Report of the
Joint Legislative Audit and Review Commission
To the Governor and
The General Assembly of Virginia

Access to State-Funded Brain Injury Services in Virginia

SENATE DOCUMENT NO. 15
2007

In Brief

Access to State-Funded Brain Injury Services in Virginia

Item 21F of the 2006 Appropriation Act directed JLARC to report on access to community-based brain injury services in Virginia.

State funding increases to the Department of Rehabilitative Services (DRS) resulted in more than 1,000 persons accessing needed services in FY 2007. Persons with brain injury appear to benefit from State-contracted case management and clubhouse/day programs.

Approximately 150,000 Virginians could have a long-term disability as a result of a traumatic brain injury (TBI). Geography and service availability limit access, and some needed services are unavailable. Also, it is estimated that thousands of TBI survivors have neurobehavioral problems. Some of these individuals have severe behavioral problems requiring intensive treatment, but treatment is only available in 20 beds statewide.

To facilitate the provision of brain injury services, improvements are needed to Virginia's brain injury registry. Such improvements could result in more complete data collection, elimination of duplicate hospital reporting requirements, and improvement in DRS' planning activities.

The extent to which the State provides brain injury services is a policy choice. If additional resources are available, the State may want to first address the needs of those with the most severe functional disabilities.

JLARC Staff for This Report

Hal Greer, Division Chief
Eric Messick, Project Leader
Jamie Bitz
Pinki Shah

This report is available on the JLARC website at http://jlarc.state.va.us

COMMONWEALTH of VIRGINIA

Joint Legislative Audit and Review Commission

Philip A. Leone
Director

Suite 1100, General Assembly Building, Capitol Square
Richmond, Virginia 23219

(804) 786-1258

October 19, 2007

The Honorable Thomas K. Norment, Jr.
Chairman
Joint Legislative Audit and Review Commission
General Assembly Building
Richmond, Virginia 23219

Dear Senator Norment:

Item 21F of the 2006 Appropriation Act directed the Joint Legislative Audit and Review Commission staff to evaluate access to brain injury services in the Commonwealth. Specifically, staff were directed to determine causes and prevalence of brain injuries, available services, private insurance coverage of these services, and how other states address the needs of persons with brain injury.

Staff findings were presented to the Commission on September 10, 2007, and are included in this report.

On behalf of the Commission staff, I would like to thank the staff at the Departments of Rehabilitative Services, Health, and Medical Assistance Services for their assistance during this study.

Sincerely,

Philip A. Leone
Director

Table of Contents

JLARC Report Summary:

Access to State-Funded Brain Injury Services in Virginia

Key Findings

- Increases in State funding for community-based brain injury services have resulted in more than 1,000 persons accessing needed services. Approximately 150,000 Virginians may have long-term disabilities as a result of a brain injury. Geography and service availability still limit access, and some needed services are not available. (Chapter 3)

- A panel of neuropsychologists in Virginia estimates that thousands of brain injury survivors have neurobehavioral consequences resulting from their acquired brain injuries. Some of these individuals may develop severe behavioral problems that could lead to admittance to a licensed local hospital or incarceration in a correctional facility. Only 20 beds are available in Virginia to provide the intensive and costly neurobehavioral residential treatment that some of these individuals may need. (Chapters 3 and 6)

- Persons with brain injury appear to benefit from State-funded case management and clubhouse/day programs. (Chapter 4)

- The centralized registry designed to collect information on persons with brain injury and provide them with information and referral services is ineffective. Two hospitals required by statute to report to the registry are not reporting due to database problems, and few people are responding to the information and referral effort. (Chapter 5)

- The extent to which Virginia provides services for the State's population with brain injury is a policy choice. If additional resources are available, addressing gaps in the availability of community-based services could reduce the number of individuals with brain injuries at risk for entering or currently in nursing homes or other long-term care facilities. These needs could be met by reallocating existing resources or gaining access to additional resources through the State's Medicaid program. (Chapter 6)

Item 21F of the 2006 Appropriation Act directs staff of the Joint Legislative Audit and Review Commission (JLARC) to report on access to brain injury services in the Commonwealth. JLARC staff are to consider (1) the availability of State-funded services to meet the service needs of persons in Virginia with brain injury, (2) the effectiveness of currently provided services at improving the condition of individuals with brain injury, and (3) oversight of State-funded brain injury services by the Department of Rehabilitative Services (DRS). JLARC staff are also directed to report on the causes and prevalence of brain injuries in the State, the extent to

which private insurers pay for brain injury services, and how other states have addressed the needs of their populations with brain injury.

Traumatic brain injuries (TBIs) occur as the result of blunt trauma or penetrating forces to the brain that result in the alteration of consciousness and permanent functional disability. According to the U.S. Centers for Disease Control and Prevention (CDC), 5.3 million Americans live with a long-term or lifelong need for help to perform activities of daily living as a result of a TBI. Since 2002, more than 80,000 Virginians have been reported to the State's brain injury registry as the result of being treated for a TBI; falls and motor vehicle accidents account for the majority of those injuries. Problems most commonly associated with TBI are loss of short-term memory and an impaired inability to control one's behavior. Someone who sustains a TBI is likely to need a variety of services, including acute medical care; post-acute rehabilitative care; physical, occupational, speech, and cognitive therapies; and case management assistance.

VIRGINIA PROVIDES SOME BRAIN INJURY SERVICES

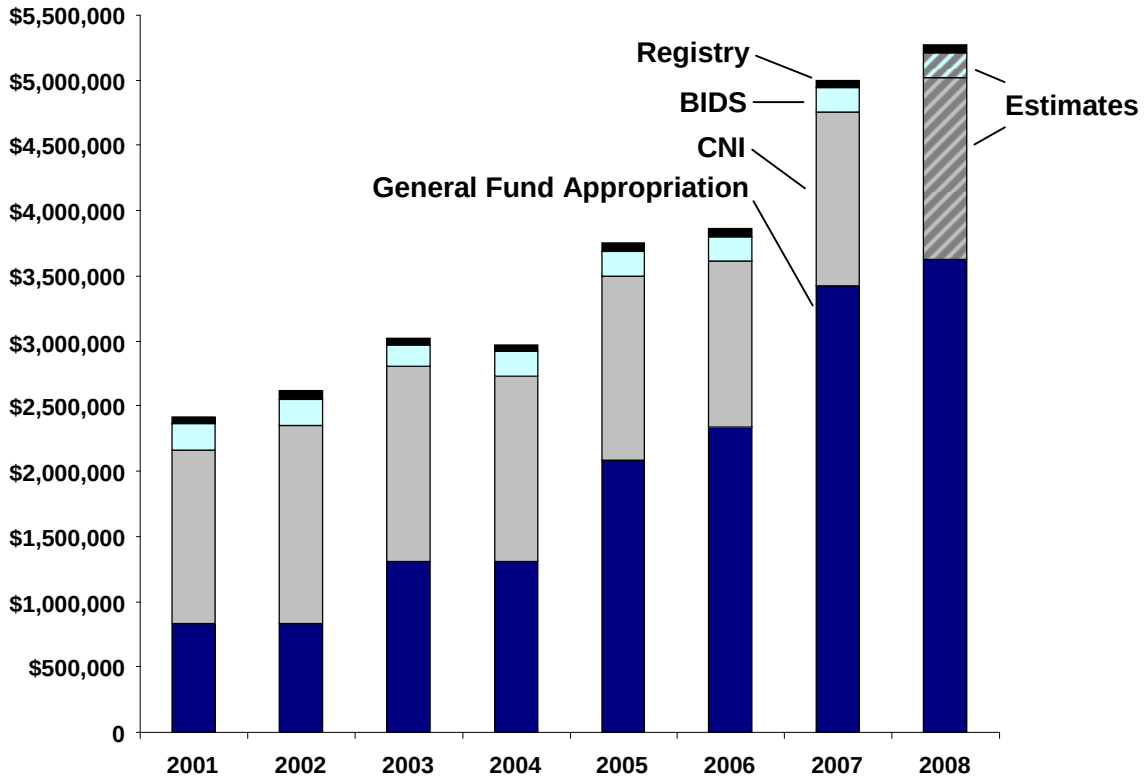
DRS administers Virginia's statewide services for people with brain injury. DRS is also required by the *Code of Virginia* to operate (1) a brain injury registry for identifying and contacting persons treated for a TBI and (2) a grant program to fund research and community-based services. Most State-funded community-based brain injury services are provided through contracts with private service providers located throughout Virginia for the following services:

- adult and pediatric case management services;
- clubhouse/day programs (these programs provide structured environments and activities for persons with brain injury);
- regional resource coordination; and
- information and referral for persons identified by the brain injury registry.

DRS provides some direct assistance to brain injury survivors through its personal assistance services program, community-based rehabilitative case management services, and vocational rehabilitation programs.

As shown in the figure on the next page, State funding for community-based brain injury services has increased by more than $2.5 million since FY 2001. The majority of the increase has occurred in State General Funds.

State Funding for Brain Injury Services Has Increased by More Than $2.5 Million Since FY 2001



Note: BIDS, Brain Injury Direct Services; CNI, Commonwealth Neurotrauma Initiative Trust Fund. Registry and BIDS amounts represent amounts allocated from DRS agency-wide appropriation. 2008 BIDS and CNI figures represent averages of FY 2001 through FY 2007.

