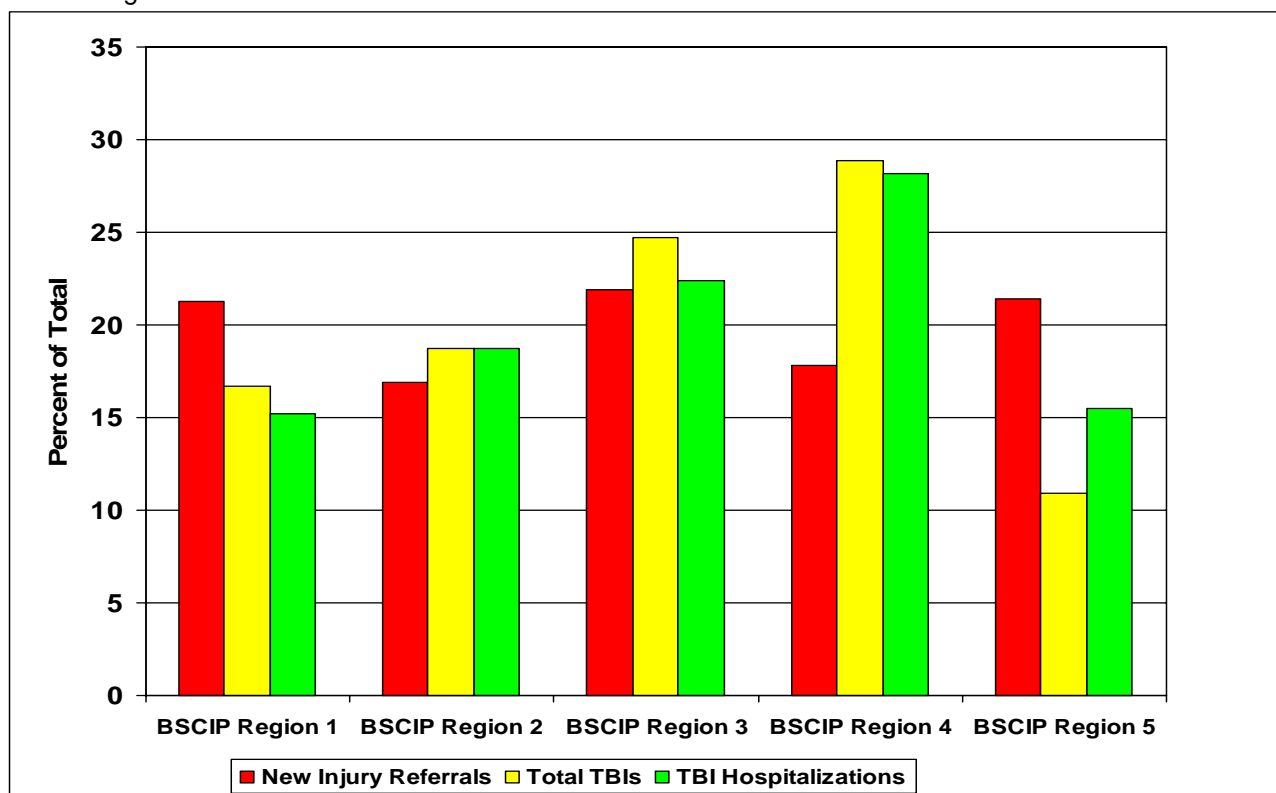
Understanding the relationship between the number of new injuries reported to the CR and the total number of TBIs, specifically moderate-to-severe injuries that occur in Florida is extremely important when making decisions regarding future planning and service delivery needs. Unfortunately, injury severity level information is not available in the Agency for Healthcare Administration hospitalization and emergency department data. Therefore, total TBIs and TBI-related hospitalization data are used as indicators to begin to examine this relationship. The total number of TBIs that occurred in Florida provides information on how well the CR matches the overall incidence of TBI in the state regardless of level of injury and TBI-related hospitalizations is included because it most closely matches the target CR population, it has been estimated that 85 percent of TBI-related hospitalizations are for moderate-to-severe injuries.⁸ Information on injury severity in Florida is required to fully understand the relationship described above.

Data presented in this section highlight the average number of reported new TBI injuries from 2002 through 2005 compared to the total number of TBIs in 2005 and the average annual number of TBI-related hospitalizations from 1999 through 2005.

From 2002 through 2005, 9,780 individuals with TBI were referred to the CR (2,445 per year). Approximately, 2.6 percent of all TBIs and 16.5 percent of all TBI-related hospitalizations were reported to the CR. The greatest percentage of annual new TBI injuries reported were from BSCIP Region 3 (21.9 percent) while the greatest percentage of total TBIs and TBI hospitalizations occurred in BSCIP Region 4 (28.9 percent and 28.2 percent, respectively). The percentage of average new TBI injuries reported to the CR by region does not correspond with the number of total TBIs and TBI-related hospitalizations (Figure 14). But as stated above, information on injury severity is required to fully understand this relationship.

- BSCIP Region 3 reported the greatest number of new TBIs to the CR per year (536), while Region 2 reported the fewest number of new TBIs to the CR per year on average (414).
- From 2002 through 2005, BSCIP Region 5 reported the greatest percentage of all TBIs (5.1 percent) to the CR and BSCIP Regions 1 and 5 reported the greatest percentage of all TBI-related hospitalizations (23.1 percent and 22.8 percent, respectively).
- BSCIP Regions 1 and 4 reported the lowest percentage of all TBIs (1.1 percent and 1.6 percent, respectively) to the CR and BSCIP Region 4 reported the lowest percentage of TBI-related hospitalizations (10.4 percent) to the CR.

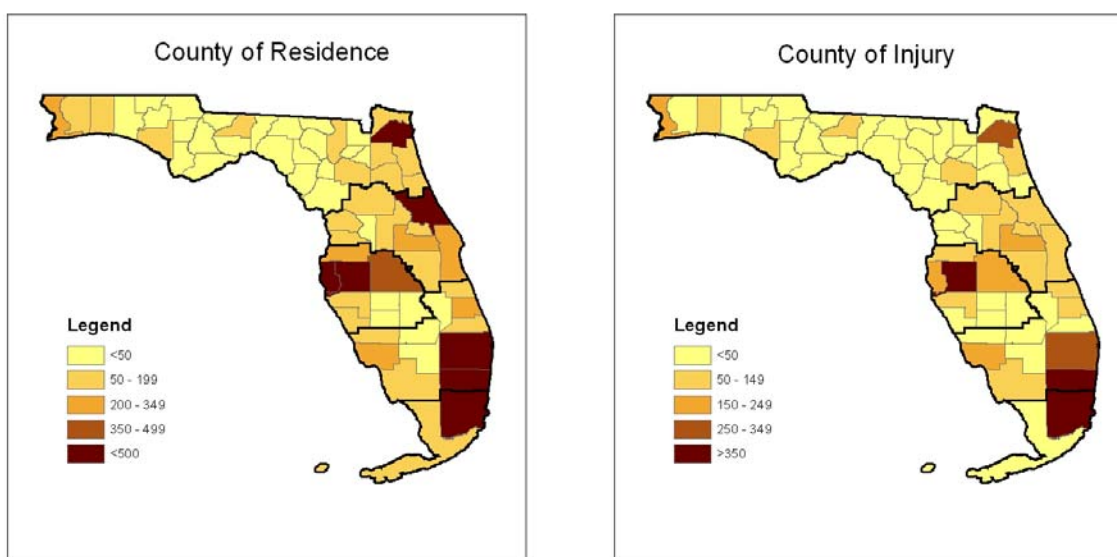
Figure 14: Percentage of Total New TBIs Reported to CR, Total TBIs and TBI-related Hospitalizations by BSCIP Region.



Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, 2002-2005, accessed March 2007; State of Florida, Department of Health, CHARTS, accessed Feb 2007; 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, AHCA, Detailed Discharge Data, 1999- 2005.
 Prepared by: WellFlorida Council Inc., 2007.

Figure 15 shows the total number of new TBI injuries reported to the CR by the most current county of residence and county of injury. The largest number of new injuries reported to the CR based on county of residence and county of injury were reported in Miami-Dade County (2,017 and 2,023), which was approximately 3 times greater than the county with the second most reported injuries. The counties with the fewest CR reported injuries based on county of residence and county of injury during this period were in counties identified as rural counties by the Florida Department of Health, Office of Rural Health.

Figure 15: Total Number of Referrals to CR by County of Residence and County of Injury, 2002-2005.



Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, 2002-2005 accessed March 2007. Prepared by: WellFlorida Council Inc., 2007.

Hospitals in Florida reported more than 90.6 percent (8,660) of new injuries to the CR from 2002 through 2005. Rehabilitation centers were the second most common referral source (5.4 percent). Twenty of the 21 trauma centers in the state were listed as the reporting facility for new injury referrals to the CR from 2002 through 2005. West Florida Hospital in Pensacola was the only state designated trauma center that did not report a new injury to the CR during this time period. Of the 8,860 client referrals made by hospitals, 7,282 (78.2 percent) were from state designated trauma centers.