Source: Data from Appropriation Acts and DRS.

AVAILABILITY OF BRAIN INJURY SERVICES HAS INCREASED, BUT ACCESS IS LIMITED AND SOME NEEDS ARE UNMET

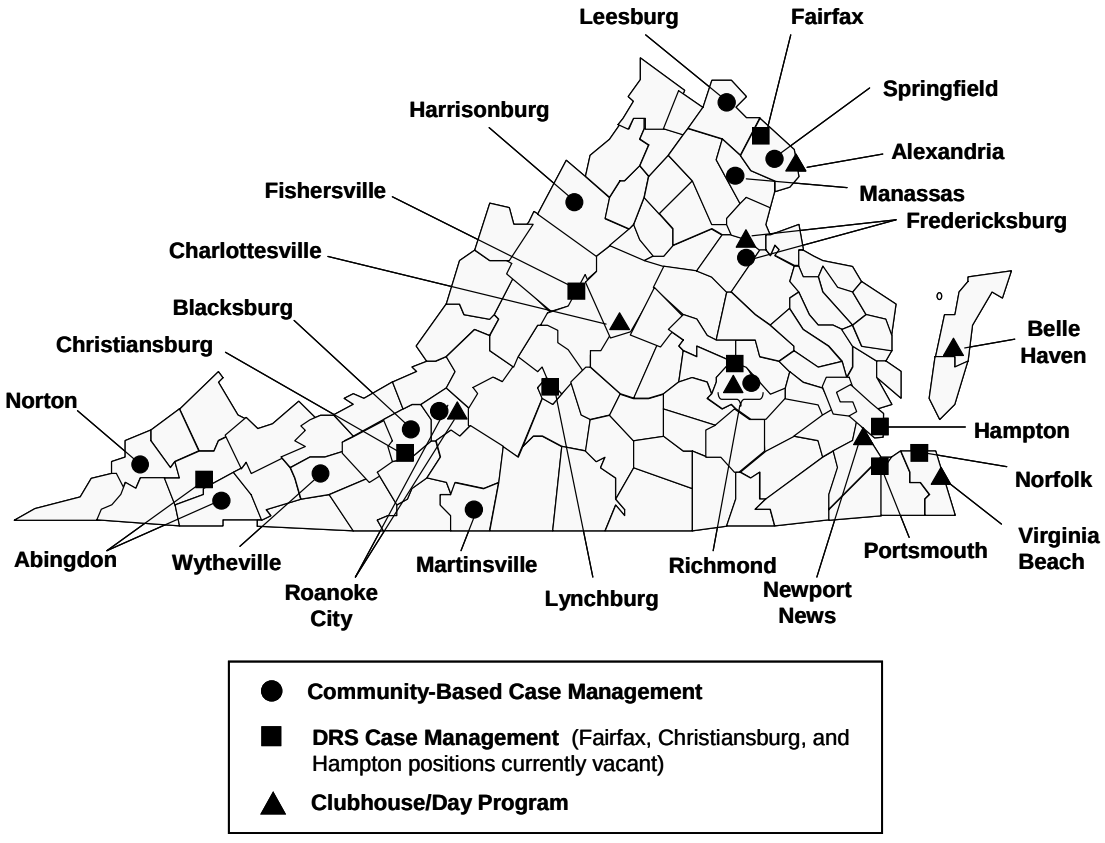
To determine whether adequate access to brain injury services exists, JLARC staff interviewed brain injury survivors and caregivers and case managers; surveyed case managers; and reviewed previously conducted statewide needs assessments.

State funding increases for case management and clubhouse/day programs have resulted in more than twice the number of persons with brain injury receiving these services compared to FY 2002. In FY 2002, the State contracted with two providers of case management services who served more than 330 individuals with brain injury; there are now six programs serving almost 750 individuals. In addition, the number of people with brain injury participating in clubhouse/day programs has risen by more than 50 percent since FY 2002.

Despite these increases, some parts of the State have no or very few services for persons with brain injury, and access to existing services remains limited, as shown by the map below. Areas such as Southside Virginia and the Northern Neck lack adequate case management opportunities for those with brain injury. Other areas of Virginia may only have one service available. For example, in March, a case management program began operating in Harrisonburg, but there are no clubhouse/day programs along the Interstate 81 corridor between Winchester and Lexington.

In addition to the lack of services, existing services are limited. The two case management programs serving the largest number of people report waiting lists for their services. Two clubhouses also report waiting lists. DRS has nine case manager positions located throughout the State serving seven disability populations, including people with traumatic brain injury, but three of the positions are vacant and there are substantial waiting lists.

Case Management and Clubhouse/Day Programs Are More Available in Urban Areas



Source: DRS.

Additional statewide service needs have been identified, but resources do not exist to address those needs. Individuals with severe behavioral and emotional problems resulting from their brain injury who present a danger to themselves or others may be placed in local hospitals, skilled nursing homes, or correctional facilities. Only 20 specialized beds in the State have the capacity to treat persons experiencing severe neurobehavioral disorders; all 20 beds are in a privately operated facility. Rehabilitation therapies designed to address cognitive impairments are also lacking. State funding for these therapies is limited, and private insurers may be reluctant to cover their use. Other unmet needs include supportive or transitional housing and transportation opportunities to reintegrate individuals with brain injury with their community, as well as resources for keeping such persons out of long-term care facilities where they are unlikely to receive the services they need.

According to medical doctors, neuropsychologists, and case managers, the availability of brain injury services is limited under most insurance plans.

The extent to which private insurance or other funding sources will cover the use of post-acute brain injury services is another limiting factor. According to medical doctors, neuropsychologists, and case managers, the availability of brain injury services is limited under most insurance plans and for those services that are available, coverage is often terminated too soon. Workers compensation and legal settlements are other funding sources that have been used to cover the costs of brain injury services, but they are only available for a small number of persons with brain injury.

Future access to community-based brain injury services may also be limited as military service members from the Afghanistan and Iraq conflicts return to Virginia. TBI is considered to be the signature combat wound in these two countries. Some estimates put the number of service members with TBI at more than half of combat casualties. There are concerns that the federal assistance available to these individuals will not adequately meet their long-term needs, forcing them to seek State-funded services. If this occurs, it is unclear whether Virginia's existing community-based services will be able to meet the demand for assistance.

CASE MANAGEMENT AND CLUBHOUSE PROGRAMS APPEAR TO BENEFIT INDIVIDUALS WITH BRAIN INJURY, BUT OTHER SERVICES MAY NOT BE AS BENEFICIAL

Brain injury survivors appear to benefit from case management and clubhouse programs. While it is difficult to measure the extent to which these services improve individual functioning, and few research studies of effectiveness have been conducted, survivors and caregivers interviewed for this study indicated high levels of support for their case managers and the value of clubhouse participation. Case managers help survivors access services, find funding for services, and navigate the systems of care. Because information

processing and memory impairments are common among brain injury survivors, the assistance provided by case managers is important. Survivors also appear to benefit from the therapeutic environment, social interaction, and "work-ordered day" structure provided by the clubhouse programs. Clubhouse members said that their participation helps them gain work-related skills and stay involved with the community around them; clubhouses also provide respite for the caregiver. In addition, respondents to the JLARC staff survey of case managers rated the clubhouses attended by their clients as effective. Nonetheless, clubhouses have been criticized for potentially serving as warehouses for individuals with brain injury.

The cost of providing case management and clubhouse/day programs is substantially less than other brain injury services. Case management services provided by the two programs serving the most persons cost approximately $2,400 per capita in FY 2007. Clubhouse/day program costs were about $5,900 per capita for four clubhouses during the same time. By comparison, personal assistance services funded by DRS cost more than $18,000 per person, and nursing facility care in a specialized TBI unit costs more than $45,000 per person.

The effectiveness of regional resource coordination, which provides outreach, advocacy, and public awareness concerning brain injury, is difficult to measure given the program goals. Coordinators are typically meeting their contractual goals of providing information to the public and the medical community about brain injury. However, the extent to which these activities have improved access to services is difficult to evaluate. According to DRS, the regional resource coordination effort has exceeded expectations for providing education, outreach, public awareness, and advocacy activities. In addition, efforts by a coordinator led to the development of case management services in Southside. Nonetheless, there are few other examples of coordinators directly contributing to an increase in the number of providers or the capacity of existing providers. It is also difficult to measure the extent to which public education efforts are working. The need for increased education efforts was first identified in 2000, and lack of awareness is still considered a problem, especially among the medical community.

DRS is responsible for providing work training services to Virginia's population with disabilities, including those with TBIs. According to DRS data, since FY 2002, the department has successfully assisted 54 percent of the more than 1,000 vocational rehabilitation TBI clients it has served to find employment. DRS' supported employment efforts, which focus on assisting the individual on the job, have resulted in successful employment for approximately 58 percent of the more than 470 served during FYs

2002 through 2007. However, there have been few, if any, definitive research studies estimating post-TBI employment rates. The employment studies that have been done have generally not measured either the quality of the work performed or job retention. Also, few studies have tried to replicate earlier findings.

Enhancing the capacity of DRS to perform program evaluation could lead to better measurement of program effectiveness. Due to limited resources, DRS focuses more on contract oversight than program effectiveness. In 2004, DRS contracted for program evaluations of several State-funded providers. However, the department has not conducted similar reviews since that time. In 2006, the department implemented a performance evaluation process to begin measuring program effectiveness, but it is too soon to determine whether this process will be sufficient. Under the process, State-contracted service providers submit quarterly reports to DRS that measure their success against established goals. DRS staff anticipated the need to revise the established goals to be more realistic given that all providers are currently "exceeding expectations."

Oversight of State-funded providers could be improved. It is recommended that the department conduct or contract with a third party to annually perform at least two program evaluations of the State-contracted brain injury providers.

REGISTRY IS NOT COMPREHENSIVE, AND OUTREACH EFFORTS RARELY RESULT IN DIRECT CONTACT

Virginia's brain injury registry was established to collect individual-level data and use the information (1) to provide everyone reported to the registry with brain injury information, and (2) to assist with planning and programming. However, the registry is not operating effectively. The registry is not as comprehensive as intended because at least two Level I Trauma Centers are not reporting to it due to database issues at DRS. In addition, the State's information and referral efforts appear to be failing. Fewer than two percent of those sent an initial outreach mailer seek additional information from the State's contracted provider. Furthermore, hospitals are required to report the same information to both the brain injury registry and the Virginia Statewide Trauma Registry (VSTR) administered by the Virginia Department of Health (VDH), each of which has its own reporting requirements.

To improve operation of the registry, this report recommends that

- the General Assembly consider eliminating the statutory requirement that hospitals report to the brain injury registry,

- the General Assembly consider amending the *Code of Virginia* to require hospitals to report brain injury information to the VSTR and that VDH provide DRS with that information, and
- the Department of Rehabilitative Services use the brain injury information contained in the registry for program, policy, and fiscal planning.

OPPORTUNITIES EXIST TO IMPROVE ACCESS TO COMMUNITY-BASED BRAIN INJURY SERVICES

The extent to which the State provides community-based brain injury services is a policy choice. Pursuant to the Appropriation Act language mandating this review, this report has identified unmet brain injury service needs as well as access issues for existing services. If additional resources are available for brain injury services, the State may want to first address the needs of those with the most severe functional disabilities.

If additional resources were available for brain injury services, the State may want to first address the needs of those with the most severe functional disabilities.

Providing funding to assist people with severe neurobehavioral problems who would likely be placed in local hospitals or other inappropriate facilities could address a segment of the population with brain injury that is generally considered underserved. Cost estimates to treat these individuals average about $470 per day.

Persons with brain injuries who are at risk of entering nursing homes or are already in nursing homes also have limited access to needed services. Few nursing homes offer brain injury-specific services such as cognitive rehabilitation, and behavioral problems exhibited by some individuals with brain injury can lead to their expulsion from such facilities. Expansion of Virginia's existing Medicaid Individual and Family Developmental Disabilities Support waiver or implementation of a specific TBI waiver program could aid the State's most severely impaired individuals.

Beyond these immediate needs, brain injury survivors could continue to benefit from expansion of case management and clubhouse programs. Additional resources could also be used to meet other needs, such as cognitive rehabilitative therapies, supportive housing, transportation, and personal assistance. Without access to these services, individuals with severe impairments must rely on family or other caregivers for assistance and may have to enter long-term care facilities, which typically do not meet their needs.

Chapter 1

Overview of Traumatic Brain Injury

In Summary

Traumatic brain injuries (TBIs) result from a blow to the head or the rapid acceleration then deceleration of the skull. More than 88,000 individuals have been reported to the State's brain injury registry since 2002. In addition, the federal Centers for Disease Control and Prevention estimates that more than 150,000 Virginians are currently living with a TBI. Falls are the leading cause of injuries in Virginia. Children, older adolescents, and the elderly are more likely to sustain a TBI, potentially leading to long-term assistance needs for the younger survivors. Brain injury survivors generally have physical, cognitive, and behavioral impairments and need a range of rehabilitative and support services, including case management, residential care, and transportation.

Brain injuries occur as a result of congenital or hereditary conditions, or are acquired due to non-traumatic events such as anoxia (a deficiency of oxygen) or stroke, or external trauma. Brain injuries that result from external trauma, such as a blow to the head or rapid acceleration and deceleration of the head and that impair cognitive abilities or physical functioning are known as traumatic brain injuries (TBIs). Problems following a TBI may include loss of short-term memory and poor emotional and behavioral control. According to the Centers for Disease Control and Prevention (CDC), an estimated 1.4 million Americans sustain a TBI annually, and 5.3 million Americans currently have a long-term or lifelong need for help to perform activities of daily living as a result of their injury.

In Virginia, demands for more rehabilitative services tailored to meet the needs of the population with brain injury have led to increased State funding in recent years as well as legislative attempts to implement a Medicaid waiver program to expand the services available. In light of these circumstances and prior to the provision of additional resources, the 2006 General Assembly directed the staff of the Joint Legislative Audit and Review Commission (JLARC) to address concerns regarding the effectiveness of current brain injury services and whether the services offered are sufficient to meet demand. The Appropriation Act language directed study in three broad areas: (1) assessing the availability of State-funded services to meet the service needs of Virginia's brain injury survivors, (2) determining the effectiveness of currently provided services at improving the conditions of those with brain

injury, and (3) evaluating oversight of State-funded brain injury services by the Virginia Department of Rehabilitative Services (DRS). (See Appendix A for the full text of the study mandate.) The primary research methods used to conduct this assessment included interviews with brain injury survivors and caregivers, case managers, clubhouse/day program staff, and other brain injury program stakeholders; a survey of case managers; and quantitative analysis of information from the brain injury registry and Virginia's Medicaid program (Appendix B).

TRAUMATIC BRAIN INJURY RESULTS IN PHYSICAL, COGNITIVE, AND BEHAVIORAL PROBLEMS

The brain is the central control agent for the human body. It controls body temperature, blood pressure, heart rate, and breathing. It directs physical motion and allows a person to think, dream, and experience emotions. It also absorbs and processes sensory information. Therefore, a TBI can lead to physical, sensory, cognitive, and psychological or behavioral impairments. The area of the brain that is damaged and the extent of damage determine the problems that result and their severity.

Each traumatic brain injury results in unique problems for the individual who has sustained the injury. What is not unique is the fact that the person has undergone emotional, behavioral, and intellectual changes. As a result of the injury, a person with a brain injury may need long-term supports to function in society. Often, these supports are not available, and the person may regress into a life of isolation and depression. In addition, TBI may be misunderstood or misdiagnosed, further alienating the individual and delaying access to proper services. Because of the lack of public awareness of TBI, including among the medical community, it is frequently referred to as a "silent epidemic."

TBI Results From Applying Strong Force to the Head

Brain injuries can be the result of congenital or hereditary traits or degenerative conditions such as Alzheimer's disease or muscular dystrophy. Brain injuries can also result from tumors and hypoxic (lack of oxygen) events. Acquired brain injuries are classified as non-traumatic or traumatic. Non-traumatic brain injuries occur as the result of a virus (such as meningitis), inadequate amounts of oxygen to the brain, exposure to toxic substances, or an infection.

TBIs are the most common type of acquired brain injury and result from external causes such as falls or accidents involving motor vehicles. The CDC defines traumatic brain injury as "an injury to the head arising from blunt or penetrating trauma or from accelera-

tion-deceleration forces" and notes the following associated symptoms or signs:

- decreased level of consciousness,
- amnesia,
- other neurological or neuropsychological abnormalities,
- skull fracture,
- diagnosed intracranial lesions, or
- death.

(Birth trauma is generally excluded from definitions of traumatic brain injury.) TBIs can occur as the result of the skull being crushed, seriously fractured, or penetrated. TBIs can also occur when the skull is not damaged, but the brain bounces against the ragged edges of the skull, resulting in bleeding and swelling.

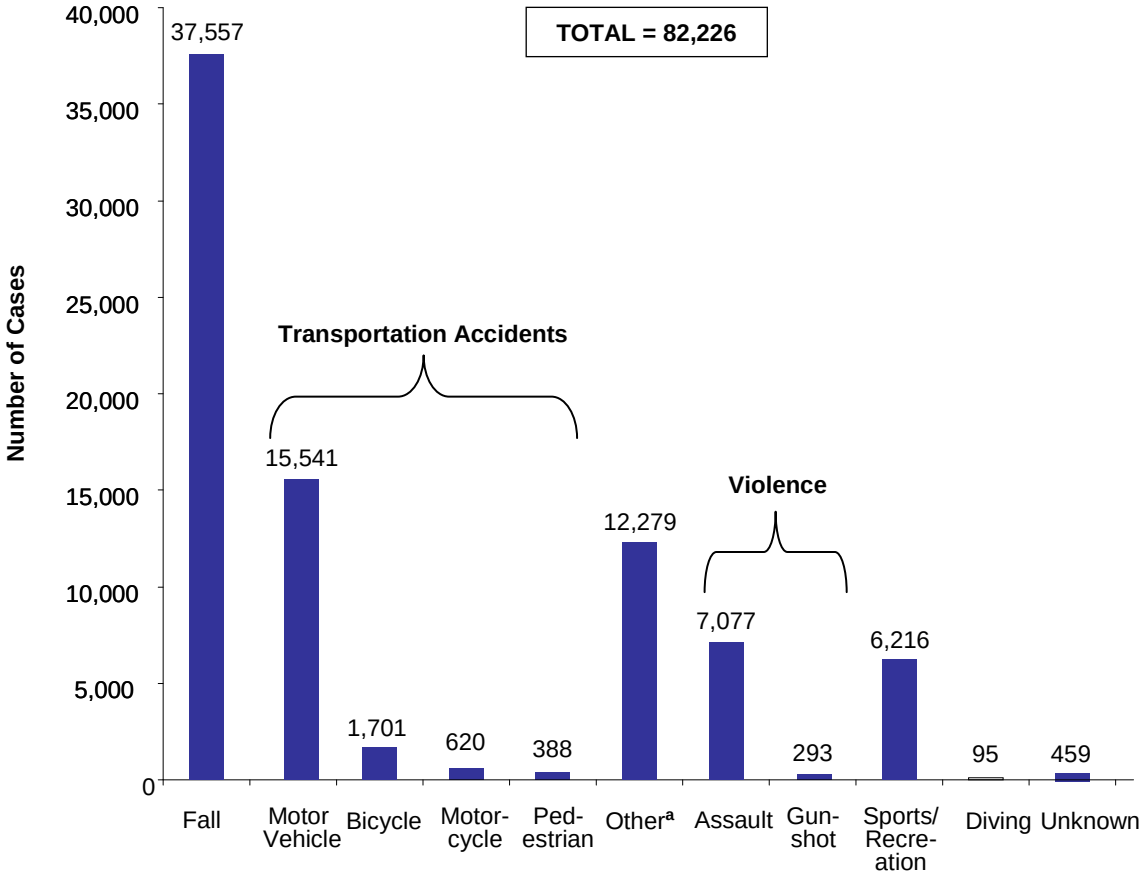
Falls Are the Leading Cause of TBI in Virginia