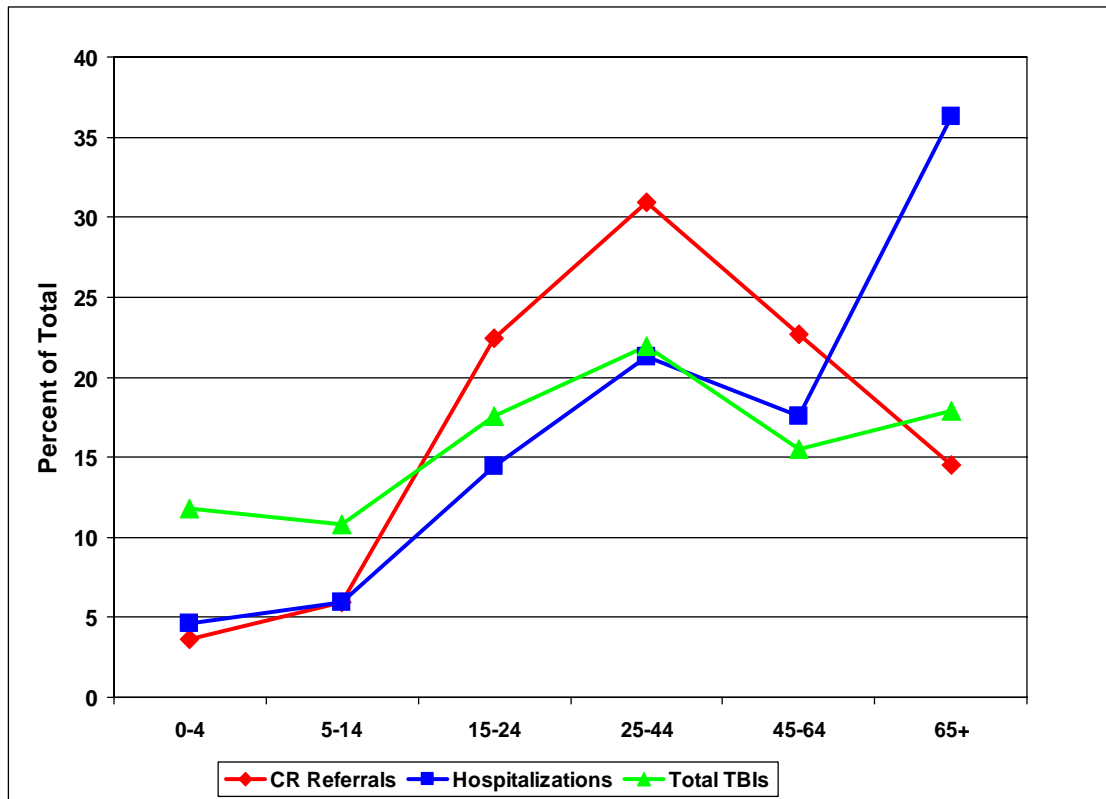
Figure 16 compares the percentage of CR new injury referrals, total TBIs and TBI-related hospitalizations by age group. A greater percentage of individuals 15 through 64 years of age were referred to the CR compared to total TBIs and TBI-related hospitalizations that occurred in the same age group. The largest disparity exists between the percentage of individuals over the age of 65 who were hospitalized for a TBI and the percentage of those individuals who were referred to the CR.

Approximately 81 percent of new injury referrals to the CR from 2002-2005 identified themselves as white, compared to 82.3 percent of all TBIs and 83.4 percent of TBI-related hospitalizations. Referrals to the CR resulted in a greater percentage of new injuries for individuals who identified themselves as black (16.1 percent) compared to the percentage of TBIs and TBI-related hospitalizations that were experienced by individuals who identify as black in Florida and a slightly lower percentage of individuals who identify as other races.

The Hispanic population in Florida accounts for approximately 20 percent of the total population and 19.2 percent of all TBIs, while it represents only 18.8 of the new injury referrals to the CR. When compared to hospitalizations alone (12.0 percent), the percentage of Hispanic new injuries referred to the CR is greater (18.8 percent).

Approximately 73 percent of all new TBI injuries reported to the CR from 2002 through 2005 were male, compared to 56.3 percent of all TBIs in 2005 and 61.2 percent of TBI-related hospitalizations from 1999 through 2005.

Figure 16: Percentage of Total New TBIs Reported to the CR, Total TBIs and TBI-related Hospitalizations by Age Group.



Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, 2002-2005, accessed March 2007; State of Florida, Department of Health, CHARTS, accessed Feb 2007; 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, AHCA, Detailed Discharge Data, 1999- 2005. Prepared by: WellFlorida Council Inc., 2007.

In Florida, falls (39.6 percent), motor vehicle-traffic accidents (20.8 percent) and assaults (11.1 percent) were the primary causes of TBI during 2005. Falls caused 30.4 percent of all TBI-related hospitalizations, followed by motor vehicle-traffic accidents (27.5 percent) and assaults (6.9 percent) from 1999 through 2005. Figure 17 indicates that the primary causes of injury for new TBI injury referrals to the CR from 2002 through 2005: motor vehicle-traffic accidents (58.3 percent), falls (16.8 percent) and assaults (10.5 percent). This is unlike the distribution in the state, where motor vehicle-traffic accidents cause approximately 20.8 percent of all TBIs and 27.5 percent of TBI-related hospitalizations. As stated above, information on injury severity in Florida could clarify this relationship.

Figure 17: Percentage of Average Annual New TBI Injury Central Registry Referrals, Total TBIs and TBI-related Hospitalizations by Cause.



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, AHCA, Detailed Discharge Data, 1999-2005; State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, accessed Mar 2007.

Prepared by: WellFlorida Council Inc., 2007.

All brain injuries resulting in the individual having a Glasgow Coma Scale, which quantifies levels of consciousness, score of 12 and below or a Rancho Scale score, which quantifies response to external stimuli and environment, of 8 and below are required to be reported to the CR. For the purposes of this report the Glasgow Coma Scale will be grouped into the following categories: non-injured brain response (15), mild brain injury (13-14), moderate brain injury (9-12), severe brain injury (4-8), and non-responsive (3). New injuries classified as moderate (27.3 percent), severe (35.3 percent) and non-responsive (32.8 percent) represent the great majority of referrals to the CR. Based on CR mandated requirements, 99.4 percent of all referrals to the CR were Rancho levels 8 or lower.

BSCIP Trust Fund

The BSCIP Trust Fund provides services for individuals with TBI that meet the program eligibility requirement. These funds can be used to access services as a payor of last resort including case management, acute care, inpatient and outpatient rehabilitation, transitional living,

assistive technology and home and vehicular modification. The individuals in BSCIP are managed by case managers (21 adult managers and 12 Children's Medical Services (CMS) nurses for individuals injured under the age of 18). Case managers work with eligible clients to access service needs to promote successful reintegration back into the community after the brain injury.

To be eligible for BSCIP services through the Trust Fund an individual must: be referred to the Central Registry, meet the state definition for TBI, be medically stable, be a legal resident of Florida and have a reasonable expectation for community reintegration. The state definition for TBI, defined by Florida statute, is an insult to the skull, brain, or its covering that results from external trauma and that produces an altered state of consciousness or anatomic, motor, sensory, cognitive, or behavioral deficit.¹ Program eligibility is determined once the patient is stable, and requires a moderate-to-severe brain injury resulting in a Rancho score of 4 through 10.

Understanding the relationship between the number of clients served by the program, new injuries reported to the CR and the total number of TBIs, specifically moderate-to-severe injuries that occur in Florida is extremely important when making decisions regarding future planning and service delivery needs. As stated above, injury severity level is not available in the AHCA hospitalization and emergency department data. Therefore, total TBIs and TBI-related hospitalization data are used as indicators to begin to examine this relationship. The relationship can not fully be understood without information on the distribution of injury severity.