According to information maintained by DRS, more than 88,000 TBIs have occurred in Virginia since 2002. (For this review, JLARC staff classified individuals as in-state (82,226) and out-of-state (5,802). The rest of this section refers to figures for Virginia residents only.) Of the 82,000 Virginia residents reported to DRS with a brain injury since 2002, two-thirds of those TBIs are the result of falls and transportation-related accidents (Figure 1). Falls are the leading cause of TBI in Virginia. More than 37,500 (46 percent) TBIs reported to DRS since 2002 were sustained as a result of a fall. Another 18,200 (22 percent) TBIs were caused by transportation-related accidents, which DRS categorizes as motor vehicle, motorcycle, bicycle, or pedestrian-related.

Sports activities are also common causes of TBI in Virginia. The most common sports-related brain injury is a concussion, which can occur in any sport, including baseball, soccer, football, and gymnastics. The risk of sustaining a concussion is highest in activities where collisions are common, such as heading the ball in soccer or tackling in football. Also, environmental factors such as an uneven playing surface or an unpadded goal post can result in an injury.

Violence is another leading cause of TBI in the State. Physical assaults, which might include a blow to the head with a bottle or a brick, account for approximately 7,000 (nine percent) of TBIs reported to DRS since 2002. Less than 300 (one percent) of TBIs were caused by gunshot wounds.

Figure 1: Falls Account for Majority of Traumatic Brain Injuries in Virginia Since 2002



Note: Total does not include approximately 5,802 residents of other states who sustained a traumatic brain injury in Virginia. The State may not be responsible for providing community-based services for these individuals.

[a]Other includes such events as being unintentionally struck by an object.

Source: DRS.

Of the approximately 82,000 TBIs reported between 2002 and 2006, more than 45,000 (56 percent) involved males, compared with 36,000 that involved females. Overall, approximately 1.2 times as many TBIs occurred among males as among females.

According to the Virginia Department of Health Center for Injury and Violence Prevention (CIVP), infants under the age of one and the elderly over the age of 70 are the two population groups at highest risk of sustaining a TBI in Virginia. The CIVP also indicated that adolescents and young adults between the ages of 15 and 24 were most likely to sustain a TBI as a result of a motor-vehicle accident. The CIVP reported that from 1999 to 2003, falls were indicated as the leading cause of TBI among infants, children, and adults over the age of 45.

Exact Number of Persons With TBI Is Unknown

An accurate accounting of the number of people with a TBI is difficult to obtain. An accurate diagnosis in the acute care setting can be missed if the patient is suffering from other physical injuries. In addition, the injury itself may not be apparent using typical medical procedures such as X-rays, magnetic resonance imaging (MRI), or computed tomography (CT) scans. Problems resulting from the injury, such as thinking and memory impairments, may not appear immediately. Additionally, some medical care providers are unfamiliar with brain injuries and may not recognize the symptoms.

CDC estimates that 1.4 million TBI-related deaths, hospitalizations, and emergency room visits occur each year in the United States. (This figure does not capture those receiving care in other medical settings or no care.) CDC also estimates that at least 5.3 million Americans (approximately two percent) currently have a long-term or lifelong need for help as a result of a TBI. Applying the two percent figure to Virginia's 2006 population of approximately 7.6 million produces an estimate of more than 150,000 State residents with severe functional problems associated with a traumatic brain injury.

Medical Consequences of TBI Vary Widely

The effects of a brain injury may include a variety of physical, cognitive, and behavioral impairments (see Table 1). Brain injury survivors constitute a heterogeneous community with a wide range of disabilities and differing functional levels. Approximately 80-85 percent of brain injury survivors sustain mild injuries. Most of these individuals will make a full recovery or have minor impairments that do not substantially impact their lifestyle. As many as 15 to 20 percent of survivors sustain moderate to severe impairments that may permanently limit their ability to perform basic activities of daily living (ADLs), develop meaningful social relationships, or return to work.

The precise constellation of impairments resulting from a brain injury will depend on the severity of the trauma. TBIs are often categorized as mild, moderate, or severe according to the Glasgow Coma Scale, which is used to measure the verbal, motor, and optical responses from a trauma victim at the time of the initial emergency response. Individuals with moderate to severe brain injuries often suffer lasting impairments such as altered gait, diminished range of motion, slurred speech, and severely impaired cognitive functions. However, the severity of a brain injury and the resulting level of impairment do not always correlate. Mild brain injuries

Table 1: Medical Consequences of TBI Include Physical, Cognitive, and Behavioral Impairments

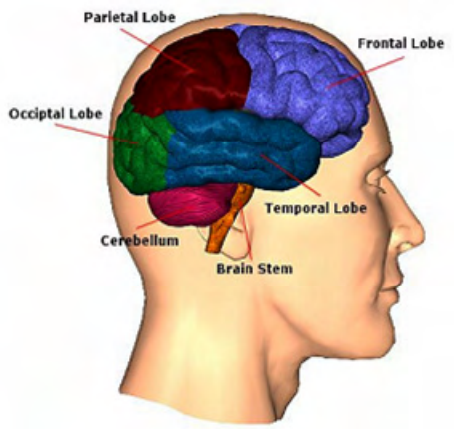
Impairment	Description
Physical	• Physical disabilities such as loss of limb functioning and diminished range of motion
	• Limited ability to perform daily activities such as eating, dressing, bathing, shopping, and managing finances
	• *Hydrocephalus*, or fluid around the brain that causes intracranial pressure and neurological impairments
	• *Post-concussion syndrome*, which includes headaches, dizziness, vertigo, sleeping problems, restlessness, and apathy
	• Additional complications such as vascular and nerve injuries, chronic pain, seizures, and blood clots in the brain
Cognitive	• Difficulty with short-term memory, reasoning, decision-making, information processing, problem-solving, and concentration
	• *Post-traumatic amnesia*, or permanent memory loss of events before and after the trauma
	• Speech-language problems affecting written and verbal communication
	• Difficulty interpreting subtle social cues and other non-verbal forms of communication
	• Impaired vision, smell, taste, and hearing and limited hand-eye coordination
Behavioral	• Psychiatric conditions such as depression, anxiety disorders, eating disorders, substance abuse, and borderline personality disorder
	• Behavioral problems such as physical aggression, disinhibition, mood swings, impulsivity, and socially inappropriate comments or actions
	• Personality changes, including changed interests and apathy

Source: *Evaluating the HRSA Traumatic Brain Injury Program*, Institute of Medicine, 2006, pp. 43-50.

can cause profound, lifelong impairments, while individuals who sustain more severe injuries may be left with relatively minor impairments.

The impairments resulting from a brain injury also depend on the parts of the brain affected by the trauma. Figure 2 shows the human brain and its associated functions. Many brain injuries resulting from car accidents or falls affect the frontal lobe, which is located directly behind the forehead and responsible for cognitive functions such as speech, reasoning, planning, problem-solving, and impulse control. Other traumas may affect parts of the brain that control sensory perception and motor functions. Importantly, damage to the brain is not necessarily localized to discrete regions

Figure 2: Basic Functions Are Located Throughout the Human Brain



Frontal Lobe
- Speech
- Problem solving
- Planning / organization
- Impulse control

Occipital Lobe
- Visual processing

Cerebellum
- Balance and coordination
- Skilled motor function

Parietal Lobe
- Sensory perception

Temporal Lobe
- Auditory processing
- Integration of sensory information and memories

Brain Stem
- Vital function (respiration, heart rate)

Source: *Evaluating the HRSA Traumatic Brain Injury Program*, Institute of Medicine, 2006, page 45.

of the brain. Diffuse axonal injury, in which neural pathways throughout the brain are damaged, can lead to severe impairments, including cognitive deficits or a persistent vegetative state.

Brain injury survivors also differ in the extent to which the medical consequences of a brain injury are apparent. Some survivors have obvious impairments such as severe physical limitations or slurred speech. Other individuals have more subtle impairments that can be difficult to identify, such as changes in personality, behavior, or cognition. Neuroimaging techniques such as MRI or CT scans may not identify damage to the brain. These individuals may not receive needed services and as a result may become involved in the mental health or criminal justice systems.

TRAUMATIC BRAIN INJURY OFTEN LEADS TO LONG-TERM REHABILITATION AND SUPPORT NEEDS

The impairments commonly associated with traumatic brain injury can leave individuals dependent on a wide range of medical and social services to promote recovery and maximize their independence. The community-based services needed by persons with a brain injury will depend primarily on the nature and severity of their impairments. The 15 to 20 percent of brain injury survivors with the most severe impairments will have the greatest need for long-term rehabilitative and support services. However, individuals with more mild impairments may also require services to remain productive in the community and workplace. Obtaining these services can be difficult, as illustrated by the following case study.

Case Study

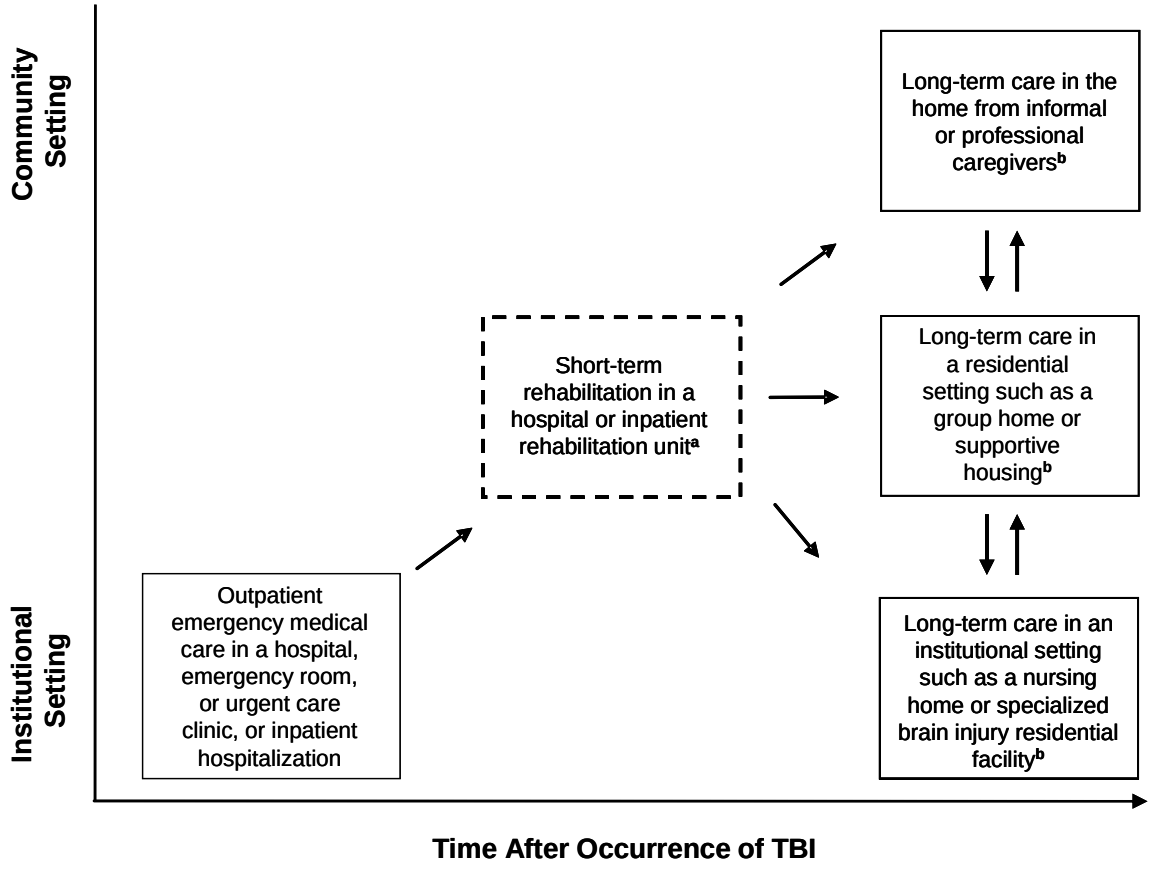
"Stacy" was a Ph.D. economist when, in 1997, she was involved in a minor car accident that did not result in loss of consciousness or significant physical injury. Within two days of the accident, she began having headaches and was unable to complete tasks at home or work. At the time, her primary care physician suggested she had suffered whiplash. Her symptoms worsened, but it was a month before she was diagnosed by a neurologist with a mild traumatic brain injury. Stacy's symptoms included short-term memory problems and cognitive deficits which made it difficult to plan, organize, or prioritize. She had difficulty performing tasks like balancing her checkbook, preparing meals, and shopping. She could no longer drive. Once energetic, she was now easily exhausted and sometimes slept up to 18 hours a day. She relied on friends to help her do things like arrange to get appropriate medical help and manage her life. At the time of the accident, she had disability income insurance through her employer, private health insurance, and automobile insurance. However, six months after the accident, her short-term disability coverage ended, and her claim for long-term disability was initially denied, then temporarily reinstated for two years, then denied again. At the time that her private insurance was first denied, a neuropsychologist confirmed the mild traumatic brain injury diagnosis, and she received some cognitive rehabilitation. She then was referred to speech and language therapy services, which she was not able to obtain until three years after her injury. Two years later, a physician recommended she receive more services, which the insurance company provided for another six months. Her automobile insurance never covered any of the services she received. In 2002, she began volunteering part-time at a university and speaking about her experiences as a brain injury survivor. Today she volunteers for a brain injury advocacy group two mornings a week as part of her rehabilitation and continues to speak. In 2006, she began receiving case management services after a two-year wait.

For severely impaired brain-injury survivors, the medical and rehabilitative services needed generally start with the acute care provided in hospital emergency rooms and trauma centers. Following emergency medical care, these individuals are likely to require inpatient medical and rehabilitative care in a hospital or free-standing clinic before returning to the community. Inpatient rehabilitative care generally consists of neuropsychological exams, or functional assessment tests, to identify cognitive impairments, as well as intensive rehabilitation therapies, such as occupational, physical, and speech therapy to begin relearning basic skills such

as walking, eating, and speaking. Many persons with brain injury will also require long-term rehabilitative therapies and other basic assistance in order to live in the community, either at home or in a residential setting with other disabled persons. This transition from institutional to community settings, illustrated in Figure 3, appears to be a common scenario for severely impaired brain injury survivors, though some individuals will return to the community more quickly, and community-based care may be less feasible for other individuals.

A primary focus of this study is the availability of community-based medical and rehabilitative services in Virginia, represented by the upper right portion of the care continuum illustrated in Figure 3. Demand for home and community-based services for

Figure 3: Continuum of Care for Brain Injury Survivors Includes Institutional and Community-Based Care



[a] Short-term rehabilitative services may be provided after the individual initially receives care in the institutional setting, or he or she may be discharged directly to long-term care in the home or a community or institutional setting.

[b] Outpatient rehabilitative services may also be provided in these settings.

Source: JLARC staff analysis.

brain injury survivors may be growing, in part because an increasing number of individuals are surviving their brain injuries. Discussions with medical professionals and brain injury advocates also indicate that most survivors go home after their acute care rehabilitation ends, in part due to a lack of residential facilities.

Table 2 describes the most commonly needed community-based services for brain injury survivors. A variety of services in different community settings is important because the needs of persons with brain injury vary widely. Individuals with moderate to severe brain injuries may require extensive services, including ongoing assistance with activities of daily living or 24-hour care in a residential setting. Mild brain injuries may require more limited services, such as short-term rehabilitative therapies while the individual relearns basic cognitive and physical skills.

Table 2: Persons With Brain Injury Need Variety of Community-Based Services

Service	Description
Assistive Technology	Provides prosthetic limbs and devices to improve functional capacity. Examples include pagers, alarms, personal digital assistants, wheelchairs, and home or vehicle modifications.
Case Management	Helps persons locate the proper services from federal, State, local, and private programs. Services include assessing needs and coordinating care.
Clubhouses/Day Programs	Provides structured activities in a non-residential setting to help individuals develop independent living, vocational, and social skills.
Cognitive Rehabilitation Therapy	Improves cognitive skills such as reasoning and memory. Helps individuals perform complex tasks like managing finances and preparing meals. Cognitive therapy may not always be available.
Neurobehavioral Therapy	Helps individuals with behavioral problems learn self-control and social skills. Usually includes a combination of medication and therapy.
Occupational Therapy	Helps individuals perform daily living skills. Improves the ability to eat, bathe, or conduct other daily functions by improving motor and reasoning abilities.
Personal Assistance Services	Provides in-home services and assistance with activities of daily living.
Physical Therapy	Improves physical capacity by restoring lost functions and enhancing mobility. Includes identifying and alleviating functional limitations.
Residential Services	Provides residential care designed for persons with brain injury in a community setting. Care may be long-term or aimed at enabling the individual to return home.
Speech Therapy	Addresses speech and language disorders. Individuals may learn sign language, improve their communication skills, and relearn chewing and swallowing skills.
Transportation	Helps individuals access rehabilitative services outside the home, maintain a job, and remain active in the community.
Vocational Rehabilitation	Helps individuals enter the workforce. Services include vocational evaluation, skills training, counseling, and placement for work in real-world or "sheltered" settings.