Trust Fund Allocation

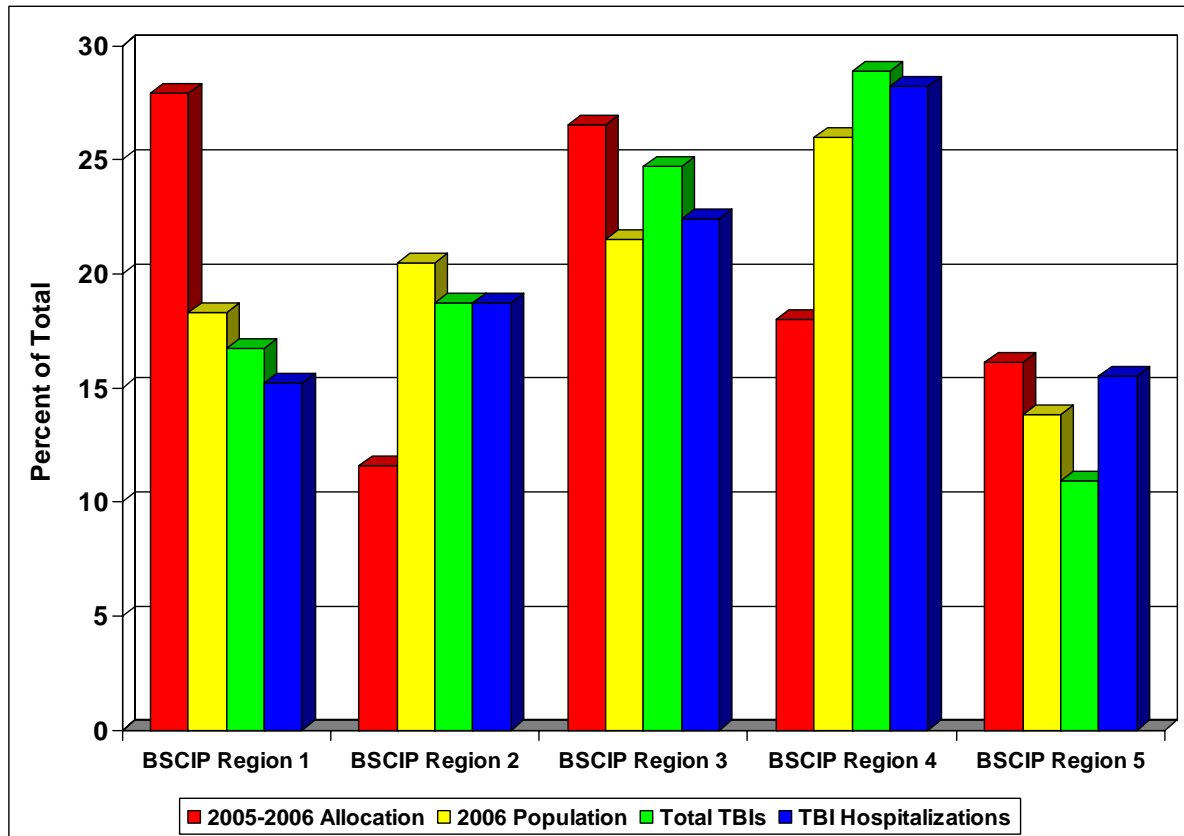
The total Trust Fund allocation for each region, brain and spinal cord injury combined, is based on four client caseload measures, each measure constituting 25 percent of the total budget allocation. Measures include: number of CR referrals during fiscal year, number of client plans written during fiscal year, number of active cases and number of clients reintegrated into the community during the fiscal year. From state fiscal year 2002-2003 through 2005-2006, the total Trust Fund allocation for BSCIP was approximately \$25 million and resulted in the expenditure of approximately \$20 million. The regional allocations ranged from approximately \$800,000 to \$2 million per year and corresponding expenditures ranged from approximately \$480,000 to \$2 million per year. The percentage of the allocation used per year ranged from approximately 50 percent to over 100 percent.

As seen in the previous section of the report, the greater the number of people in a population the greater the number of TBIs that occur. Figure 18 compares the percentage of the total BSCIP Trust Fund allocation for fiscal year 2005-2006 to the percentage of people in the population, percentage of total TBIs and percentage of TBI-related hospitalizations by region. BSCIP Regions 1, 3 and 5 received a greater percentage of the Trust Fund allocation compared to the percentage of the total population that resides in the region. BSCIP Regions 2 and 4 received a smaller percentage of the Trust Fund allocation compared to the percentage of the total population that resides in the region.

When comparing the percentage of Trust Fund allocations with the percentage of total TBIs in 2005 and average annual TBI-related hospitalizations:

- BSCIP Regions 2 and 4 experienced a greater percentage of total TBIs and TBI hospitalizations compared to the percentage of total BSCIP Trust Fund allocation. While the opposite was true in BSCIP Region 1.

Figure 18: Percentage of Total BSCIP Trust Fund Allocation by the Percentage of Total Population, Total TBI and TBI-related hospitalizations by Region.



Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, accessed March 2007; ESRI Business Solutions, 2006; 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, AHCA, Detailed Discharge Data, 1999-2005.
 Prepared by: WellFlorida Council Inc., 2007.

BSCIP Trust Fund Clients Served

Data presented in this section include all BSCIP Trust Fund clients with a TBI, 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 brain injury that meets the state definition and that was referred to the BSCIP Central Registry. Additionally, 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.

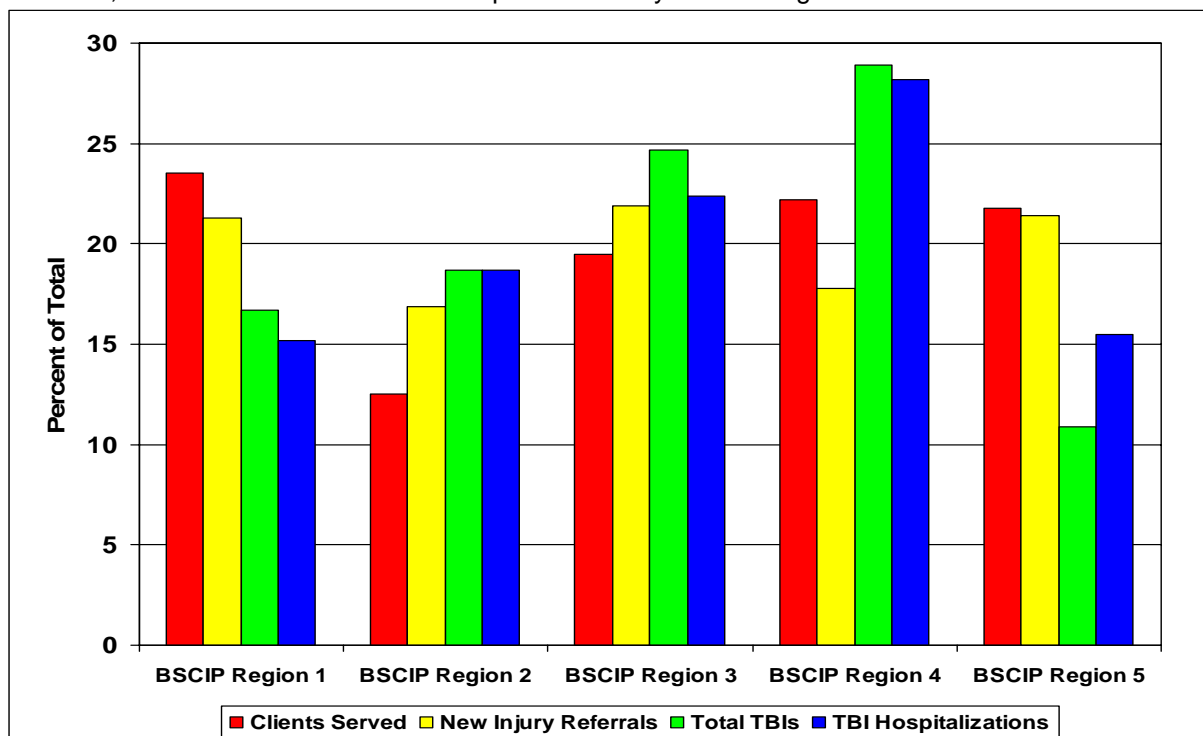
For this report, the data presented includes all Trust Fund clients for calendar years 2002 through 2005. The clients were identified using the Rehabilitation Information Management System (RIMS). Trust Fund clients were included in this analysis if they were identified as having “in-

service” status at any point during the calendar year. Please note total TBIs and TBI-related hospitalizations are used to serve as an indicator, but injury severity information from these populations are unknown. Injury severity data is necessary to truly understand the relationships described below.

From 2002 through 2005 approximately 6,400 individuals with TBI were served by the BSCIP Trust Fund programs (1,600 per year). Figure 19 compares the percentage of TBI BSCIP Trust Fund clients served to the percentage of TBIs reported to the CR, total TBIs, and TBI-related hospitalizations by BSCIP Region.

- Overall, BSCIP Region 1 served the greatest percentage of Trust Fund clients (23.5 percent), while Region 2 served the smallest percentage of clients (12.5 percent).
- BSCIP Region 2 contained approximately 20 percent of the state’s population, 19 percent of all TBIs, 18.7 percent of TBI hospitalizations and 16.9 percent of new injury referral, while representing only 12.5 percent of the BSCIP Trust Fund active clients from 2002 through 2005.
- BSCIP Regions 1 and 5 provided services to a larger percentage of Trust Fund clients than the percentage of new injury referrals, total TBIs, TBI hospitalizations and the percentage of the total population that reside in their respective regions.

Figure 19: Average Annual Percentage of Total TBI BSCIP Trust Fund Clients Served, New Injury CR Referrals, Total TBIs and TBI-related Hospitalizations by BSCIP Region.