Source: *Evaluating the HRSA Traumatic Brain Injury Program*, Institute of Medicine, 2006.

Although service needs vary considerably among persons with brain injury, a core set of services is often needed. Rehabilitative therapies to help a person regain or adapt to the loss of skills are generally needed for some period. Case management also appears to be a critical need, mainly because finding services in the community can be challenging for many survivors and caregivers. Residential care in nursing homes, group homes, assisted living facilities or other supported living arrangements may be necessary when an informal caregiver and personal care assistance are not available. Services promoting community and social integration let survivors practice coping skills and behavior modifications learned in rehabilitation. Transportation may be an important service in both rural and urban areas because driving can be difficult for some brain injury survivors. Finally, for a small group of individuals, intensive neurobehavioral supports may be needed to treat social, behavioral, and psychological impairments.

Chapter 2

Virginia's Community-Based Traumatic Brain Injury Program

In Summary

No federal programs provide community-based brain injury services. Federal law that directly addresses traumatic brain injury, the TBI Act, is designed to help states develop their brain injury service programs and fund research into treatment and prevention. In 2006, the Department of Rehabilitative Services (DRS), which coordinates statewide services for persons with brain injury, spent approximately $3.8 million providing more than 1,000 individuals with case management and social/prevocational services. DRS also funded public awareness and outreach to specific areas in the State. Approximately $1.4 million is also available each year in State grant funds for research and community-based rehabilitative services. It appears that more individuals with brain injury in Virginia are accessing services than in surrounding states.

The role of the federal government has been limited to assisting states with developing their brain injury programs and expanding efforts at the local level. General Assembly action in 1984 made Virginia the first state to require reporting of brain injuries to a central registry. The General Assembly first appropriated State funding for brain injury services in 1989.

FEDERAL ROLE FOCUSES ON RESEARCH AND IMPROVING STATE PROGRAMS

The federal government currently plays a limited role in directly serving individuals with traumatic brain injuries. Although some persons with brain injury likely receive services through federal programs that serve disabled or low-income populations, there are no federal programs dedicated to providing services to brain injury survivors. The only federal legislation that directly addresses traumatic brain injury, the TBI Act of 1996, is designed to help states develop their brain injury service programs and fund research into the treatment and prevention of traumatic brain injury.

Table 3 summarizes federal efforts regarding traumatic brain injury, including programs mandated by the TBI Act. The main thrust of the act was a competitive grant program to help states develop systems to serve individuals with brain injuries. Initial grants were available to states that developed a plan to implement four program components:

Table 3: Federal Government Addresses TBI Through Five Types of Programs

Activity	Federal Agency	Description
Infrastructure Grants	Health and Human Services (HHS)	Provides competitive grants to help states develop their brain injury programs
Surveillance and Prevention	Centers for Disease Control and Prevention	Supports state surveillance programs and funds prevention research
Clinical Research	National Institutes of Health	Provides grants to fund research on the diagnosis and treatment of brain injuries
Model Service Systems	Department of Education (DOE)	Maintains a system of model care centers and pools data to facilitate clinical research
Services for the Disabled	HHS and DOE	Includes Social Security cash assistance, Medicaid, Medicare, and the Vocational Rehabilitation program

Source: Traumatic Brain Injury Act of 1996 and the Children's Health Act of 2000.

- a lead state agency to coordinate brain injury services,
- a board to advise the lead agency and develop policy recommendations,
- a statewide assessment of TBI needs and resources, and
- an action plan to develop a statewide system of care.

Once these components were in place, states were eligible to receive two subsequent grants to expand access to services by implementing their state action plans and building service capacity. Since 1997, Congress has appropriated $42 million for state grants. Virginia has implemented all four components and has received approximately $800,000. Federal statutes have generally prohibited states from using grant funds to provide direct services for brain-injured survivors.

Reauthorization of the TBI Act in 2000 added grants to help states improve their protection and advocacy services for persons with brain injury. Under the Protection and Advocacy for TBI (PATBI) program, all states have received annual allotments ranging from $50,000 to $117,000 since FY 2002. States can use these grants to provide information and referral services, legal representation, and advocacy for individuals with brain injury and their families.

The TBI Act has also funded efforts to prevent TBIs and identify survivors. The CDC was tasked with tracking the incidence and prevalence of brain injuries, identifying effective prevention strategies, and expanding public awareness. As of September 2006, CDC supported surveillance programs in 30 states, and in 2005 it gathered researchers, advocates, and state TBI registry managers to address the future of state identification systems. The agency also published a 2004 report that provided national estimates of brain injury deaths, hospitalizations, and emergency room visits.

The federal government also funds clinical research aimed at developing more effective diagnostic tools and treatment strategies for persons with brain injury. The TBI Act of 1996 gave the National Institutes of Health (NIH) primary responsibility for conducting research to improve the diagnosis and treatment of traumatic brain injuries. NIH oversees clinical trials and distributes grants for research into the treatment of brain injuries.

TBI Act funding for research and state grants may not be available in the future. The TBI Act expired in 2006, and the proposed federal budget for FY 2008 did not include funding for the act. In 2006, Congress considered but did not pass legislation reauthorizing the Act through 2010 and expanding it to include federal grants to states and private organizations working to improve access to brain injury services. Similar legislation is currently pending before the U.S. House of Representatives and Senate.

In addition to the TBI Act, the U.S. Department of Education has managed the TBI Model Systems of Care (TBIMS) program since 1987. The program maintains a system of model TBI care centers throughout the country. Research grants through TBIMS are used to identify cost-effective treatments and improve the rehabilitation outcomes of persons with brain injury. There are 16 model system centers around the country, including the Virginia Commonwealth University Medical Center in Richmond, that provide a comprehensive array of services ranging from emergency medical care to long-term rehabilitation. The centers also contribute research and data to maintain a directory of outcome measures for persons with brain injury.

Another way the federal government is involved with brain injury activities is through programs designed for the disabled population in general. Individuals with brain injury may be able to access financial, health, and vocational services through the following programs:

- Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs, which provide cash benefits for individuals unable to work;
- Medicare and Medicaid, which provide health insurance and cover a variety of rehabilitative and support services; and
- Vocational Rehabilitation, which helps individuals regain job skills and return to work.

DEPARTMENT OF REHABILITATIVE SERVICES COORDINATES COMMUNITY-BASED BRAIN INJURY SERVICES

In 1984, Virginia became the first state to require reporting on head and brain injuries. Having subsequently identified a need for brain injury services, the General Assembly initially appropriated funding in the amount of $250,000 in 1989. Section 51.5-9.1 of the *Code of Virginia* designates DRS as the "State agency for coordinating rehabilitative services to persons with functional and central nervous system disabilities," including traumatic brain injuries. The statute also identifies the following functional activities for the department to perform:

- Provide for the comprehensive assessment of the need for rehabilitative and support services of such persons;
- Identify gaps in services;
- Promote interagency coordination;
- Develop models for case management; and
- Advise the Secretary of Health and Human Resources, the Governor, and the General Assembly on programmatic and fiscal policies and the delivery of services to such persons.

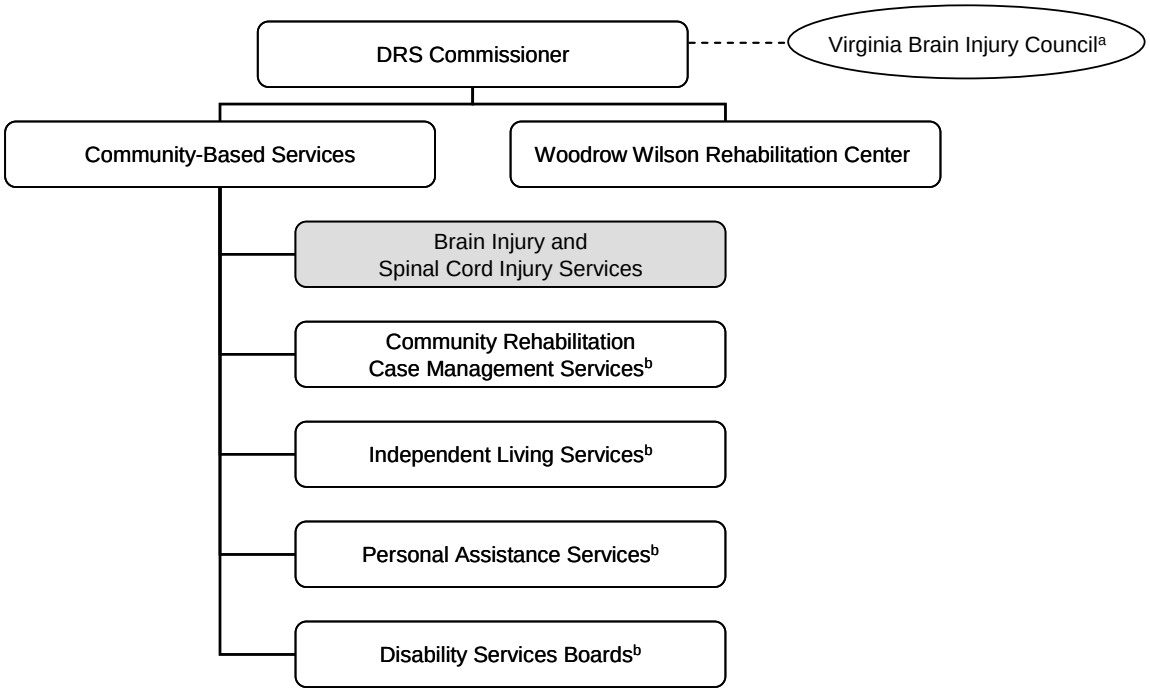
DRS organizes its brain injury service efforts within the Brain Injury and Spinal Cord Injury Services unit located in the department's central office in Richmond (Figure 4). The unit manages multiple programs, contracts, and federal/state grants that provide brain injury services throughout the State and coordinates with other DRS programs that provide direct client services (see Appendix C for a list of these services). Most community-based brain injury services are provided through contracts with private service providers. The unit administers or manages contracts for the following services:

- adult and pediatric case management;
- clubhouse/day programs;
- community-support services, including life skills services;
- regional resource coordination; and
- supported residential services in Northern Virginia.

Additionally, the unit manages Virginia's three-year federal TBI Act grant to strengthen the State's infrastructure for the delivery of brain injury services.

The unit's two full-time positions consist of a program manager and a program specialist. In addition, an office services specialist

Figure 4: Organizational Structure of DRS' Community-Based Services Division



Note: In addition to Community-Based Services and Woodrow Wilson Rehabilitation Center, DRS also operates two other divisions—Field Rehabilitation Services and Disability Determination Services.

[a] The Virginia Brain Injury Council reports to and advises the DRS Commissioner.

[b] These services are available to all disability populations.

Source: DRS organizational chart, March 12, 2007.

serves both the unit and the Community Rehabilitation Case Management Services unit, while a part-time position provides administrative assistance. The program manager is responsible for managing contracts, grant funding, and writing federal grant proposals. Staff also support the Virginia Brain Injury Council (VBIC), a statewide, interagency advisory council comprised of consumers (for example, survivors of brain injury and family members, caretakers, and representatives of survivors); healthcare professionals; service providers; State agency representatives; and other ad hoc advisory members. The mission of the council is to promote accessible, affordable, and appropriate services for Virginians with brain injuries and their families by advising DRS.

DRS Administers Virginia's Brain Injury Registry and Commonwealth Neurotrauma Initiative Trust Fund

The unit is responsible for two programs mandated by the *Code of Virginia*, the Virginia Central Registry for Brain Injury and Spinal Cord Injury (registry) and the Commonwealth Neurotrauma Ini-

tiative (CNI) Trust Fund. The registry and CNI Trust Fund are designed to assist the State with identifying persons with brain injury and funding innovative services and research, respectively. According to the *Code of Virginia*, DRS is required to maintain the registry "in order to facilitate access to appropriate rehabilitation services" for brain injury survivors. In 1984, Virginia became the first state to implement a central registry for the purpose of identifying persons with brain injuries. (A registry for persons with spinal cord injuries had already been established in 1982.) All hospitals in the State are required to report individuals treated for a TBI to DRS within 30 days. Information that must be reported includes the name, age, and residence of the person, as well as the date and cause of the injury. The department currently contracts with the Brain Injury Association of Virginia (BIAV) to mail information packets and handle any requests for additional information that result.

The CNI Trust Fund was established to improve the treatment and care of Virginians with traumatic brain or spinal cord injuries. CNI is funded through a $30 fee charged by the Department of Motor Vehicles (DMV) to drivers convicted of alcohol-related and other driving offenses when those drivers apply for reinstatement of their licenses. (The fund receives $25 and the remaining $5 goes to DMV for administrative costs.) The fund raises about $1.4 million annually for research and rehabilitative programs. Grants of one to three years are competitively awarded from the fund by the CNI advisory board.

Statewide Needs Assessment Prioritized Case Management, Clubhouse/Day Programs, and Regional Resource Coordination

In 1998, DRS conducted a statewide needs assessment for brain injury services under the State's federal TBI Act grant. The result of that needs assessment, which included a mail survey of 10,000 brain injury survivors and caregivers and 19 town meetings, was a strategic action plan published in 2000. The plan drives the State's overall policy towards brain-injured survivors. VBIC identified the following six priorities in the plan:

- creation of regional resource centers, which would be responsible for information referral and advocacy; community living services; employment; transportation; social, recreational, and peer support; and individual and family support;
- establishment of short- and long-term neurobehavioral residential treatment options;
- enhancement of the Virginia Central Registry for Brain Injury;

- expansion of long-term rehabilitation case management and personal assistance;
- development and expansion of day programs/services; and
- increased education/awareness, including prevention information and activities.

Despite identifying six priority functions, the department has focused on three core programs: case management, clubhouse/day programs, and regional resource coordination (Table 4). BIAV conducted another round of town meetings in 2005, and DRS is in the process of updating the action plan.

In addition to the services administered and contracted by the unit, DRS also assists persons with brain injury through other department programs. For example, nine community-based case management positions are allocated to provide assistance in identifying and accessing services for individuals with disabilities, including TBIs. These case managers served more than 100 individuals with brain injury in 2006. Among the services they coordinate for brain injury survivors are support groups, job training and placement, and individual and family counseling.

DRS also operates the Woodrow Wilson Rehabilitation Center (WWRC) Brain Injury Services Program. Located in Fishersville, WWRC offers residential/outpatient programs that provide services such as comprehensive rehabilitation therapy, vocational training, case management, and neuropsychological assessments.

Table 4: DRS Focuses on Three Core Brain Injury Services

Service	Description	Number of State-Contracted Providers, 2007	Number of Persons Served, 2007
Case Management	Comprehensive approach to identifying, planning, coordinating, monitoring, and evaluating services to meet the needs of individuals with brain injury	6	749
Clubhouse/Day Programs	Designed to increase the independence and employability of brain injury survivors, by focusing on social and behavioral skills, independent living skills, vocational training, and compensatory strategies	7[a]	227
Regional Resource Coordination	Public education, outreach, awareness, and advocacy activities, service provider recruitment and development, and support groups	1	300[b]

[a] An eighth clubhouse/day program has opened in Roanoke. However, that facility is currently receiving CNI grant funding.

[b] Count includes one-on-one consultations and support group attendees only.

Source: Brain Injury Association of Virginia and data provided by DRS.

Other State Agencies Also Have Responsibility for Persons With Brain Injury

Several State agencies in addition to DRS interact with Virginia's population of individuals with brain injury. Table 5 identifies some of these State entities, the role they play regarding persons with brain injuries, and the size of the population they serve. Other State agencies are included as non-voting members on VBIC, including the Departments of Health (VDH), Education (DOE), Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), and the Virginia Office for Protection and Advocacy.

Each agency's mission determines the services it provides to individuals with brain injury. For example, as of August 2007, DMHMRSAS was treating 14 persons with TBI through its State mental health institutions and mental retardation training cen-

Table 5: Other State Agencies Involved With Persons With Brain Injury

State Agency or Entity	Programs or Services Offered	Estimated Population	Timeframe
Department of Corrections	Services will be those already available to regular inmate population. May access physical therapy through UVA or VCU health systems.	No data available	--
Department of Education	Children with TBI are served as any other child with specialized needs. Includes creation of an individualized education program and necessary strategies and accommodations.	369	2005
Department of Health	No direct services. Collect information through the Virginia Statewide Trauma Registry about traumatic injuries, including brain injury.	n/a	--
Department of Juvenile Justice	Each juvenile receives a mental health evaluation at intake, and those with signs of mental illness receive services through the behavioral service unit.	319	2003
Department of Medical Assistance Services	Reimburses service providers for cost of services based on Medicaid reimbursement rates.	931[a]	FY 2004-FY 2006
Department of Mental Health, Mental Retardation and Substance Abuse Services	May house a person with a brain injury in one of the State's mental health facilities or mental retardation training centers. Persons must have a primary diagnosis of mental health illness to be admitted. Person is likely to receive treatment to stabilize mental health issue, not necessarily brain injury issue.	14	August 2007
Virginia Office for Protection and Advocacy	Uses federal TBI grant funding to provide advocacy and support of persons with brain injury and their families.	214	Nov. 1, 2005-Oct. 31, 2006

[a] Data represents the number of persons with a TBI diagnosis who accessed Medicaid home and community-based waivers. Numbers of waiver recipients can fluctuate widely and may be different for other time periods. An additional 16,724 had a TBI diagnosis and accessed the statewide Medicaid program during this period. JLARC staff were unable to determine whether Medicaid services were for a brain injury or another condition.

Source: State agency staff and documents.

ters. However, the focus of these facilities is to treat and stabilize persons with mental illness, and patients with a brain injury may not be receiving the most appropriate care, according to brain injury advocates. Likewise, inmates with a brain injury at one of the State's correctional facilities may only have access to services offered at the facility in which they are incarcerated. Such programs are not likely to have a brain injury component specific to them, according to staff at the Department of Corrections.