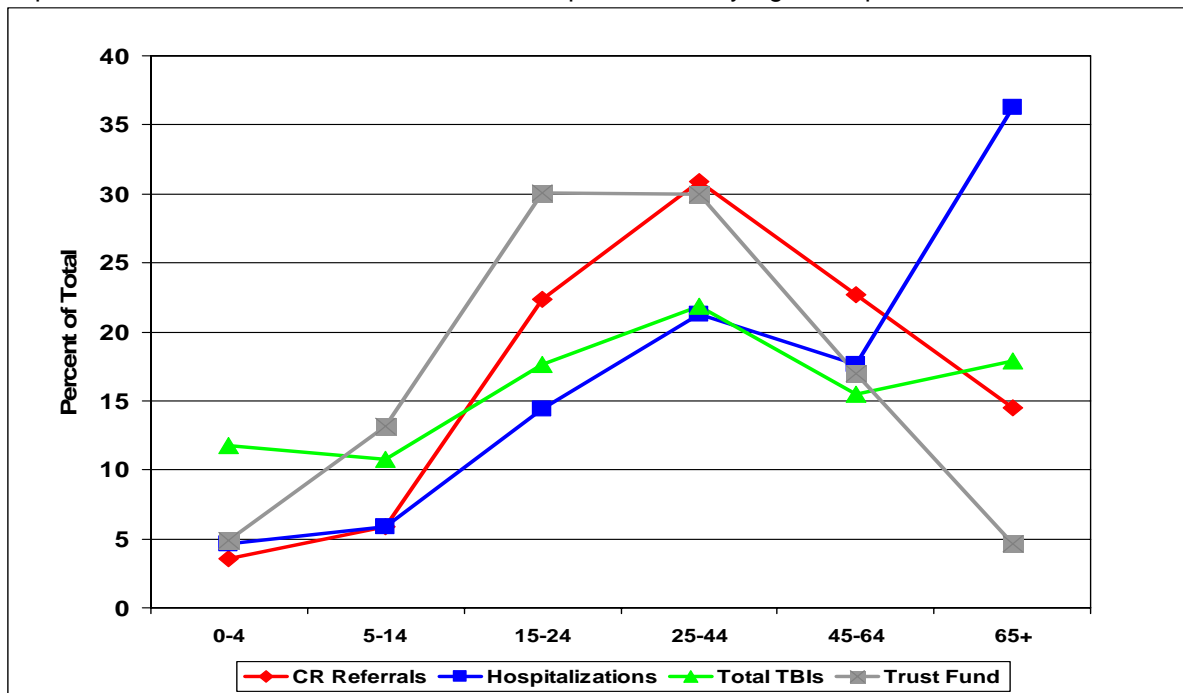


Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, 2002-2005 accessed March 2007; State of Florida, Department of Health, CHARTS, accessed Feb 2007; State of Florida, Department of Health, Office of Vital Statistics, Public Health Statistics, 2005; State of Florida, AHCA, Detailed Discharge Data, 2005; State of Florida, AHCA, Emergency Department Data; 2005 State of Florida, AHCA, Detailed Discharge Data, 1999-2005. Prepared by: WellFlorida Council Inc., 2007.

Figure 20 compares the percentage of TBI BSCIP Trust Fund clients served from 2002 through 2005 to the percentage of new injuries reported from 2002 through 2005, total TBIs from 2005 and average annual TBI-related hospitalizations from 1999 through 2005 by age group.

- The BSCIP Trust Fund served a greater percentage of individuals between the ages of 5-24 compared to CR referrals, total TBIs and TBI-related hospitalizations.
- Individuals over the age of 45 were less likely to be served by the BSCIP Trust Fund compared to the percentage of new injury referrals in that population.
- The greatest disparity between TBI-related hospitalizations and being served by the BSCIP Trust Fund was in the 65 years of age and older population.

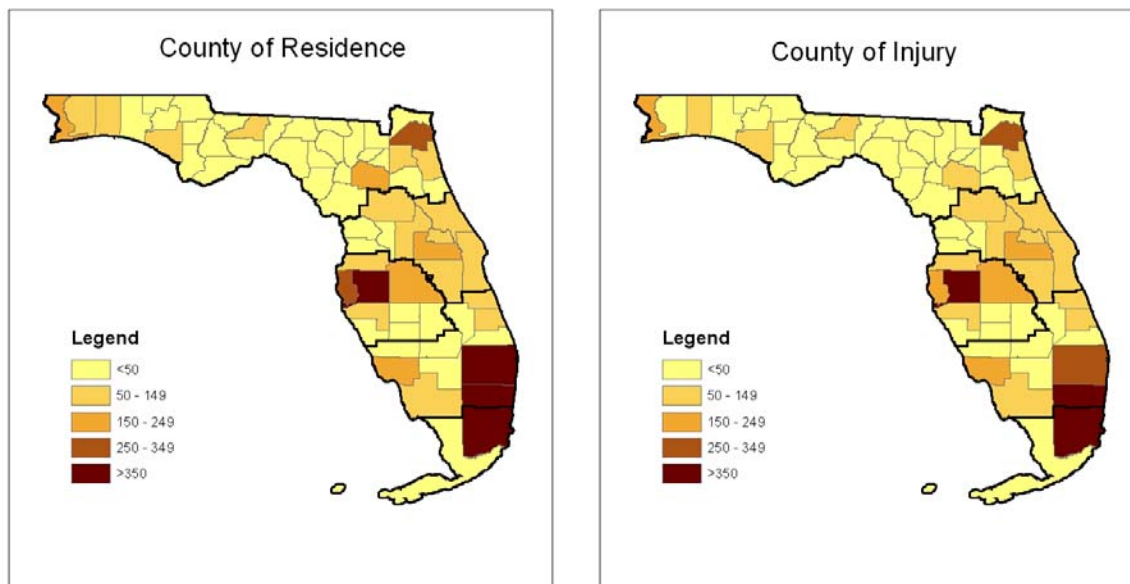
Figure 20: Average Annual Percentage of Total TBI BSCIP Trust Fund Clients Served, New TBIs Reported to CR, Total TBIs and TBI-related Hospitalizations by Age Group.



Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, 2002-2005 accessed March 2007; State of Florida, Department of Health, CHARTS, accessed Feb 2007; 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, AHCA, Detailed Discharge Data, 1999-2005. Prepared by: WellFlorida Council Inc., 2007.

Figure 21 shows the total BSCIP Trust Fund clients served by county of residence and county of injury. The greatest number of BSCIP Trust Fund clients served based on county of residence and county of injury were reported in Miami-Dade County (1,362 and 1,331, respectively). The counties with the fewest CR referrals based on county of residence and county of injury during this period were all identified as rural counties by the Florida Department of Health, Office of Rural Health.

Figure 21: Total Number of TBI BSCIP Clients Served by County of Residence and County of Injury, 2002-2005.



Source: State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, 2002-2005 accessed March 2007. Prepared by: WellFlorida Council Inc., 2007.

A referral to the BSCIP Central Registry is required for Trust Fund service eligibility. The Florida Statute 381.74 mandates the collection of information on individuals who experience a moderate-to-severe brain or spinal cord injury from every public health agency, private health agency, public social agency, private social agency, and attending physicians. Hospitals in Florida referred more than 83 percent of the clients who received Trust Fund services from 2002-2005. Rehabilitation centers were the second most common referral source. Twenty of the 21 trauma centers in the state were listed as the referral source for BSCIP Trust Fund clients from 2002- 2005. West Florida Hospital in Pensacola was the only state designated trauma center that was not identified as a referral source during this time period. Of the 5,325 client referrals made by hospitals, 3,969 (74.5 percent) were from hospitals with state designated trauma centers.

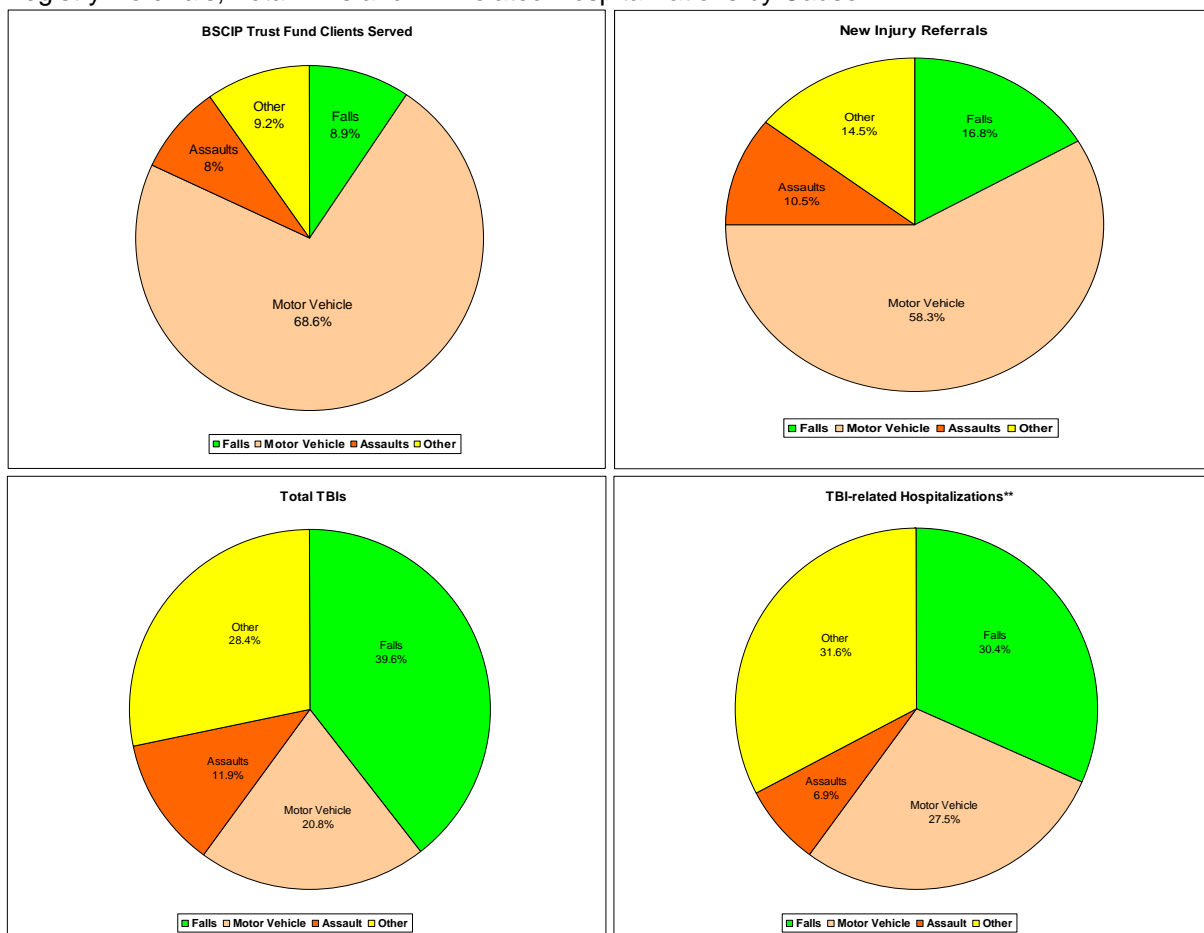
Approximately 80 percent of TBI BSCIP Trust Fund clients served from 2002-2005 identified themselves as white, compared to 82.3 percent of all TBIs, which includes deaths, hospitalizations and ED visits. The BSCIP Trust Fund serves a larger percentage of TBI clients who are black (18.8 percent) compared to the percentage of new injuries referred to the CR (16.1 percent) and total TBIs (14.1 percent) that were experienced by individuals who identify as black. The Trust Fund serves a lower percentage of individuals who identify as all other races (1.3 percent) compared to new injury referrals (2.5 percent) and total TBIs (2.8 percent).

Hispanics in Florida account for approximately 20 percent of the total population, while they represent only 12.6 of the TBI clients served by the BSCIP program. Compared to the percentage of Hispanic individuals with TBI referred to the CR (18.8 percent), the percentage of clients served was smaller (12.6 percent) from 2002- 2005. This decrease may be due to the residency requirement set forth by the Trust Fund program. Since 2002, the number of Hispanic residents served by the BSCIP Trust Fund program has increased each year.

Approximately 70 percent of the clients served by the BSCIP Trust Fund program from 2002 through 2005 were male, averaging 1,127 males and 472 females each year. This distribution was consistent over time and throughout each of the BSCIP regions. The percentage of male clients served was slightly lower than the percentage of males referred to the CR (73.3 percent) during the same time period and greater than the percentage of males for all TBIs (56.3 percent) in Florida in 2005 and for TBI-related hospitalizations (61.2 percent) from 1999-2005.

Figure 22 compares the cause of injury for TBI clients served by the BSCIP Trust Fund program, new TBI injury referrals, total TBIs and TBI-related hospitalizations. The primary causes of injury are motor vehicle-traffic accidents (68.6 percent), falls (8.9 percent) and assaults (8.0 percent) for TBI clients served by the Trust Fund.

Figure 22: Percentage of Average Annual BSCIP TBI Trust Fund Clients Served, New TBI Injury Central Registry Referrals, Total TBIs and TBI-related Hospitalizations by Cause.



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, AHCA, Detailed Discharge Data, 1999-2005; State of Florida, Department of Health, Brain and Spinal Cord Injury Program, RIMS, accessed Mar 2007.

Prepared by: WellFlorida Council Inc., 2007.

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. Waiver programs are viewed as beneficial because they provide an alternative for expensive long-term institutionalization by enabling individuals to remain among family and friends. Eligibility for the Waiver eligibility includes: permanent Florida residency, being 18 years of age or older, referred to Central Registry, 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. Core Waiver services include:

- Adaptive health and wellness services;
- Attendant care services;
- Assistive technology and adaptive equipment;
- Behavioral programming;
- Community support coordination;
- Companion services;
- Life skills training;
- Environmental accessibility adaptation;
- Personal adjustment counseling;
- Rehab engineering evaluations;
- Personal care assistance;
- Consumable medical supplies.

The current BSCIP Home and Community-Based Waiver became effective in July 2002 and remains effective until June 2007. The current Waiver provides services to 325 brain and spinal cord injured individuals annually. This program has recently expanded from 300 to 325 slots in an attempt to meet the increased need for services. The program has also implemented a prescreening tool to establish a protocol for placing individuals in the Waiver program when an opening occurs.

Since 2003, the TBI population in the Waiver program has grown each year, from 96 TBI waiver clients in 2003 to 129 TBI Waiver clients in 2005. From 2003 through 2005, the greatest percentage of Waiver participants lived in BSCIP Region 3. BSCIP Region 2, which has the lowest percentage of new injury CR referrals and BSCIP Trust Fund clients served, has the lowest percentage of Waiver clients in 2004 and 2005.

As expected, the percentage of males is greater than the percentage of females in the Waiver program. During all three years, Waiver participants were most likely to be in the 15-24 years and 25-44 years of age groups when injured. These percentages were higher than the new injury referrals and BSCIP Trust Fund clients served, but do represent the most frequently referred and served population groups.

Between 2003 and 2005, 11,477 Medicaid Home and Community-Based Waiver services have been provided to individuals with TBI, resulting in an average of 3,826 services per year. The

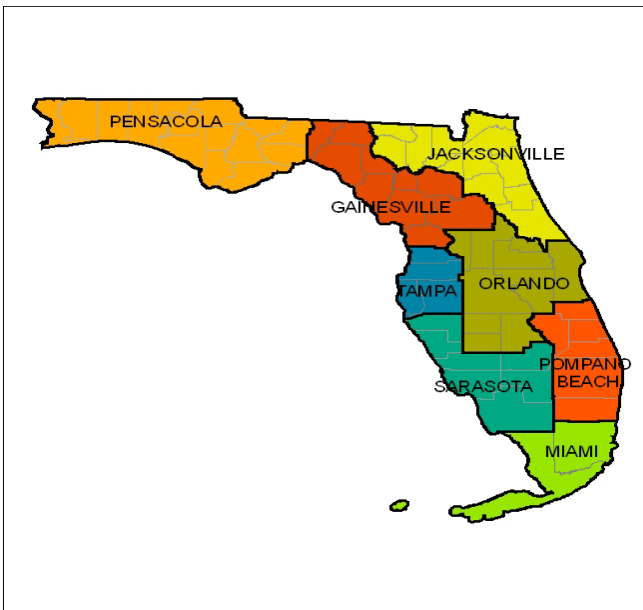
total cost of the services was \$7,070,932 over this time period, resulting in an average of \$2,356,977 per year.

- Community support coordination (28.9 percent) and companion services (27.3 percent) were the most frequently utilized services by participants in the Waiver program.
- Companion services and personal attendant services were the most costly for participants in the Waiver program; each service accounting for approximately 35 percent of all Waiver service costs from 2003 through 2005.
- Community support coordination, which represented 28.9 percent of all services used by Waiver participants, represented only 5.6 percent of service costs from 2003 through 2005.
- Behavioral programming and assistive technology were reported as needed by focus group participants. However, these services only represented approximately 8.6 percent of all service units and 6.8 percent of service costs.

Brain Injury Association of Florida

The Brain Injury Association of Florida (BIAF) is a nonprofit organization founded in 1985 by the mother of a son who was severely brain injured in a motor vehicle accident. Its mission is to improve the quality of life for persons with brain injuries and their families by creating a better future through brain injury prevention, research, education, support services and advocacy. BIAF assists individuals with brain injuries, their families and professionals by providing statewide information and resource center, education and training opportunities, support services, a toll-free helpline, awareness and prevention programs and advocacy activities. Two important components of BIAF are the Information and Resource Center and the Family and Community Support Program (Figure 23), both of which are funded through contacts with BSCIP.

Figure 23: BIAF Family and Community Support Specialists Areas, 2006.



Source: Brain Injury Association of Florida, 2006.
Prepared by: WellFlorida Council Inc., 2007.

Since 2003, BIAF identified 10,658 contacts for basic information or resources, resulting in an average of 2,662 contacts per year. The individuals who contacted BIAF for information were more likely to be male, white and ages 25-44. Residents from BSCIP Regions 4 (22.4 percent) and 5 (23.9 percent) were most likely to contact BIAF for information.

Since 2003, BIAF served 2,216 individuals by the Family and Community Support Program, an average of 554 individuals per year. Like the individuals who contacted BIAF for information, individuals who contacted BIAF for support services were more likely to be male, white and ages 25-44. Residents from BSCIP Regions 2 (23.0 percent) and 4 (23.1 percent) were more likely to contact BIAF for support services. Unlike the contacts for general information, residents from BSCIP Region 5 were the least likely to contact BIAF for support services (12.8 percent). BSCIP region was determined by county of residence.

Family and Community Support specialists work with clients to provide assistance in areas of need. The areas of assistance needed most often included: medical (28.6 percent), financial (14.4 percent), housing (13.4 percent) and employment (10.0 percent).

Key Community Partners

It is common for individuals with TBI to work with a variety of community providers in order to access the services and support they need. Department of Education Division of Vocational Rehabilitation (DVR) and Exceptional Student Education Program (ESE), Florida Alliance for Assistive Services and Technology (FAAST), protection and advocacy and Centers for Independent Living (CIL) represent a sample of services and providers used by this population. Data were provided by these departments and organizations to help describe the current service utilization of individuals with TBI in their respective organizations.

Division of Vocational Rehabilitation

- DVR works with individuals with disabilities to achieve, find, and maintain employment.
- Individuals with TBI are most likely to participate in the general Vocational Rehabilitation Services, which assist individuals with disabilities to pursue meaningful careers commensurate with their abilities and capabilities.
- In August 2006, an interview was conducted with DVR staff to learn about their experiences working with individuals with TBI. They reported that individuals are most successful in employment when they receive additional external support and that people with TBI tend to take longer in both the eligibility and planning phase of the vocational rehabilitation process compared to other populations.
- During state fiscal year 2005-2006, DVR served 91,737 consumers of which 1,315 (1.43 percent) had sustained a TBI.
- Of all consumers who were gainfully employed during 2005-2006, 163 of 10,637 (1.53 percent) had a TBI.
- At the end of state fiscal year 2005-2006, 1,248 consumers were identified as having head trauma (Code 07). Of the 609 head trauma consumers with closed cases during the year; 19.5 percent (119 consumers) were successfully closed by maintaining employment for 90 days.

Exceptional Student Education and Student Services

- The Bureau of Exceptional Education and Student Services supports school districts and others in their efforts to provide exceptional student education programs for students ages 3 - 21 who have disabilities and students who are gifted. Each school district is responsible for developing and providing services to students who are eligible for exceptional student education (ESE) programs.
- The Traumatic Brain Injured Program represents less than 1 percent of the entire ESE program throughout the state of Florida. Please note that individuals with TBI may be served in other ESE programs and are not captured in the data presented.

Florida Alliance for Assistive Services and Technology

- Florida Alliance for Assistive Services and Technology (FAAST) works with people with and without disabilities throughout the state to provide: hands on assistive technology demonstrations and trainings; financing for assistive technology purchases; assistive device lending programs; community outreach to rural and underserved groups; accessible, affordable housing; and advocacy and education on consumer choice.
- In 2005-2006, FAAST served 135 individuals with disabilities in the housing program (not specific to TBI). Through the second quarter of state fiscal year 2006-2007, the housing program served 114 individuals with disabilities.
- As of January 22, 2007 the vendor recruitment program currently recruited 364 service providers for the Brain and Spinal Cord Injury Program compared to 264 vendors during state fiscal year 2004-2005.
- In 2006, 30.9 percent of the nursing homes who completed the nursing home survey (92 of 298) reported caring for an individual with TBI or spinal cord injury. They reported a total of 245 consumers within these facilities, of which 69.8 percent (171) sustained a TBI. Motor vehicle accidents were the most common cause of TBI for residents of the nursing home facilities.

Protection and Advocacy Services

- The federally mandated protection and advocacy services in Florida are provided by the Advocacy Center for Persons with Disabilities, Inc. The goals for the center include: improving conditions in institutional facilities; increasing community access to resources, entitlements and services; increasing access to education and related services; increasing opportunities for employment; increasing physical and programmatic access to the community; expanding opportunities for self-determination; improving intake and referral services; and expanding community outreach and education.
- From October 2005 through September 2006, 56 information and referral service requests for 51 individuals were made to the Protection and Advocacy TBI program (PATBI), representing 26 of the 67 counties in Florida.
- From October 2005 through September 2006, 29 case service requests were made to the PATBI program for 28 individuals from 14 of the 67 counties.
- Healthcare was the most common issue for PATBI cases (10 cases).

- An interview with a representative from the Advocacy Center for Persons with Disabilities identified the following as common issues for individuals with TBI: lack of affordable residential and outpatient treatment; the BSCIP Home and Community Medicaid Waiver waiting list; finding accessible, affordable housing; transportation services; community support coordination; and guardianship issues.

Centers for Independent Living

- There are 16 Centers for Independent Living (CILs) in Florida each working to support persons with disabilities through the development of an independent living plan including long and short-term goals
- This project surveyed the executive directors for each CILs in Florida. Findings indicate:
 - The percentage of the consumers with cognitive disabilities who sustained a TBI varied by center from less than one percent to approximately 30 percent.
 - CILs identified employment, transportation and housing services as the most frequently requested services by persons with TBI.
 - Three of the centers reported having programs specific for persons with TBI. Two of the centers reported that the funding for these programs comes from BIAF.

Community Input

This section describes three critical areas of public perspective including the findings from a series of 17 focus groups conducted throughout the state targeting individuals with TBI, caregivers and selected underrepresented/underserved populations; the results from interviews with key leaders who are knowledgeable about the needs of individuals with TBI in the state of Florida and are likely to be influential over the opinions of others about the concerns for these individuals; and the results of a service provider survey, in which providers shared their opinions about the needs of individuals with TBI.

- The focus groups included 142 consumers and caregivers. Of the 131 participants providing demographic information, 45 percent were survivors of a TBI and the remaining 55 percent were caregivers. Ages ranged from 17-89 years. Females represented 62.5 percent of participants. Only 9 percent participants identified themselves as something other than white and 4.5 percent reported they were of Hispanic background.
- Interviews were conducted with 26 key leaders. Of the interview participants, eight noted working primarily with selected underserved and under-represented populations: youth, rural residents, individuals of Hispanic descent and individuals with mild TBI. Participants also included caregivers and survivors.
- Surveys were completed by 58 providers including BSCIP case managers, BIAF Family and Community Support specialists, CMS nurses, physicians, psychologists and therapists. Approximately 45 percent (26) of the respondents reported working with adults only and 14 percent (8) worked with only children and youth. Each BSCIP was represented by at least 9 respondents.

The following are the key observations derived from an analysis of the comments and insights gathered during the community input phase of the needs assessment:

- Focus group participants, TBI leaders and service providers expressed satisfaction with Florida’s trauma system and its ability to save the lives of those injured.
- Access to the appropriate rehabilitation and therapies was viewed by participants as the most helpful for individuals with TBI. These services included physical, occupational, speech, cognitive, counseling and neuropsychological therapies. Leaders and focus group participants commented on the importance of accessing these services long-term. Participants expressed difficulty when trying to access behavioral, cognitive and neuropsychological therapies.
- Other key services needs include access to affordable and accessible housing, financial assistance, transportation services, employment services and alcohol and drug addiction services. Caregivers, leaders and providers were more likely than survivors themselves to discuss the availability of housing for individuals with TBI. Housing included safe residential and transitional living treatment facilities for those dealing with significant cognitive and behavioral issues and less restrictive, affordable and accessible housing for those who would qualify. Focus group participants reported difficulty accessing benefits including Social Security and Medicaid. Those with private insurance also had significant financial strains. Many consumers and caregivers said that without transportation, access to other services would not matter because they would not be able to get there. Alcohol and other drug addiction services were identified by providers, leaders, and caregivers as needed. Participants felt that this is an area often overlooked and that current providers are not trained to work with the TBI patient.
- Access to support groups and support networks was also identified as an important need for individuals with TBI and their families. Survivors and caregivers who participated in the focus groups found the support to be helpful and stressed the need for additional opportunities for support from other survivors and families. The support groups and support networks often serve as a resource to survivors and families for information regarding services and supports.
- The lack of public and professional awareness and knowledge of brain injury was perceived as a key issue for participants. The lack of qualified, knowledgeable providers was a common theme throughout the focus groups and key informant interviews. Providers included medical professionals, therapists, counselors and other service providers such as personal attendants, transportation service providers and community agency personnel. Participants felt it was very important to work with providers who know and understand brain injury, but these individuals are very hard to find. Focus group participants felt that the lack of public awareness impacted their ability to access services, engage in socialization activities and employment. The term “invisible disability” was heard numerous times while gathering the community perspectives. TBI leaders commented on the importance of increasing public awareness of TBI to help with advocacy activities and ultimately to increase funding and resources.

- Participants felt there is limited access to information and education. Focus group participants often commented on not knowing where to go for services and the limited connectivity of services. Many people mentioned the need for a central point of information. Service providers, like community agencies, are not aware of the resources available to individuals with TBI, making linkage and referral difficult. The lack of information and education was identified by key leaders as one of the weaknesses in the current system of care for individuals with TBI.
- The lack of long-term support and services was a primary issue identified by focus group participants, key informants and service providers. Participants commented on the void in services once the patient is discharged from the hospital, rehabilitation, or BSCIP case management services. Participants felt that having access to long-term support could reduce some of the challenging issues that arise during points of transition. TBI leaders stressed that the long-term needs of individuals are dynamic and change over time. Therefore, continued access to care and resources is critical.
- Community leaders, caregivers, survivors and providers commented on BSCIP. Strengths of this program include having a centralized state department designated for brain injury; the Trust Fund that provides case management and financial support for survivors; the Central Registry, which serves as the immediate entrée to the service delivery system; dedicated staff who work with survivors and families; and the Medicaid Waiver program to help access long-term support for those who qualify. Overwhelmingly, the weaknesses identified with this program were the lack of long-term support and follow-up services, restrictive service eligibility requirements and missed referrals to Central Registry.
- Many participants commented on the strong organizations and partnerships working in the area of brain injury in Florida. BIAF was mentioned most frequently as a resource to survivors, caregivers and providers. Referral to BIAF was often viewed as the linkage to long-term community support services. Many focus group participants commented on working with Family and Community Support specialists to identify resources in the community to help with their long-term care needs.
- Participants overwhelmingly agreed that caregivers were not adequately prepared to deal with the behavioral issues brought on by the TBI. Caregivers reported using peer support, such as attending support groups and talking with other caregivers, to deal with the behavioral challenges. Suggestions for preparing caregivers include: education, regular reassessment of behavioral issues and an increase in the number of behavior specialists trained to work with the TBI population.
- Caregivers placed an emphasis on the need for long-term life planning for their loved one; guardianship issues; long-term accessible, affordable housing including residential and transitional living treatment facilities; and barriers to accessing services or information because of HIPAA restrictions. They expressed the need for transportation assistance with increased frequency compared to other populations.

Summary of the community perspectives on the selected underrepresented and/or underserved populations:

- Leaders provided insight into the Hispanic culture that may impact access to services. These include: the tendency to have strong family support networks, the tendency to be private and not talk about their issues with people they do not know and a possible fear of accessing government services. Suggestions for reducing the barriers when working with individuals of Hispanic descent include: providing materials in Spanish, using local churches and hiring individuals from within the culture to provide services and resources. The insight provided by leaders validated the focus group recruitment barriers.
- Individuals with mild TBI and leaders who work with this population stressed the importance of appropriate diagnosis and identification of the injury. They emphasized the importance of increasing education about mild brain injuries and prevention activities. They acknowledge that most providers do not understand their needs because of the lack of knowledge about brain injury and mild brain injury. TBI leaders also discussed the limited access to services faced individuals with mild TBI because of the classification of their injury.
- Parents and leaders in the TBI community emphasized the importance of working with the public education system to better meet the needs of their children. They stressed the importance of the schools and therapists working together, educating and training school staff about TBI and appropriate interventions and strategies and increasing flexibility to increase the likelihood of success for their children. Leaders in the TBI community and providers discussed the importance of working to appropriately identify students with TBI in the schools to increase the likelihood of providing appropriate interventions and strategies.
- Barriers to services for rural residents include: transportation issues, limited providers and specialists and isolation issues. Survivors and caregivers emphasized the importance of support groups and the need for socialization and recreation activities. Leaders in the TBI community stressed using alternative methods to reach the survivors in their home or community.

Resource Summary

To fully describe traumatic brain injury (TBI) in Florida, it is necessary to examine the service resources currently available to survivors and family members. This summary is designed to highlight the primary areas of service for individuals with TBI designated by the Health Resources and Services Administration (HRSA), Traumatic Brain Injury Needs and Resources Assessment Tool⁹ including acute medical, rehabilitation, employment, prevention, education, and long-term community support services. Knowing the services that are currently available will help with future planning for individuals with TBI in Florida.

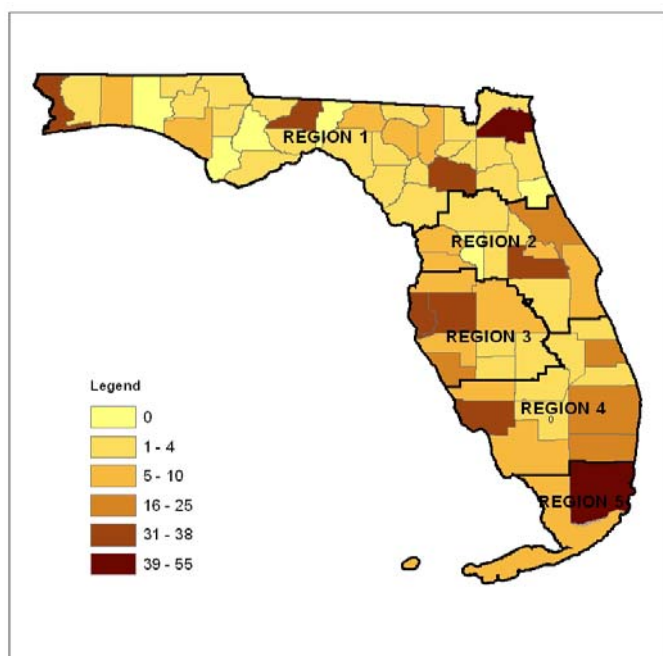
The purpose of the summary is to create a snapshot of the current delivery system in Florida for individuals with TBI. The summary is designed to quantify the extent of resources available in

each of the designated service areas. Services were not examined with regard to quality and effectiveness.

A total of 611 total resources were identified by participants for individuals with TBI. Of the counties in Florida, 91 percent (61 of 67) have at least one resource available for individuals with TBI. BSCIP Region 1 (210 resources) identified the greatest number of resources for individuals with TBI. It is important to note that, BSCIP Region 1 is the largest geographical region. BSCIP Region 5 identified the fewest number of resources, but this is the smallest region in regards to population and geographic size.

The counties with the most TBI related resources include: Miami-Dade (55 resources); Duval (39 resources); Orange and Pinellas (38 resources each); and Escambia, Hillsborough and Leon (35 resources each). The aforementioned counties contain 45 percent of all the TBI related services. Five of the six counties without TBI-related services are located in BSCIP Region 1 and all are identified as a rural county by the Department of Health, Office of Rural Health. Figure 24 shows the density of TBI related services by county in Florida.

Figure 24: Density of TBI-Related Services by County.



Prepared by: WellFlorida Council Inc, 2007.

Long-term community support services represent more than 53 percent (325 resources) of resources and are also the most available resource in each BSCIP region. Employment services (139 resources) are the second most available resource in the state and in each region. Acute care medical facilities represent the smallest percentage of resources in the state (9.7 percent) and in each region.

- Acute care facilities are available in 26 of the 67 (38.8 percent) counties in Florida. The most acute medical care facilities (22 facilities) are in BSCIP Region 1 and the fewest are in BSCIP Region 2 (2 facilities). Ten of the facilities are BSCIP acute care designated

facilities and 19 are state designated trauma centers. Two of the 21 state certified trauma centers in Florida were not identified as resources by respondents are Holmes Regional Medical Center in Melbourne and North Broward Medical Center in Deerfield Beach.

- In Florida, 108 rehabilitation resources are available, representing 53.7 percent (36 of the 67) counties. Outpatient rehabilitation services are the most available type of rehabilitation service in Florida, with services at 61.6 percent of rehabilitation resources. Only 6.5 percent of the resources offer community re-entry programs.
- In Florida, 139 employment services are available for individuals with TBI. Employment services are available in 70.1 percent (47 of 67) of the counties in Florida. Over 90 percent of the counties in BSCIP Regions 2 through 5 have employment services available to individuals with TBI. In BSCIP Region 1, 48.6 percent of the counties (17 of 35) have employment services available. The Division of Vocational Rehabilitation (DVR) is the most frequently identified employment service available (81 locations). Of the 139 employment services, 93.5 percent (130) offer job placement services and 84.9 percent (118) provide vocational training.
- There are 89 prevention and education resources available in Florida. Of the 67 counties in Florida, 26 (38.8 percent) have prevention and/or education services available. The primary prevention activities for intentional and/or unintentional injuries (27 resources) included resources such as the local chapters of Florida SafeKids Coalitions. Education services are provided by 68 resources. Education providers include: the DVR, local YMCA organizations, CILs, and the Children's Medical Services Early Steps Program.
- Throughout the state, 325 resources for long-term community support are available for individuals with TBI. Long-term community support services are available in 68.7 percent (46 of the 67) of the counties in Florida. The most long-term community support services are available in BSCIP Region 1 (102 resources) and the fewest are in BSCIP Region 5 (28 resources).

Comparing the distribution of TBI-related resources to the total population and TBI population distribution in the state provides insight into potential service inequities or gaps in service. Disparities between population size and resource density within BSCIP regions exist across the state. BSCIP Region 1 contains a greater percentage of TBI-related resources (34 percent) that were identified through the Resource Summary than percentage of the total and TBI-related disability (18.3 percent) populations. All of the other regions have a gap between the percentage of the total and TBI populations within the region and the percentage of TBI-related resources available identified through the Resource Summary.

In Florida, 43.3 percent of counties have 5 or more TBI-related resources. Only 13.4 percent have more than 30 TBI-related resources. Over 55 percent of all the TBI-related resources are located within the nine counties with 30 or more resources. These counties are some of the most populated counties in the state including: Miami-Dade, Orange, Hillsborough, Duval, Pinellas, Lee, Escambia, Leon and Alachua.

- BSCIP Region 1 is the largest in terms of the number of counties and geographic area, representing approximately 43.8 percent of the state's geography and houses only 34.4 percent of all TBI-related resources in the state. This region is considered most rural based on the number of people per square mile. Only 25.7 percent of the counties in this

region have five or more TBI-related resources. Four counties in the region contain more than 66.6 percent of the TBI-related resources in this region.

- BSCIP Region 2 contains 10 counties and represents approximately 16.3 percent of Florida's geographic area. This region houses 14.4 percent of the TBI-related resources in the state. Orange County alone contains over 43 percent of the resources identified in this region. Sumter County is the only county in the region without TBI-related services.
- BSCIP Region 3 represents 13.9 percent of the state's geography, while containing 20.6 percent of the available TBI-related resources. Of the nine counties in the region, six contain more than five resources. Hillsborough and Pinellas counties contain more than 30 TBI-related resources. All counties in this region have at least one TBI-related resource.
- BSCIP Region 4 represents 20.5 percent of the state's geography and contains 20.6 percent of the available TBI-related resources. Of the eleven counties in the region, six contain more than five resources. Lee County contains more than 30 TBI-related resources and both Broward and Palm Beach counties contain more than 20 TBI-related resources. All counties in this region have at least one TBI-related resource.
- BSCIP Region 5 represents 5.5 percent of the state's geography, while containing 10.0 percent of the available TBI-related resources. Both of the counties in the region contain more than 5 resources, but Miami-Dade County contains 55 of the 61 TBI-related resources in the region. Miami-Dade County has more TBI-related services available than any other county in the state.

When addressing the issue of service capacity, it is important to include discussion of how the projected population increase may impact the demand for services within given geographies. For the purpose of this report, service capacity will be defined as the number of resources within the given geography. Florida is anticipating a 21.5 percent increase in total and TBI-related disability populations by 2015. To maintain the existing service capacity level given the projected population increase, the total amount of resources in Florida would need to increase by 17 percent. BSCIP Region 4, which is expecting the largest increase in population, would need to increase capacity by approximately 24 TBI-related resources to maintain the current service capacity. TBI-related disability growth in BSCIP Region 2 is expected to exceed the state growth rate with 24.3 percent growth. To maintain service capacity levels, 14 TBI-related resources are needed.

By 2015 seven counties in Florida are projected to increase the number of people in the county per square mile to over 100, therefore losing their rural county designation by the Florida Department of Health, Office of Rural Health. These counties may experience additional hardships while trying to increase service capacity to meet the increased service demands because existing infrastructure might not be in place.

Conclusion

Traumatic Brain Injury in Florida: A Needs and Resource Assessment, was conducted to identify the needs of a continuum of individuals with TBI including mild, moderate and severe brain injury across all age groups and in culturally distinct populations. The findings from the study

will be used to guide the creation and implementation of a comprehensive, consumer-directed strategic plan that addresses the needs of Florida's TBI population and their families.

Florida's current population is nearly 18.5 million, with the largest percentage of the population located in BSCIP Region 4 (26.0 percent). The population of Florida is projected to increase approximately 21.5 percent by 2015, with the largest increase projected in BSCIP Region 2 (27.0 percent). Some of the increases in population include populations that are at increased risk for TBI such as: age group 0-4 years and age group 65 years or more and all other races and Hispanics.

Currently, 369,566 people (2 percent) are living with a TBI-related disability in Florida. By 2015, this is expected to increase to approximately 435,350 people. In 2005, there were approximately 93,000 TBIs in Florida, which included 71,400 emergency department (ED) visits (76.8 percent), 17,700 hospitalizations (19.0 percent) and 3,900 deaths (4.2 percent). Florida's age-adjusted rate for all TBIs, TBI-related deaths and TBI-related ED visits were higher than the national rate, while the rate for TBI-related hospitalization was slightly less than the national rate.

- In 2005, the groups at greatest risk for all TBIs include children 0-4 years of age, young adults 15-24 years of age and adults over the age of 65.
- In Florida, 82.3 percent of all TBIs that occurred in 2005 were to whites, 14.1 percent were to blacks and 2.8 percent were to individuals who were classified as other races. During 2005, individuals classified as other races had the highest rate of total TBIs in Florida, followed by whites and blacks.
- In 2005, 15 percent of all TBIs were sustained by individuals who identify themselves as Hispanic, resulting in a rate of 402.9 per 100,000 of the population.
- In Florida, males were 1.2 times more likely to experience a TBI than females during 2005.
- During 2005, falls caused 39.6 percent of all TBIs in Florida, followed by motor vehicle accidents (20.8 percent) and assaults (11.1 percent). The rates for TBI were highest for falls, followed by motor vehicle-traffic accidents and assaults. These rates were higher than their respective rates nationally.
- In 2005, the rural population of Florida accounted for 5,191 (5.6 percent) of the total TBIs in the state. The total rate for TBI in the rural counties of Florida was less than the rate for the non-rural counties.

The loosely defined TBI system in Florida includes the state government administered Brain and Spinal Cord Injury Program, Brain Injury Association of Florida (BIAF), and key community partners such as Division of Vocational Rehabilitation (DVR), Department of Education Exceptional Student Education Services, Florida Alliance for Assistive Services and Technology (FAAST), protection and advocacy and Centers for Independent Living (CILs). BSCIP and BIAF are the primary entities for TBI in the state. The community partners that individuals with TBI depend on for services serve multiple disability populations. Therefore, the individuals with TBI represent only a portion of the consumers they serve. Providing education and training about appropriate interventions and strategies to work with this population is vital. Additionally, it is hypothesized that the number of people with TBI served by these agencies is underestimated

because of inappropriate identification and/or classification. Therefore, strengthening partnerships with community partners is vital to increasing access to services and resources.

TBI survivors, caregivers, community leaders and stakeholders shared their thoughts and opinions about the needs of individuals with TBI in Florida. The following are the key observations derived from an analysis of the comments and insights gathered during the community input phase of the needs assessment:

- Access to appropriate rehabilitation and therapies was viewed by participants as the most helpful for individuals with TBI.
- The primary service needs include access to affordable and accessible housing including residential and transitional living facilities, financial assistance, transportation services, employment services and alcohol and drug addiction services. Access to support groups and support networks was also identified as an important need for individuals with TBI and their families.

The lack of public and professional awareness and knowledge of brain injury was perceived as a key issue for participants. Also, participants felt there was limited access to information and education including not knowing where to go for services and the limited connectivity of services. Many participants discussed the lack of long-term support and services, and commented on the void in services once patients are discharged from hospitals, rehabilitation, or BSCIP case management services. Participants felt that having access to long-term community supports could reduce some of the challenges that arise during points of transition. Participants overwhelmingly agreed that caregivers were not adequately prepared to deal with the behavioral issues brought on by the TBI.

Community leaders, caregivers, survivors and providers commented on BSCIP. Strengths of this program include having a centralized state department designated for brain injury; the Trust Fund, which provides case management and financial support for survivors; the Central Registry, which serves as the immediate entrée to the service delivery system; dedicated staff who work with survivors and families; and the Medicaid Waiver program to help access long-term support for those who qualify. Overwhelming weaknesses identified with this program were the lack of long-term support and follow-up services, restrictive service eligibility requirements and missed referrals to Central Registry.

Many participants commented on the strong organizations and partnerships working in the area of brain injury in Florida. BIAF was mentioned most frequently as a resource to survivors, caregivers and providers. Referral to BIAF was often viewed as the linkage to long-term community support services. Many focus group participants commented on working with Family and Community Support specialists to identify resources in the community to help with their long-term care needs.

The following is a summary of the community perspectives on the selected underrepresented and/or underserved populations:

- Leaders provided insight into the Hispanic culture that may impact access to services.

- Individuals with mild TBI and leaders who work with this population stressed the importance of appropriate diagnosis and identification of the injury.
- Parents and leaders in the TBI community emphasized the importance of working with the public education system to better meet the needs of their children.
- Barriers to services for rural residents include: transportation issues, limited providers and specialists and isolation issues.

Through the Resource Summary, 611 total resources were identified by participants for individuals with TBI. Of the counties in Florida, 91 percent (61 of 67) have at least one resource available for individuals with TBI. The counties with the most TBI-related resources include: Miami-Dade (55 resources); Duval (39 resources); Orange and Pinellas (38 resources each); and Escambia, Hillsborough and Leon (35 resources each). The aforementioned counties contain 45 percent of all the TBI related services statewide.

¹ Florida Statute. Title XXIX, Public Health Chapter 381 Public Health: General Provisions; 2006.

² Langlois JA, Ruthland-Brown W, Thomas KE. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Injury Prevention; 2006.

³ Thurman D, Alverson C, Dunn K, Guerrero J, Sniezek J. Traumatic brain injury in the United States: a public health perspective. *Journal of Head Trauma Rehabilitation*. 1999;14(6):602-15.

⁴ Langlois JA, Kegler SR, Butler JA, et al. Traumatic brain injury-related hospital discharges: results from a fourteen state surveillance system, 1997. *Morbidity and Mortality Weekly Reports*. 2003;52(SS-04):1-18.

⁵ U.S. Department of Health and Human Services, The Offices of Minority Health. Hispanic/Latino Profile. <http://www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=54>. Accessed Feb 2007.

⁶ Florida Department of Health. Office of Rural Health. Rural Health Plan; 2002.

⁷ Florida Statute. Title XXXIX. Public Health: General Provisions, Office of Rural Health 381.0405; 2006.

⁸ National Center for Injury Prevention and Control. Report to Congress on mild traumatic brain injury in the United States: steps to prevent a serious public health problem. Atlanta, GA: Centers for Disease Control and Prevention. 2003.

⁹ U.S. Department of Health and Human Services, Health Resources and Services Administration, Material and Child Health Bureau, Federal Traumatic Brain Injury Program. Traumatic brain injury needs and resource assessment tool; 2006.