DMHMRSAS is also responsible for the licensing and oversight of residential programs for those with brain injuries. Programs may include transitional living, long-term rehabilitative care, behavioral management, and on-site nursing and neuropsychology. Emergency regulations to license brain injury residential providers were developed in 2005 in anticipation of a Medicaid waiver, and permanent regulations were implemented in early 2007. For the most part, these regulations mirror the regulations for other residential providers operating in Virginia. Providers operate under provisional, one-year, two-year, or three-year licenses. Although there are no minimum staffing ratios, State regulations require direct care staff to have a high school diploma, have a minimum of two years' experience with disabled persons, and complete a training curriculum on brain injuries within six months of employment. Providers also are required to employ or contract with a neuropsychologist (or licensed clinical psychologist specializing in brain injury) to conduct individual needs assessments, develop service plans, and provide training for direct care staff. According to DMHMRSAS staff, only four facilities with a total of approximately 75 specialized neurorehabilitative beds are currently licensed specifically as residential facilities for brain injury survivors.

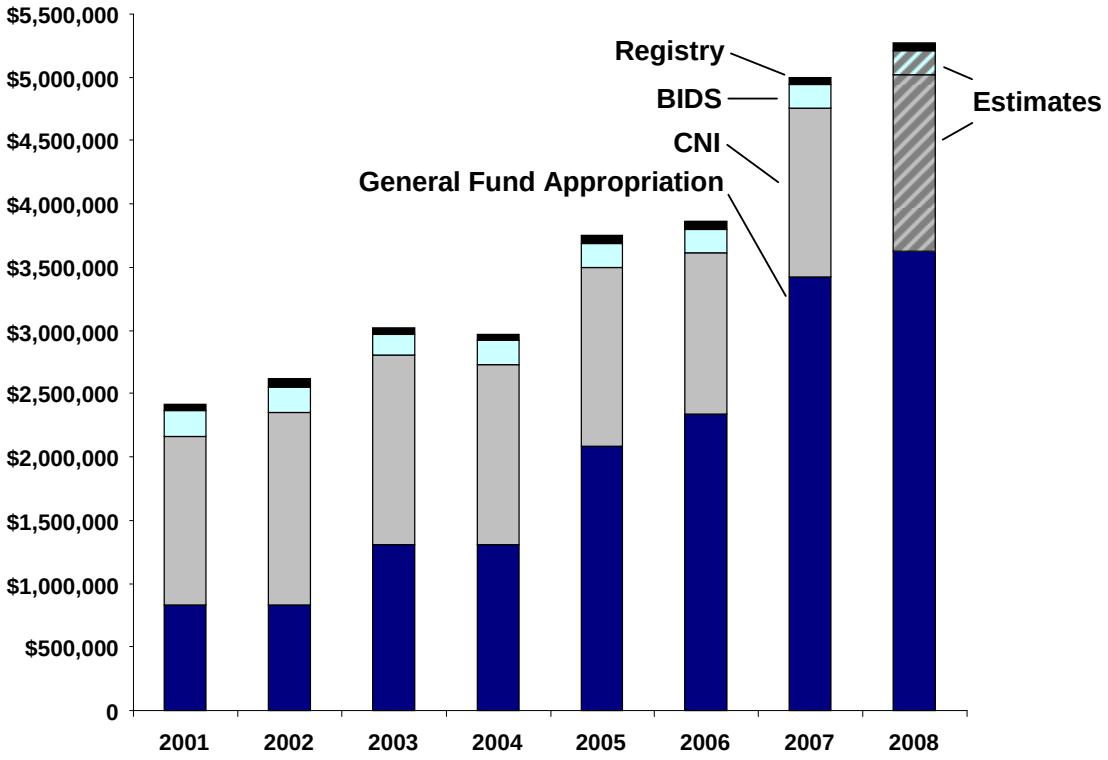
FUNDING FOR TRAUMATIC BRAIN INJURY IN VIRGINIA IS ABOUT $5.3 MILLION

As a result of substantial increases since the start of the decade, funding for Virginia's program to provide community-based brain injury services amounts to about $5.3 million annually. State General Funds specifically for community-based brain-injury services account for approximately $3.6 million of this amount and another $1.4 million in State funds are available through fees assessed against those convicted of reckless driving. There is minimal federal funding available for community-based brain injury services, and almost none of it can be used to provide direct services. DRS' three core services account for the majority of the department's brain injury-related allocations; however, case management receives the largest share (56 percent) of any service.

More Than $5 Million in State Funding for Brain Injury Services in FY 2007

In FY 2007, Virginia allocated almost $5 million for brain injury services and research, an increase of $2.8 million since FY 2001. The majority of State funding and the majority of the increased funding comes from State General Fund appropriations, which total more than $3.8 million in FY 2008. As shown in Figure 5, General Fund appropriations specifically for community-based brain injury services have increased significantly since 2001. In FY 2008, more than $3.6 million was appropriated to DRS for brain injury services. Most of these funds, about $3.2 million, are specifically for continuing and expanding existing community-based programs and services, while another $285,000 is for supporting case management services in Southwest Virginia, which has received funding since FY 2005, and $150,000 is for case management services in unserved or underserved regions in the Commonwealth (including Southwest). (In fiscal years 2007 and 2008, the Commonwealth provided $75,000 in non-State agency funding to a program providing services to persons with mild and moderate brain injuries.)

Figure 5: State Funding for Brain Injury Services Has Increased by More Than $2.5 Million Since FY 2001



Note: BIDS, Brain Injury Direct Services; CNI, Commonwealth Neurotrauma Initiative Trust Fund. Registry and BIDS amounts represent amounts allocated from DRS agency-wide appropriation. 2008 BIDS and CNI figures represent averages of FY 2001-2007.

Source: Data from Appropriation Acts and DRS.

The second largest component of public funding for brain injury services comes from the CNI Trust Fund. CNI funds are available to Virginia-based organizations, institutions and researchers to address the needs of people with acquired neurotrauma, including spinal cord injuries as well as traumatic and non-traumatic brain injuries, through research efforts and innovative community-based rehabilitation programs. CNI is funded through fees on reinstated driver's licenses and generally collects about $1.4 million annually. While the funding is used for brain injury activities, CNI money is allocated by an advisory board separate from DRS and is not counted towards the department's overall funding allocation.

In addition, since FY 2004, DRS has set aside about $249,000 of the department's General Fund appropriation for brain injury-related functions, including the cost of the registry and State matching funds for the federal TBI Act grant. In FY 2007, DRS obligated $191,000 of its General Fund appropriation to support the Brain Injury Direct Services (BIDS) Fund. BIDS funding is available for short-term specialized services, assistive technology, and other equipment to help persons live more independently, but does not pay for inpatient hospital or residential services. The department allocated another $57,000 of its FY 2007 General Fund appropriations to support the registry.

Virginia Has Received More Than $800,000 in Federal TBI Act Grant Funding Since 1998

There is minimal federal funding available for community-based brain injury services. As discussed, the TBI Act funds three types of grants to state agencies to create programs assisting brain injury survivors and their families: planning grants, implementation grants, and implementation partnership grants. DRS received a two-year, $150,000 TBI planning grant in 1998 to identify the needs of the State's population with brain injury and develop an action plan to address those needs. The department matched this funding with $54,000 in State dollars over the two years. Subsequently, DRS received a three-year, $300,000 TBI implementation grant in 2002 (which did not include the State match worth $50,000 annually plus $25,000 of in-kind match) and a three-year, $318,000 implementation partnership grant in 2006 ($40,000 in State matching funds each year). In FY 2007, DRS's TBI grant amount was $100,000. In addition to the grants awarded to DRS, in FY 2006 the Virginia Office for Protection and Advocacy received $55,000 through the Protection and Advocacy TBI grant program.

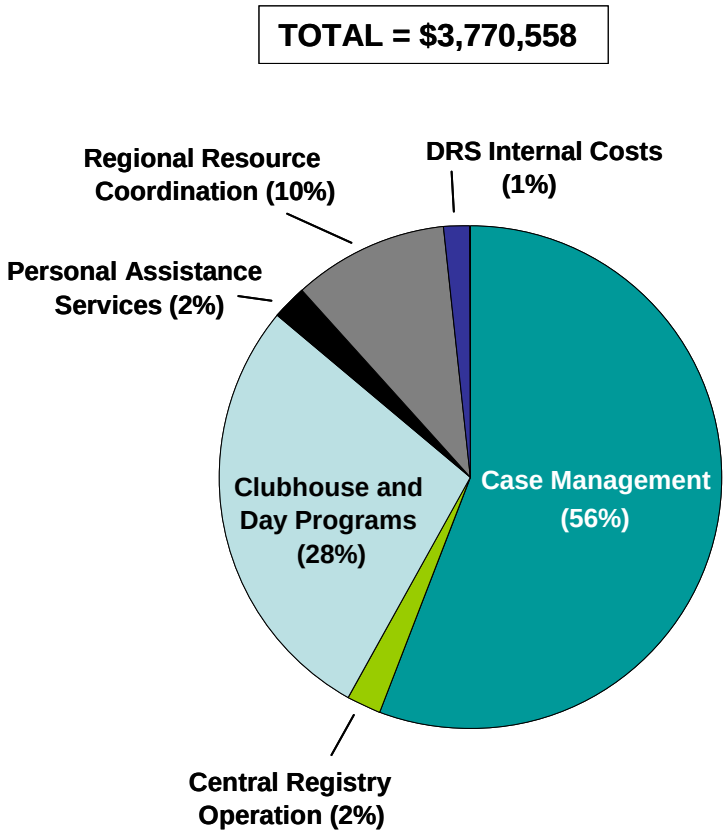
State-Funded Programs Are Attracting Non-State Funding

The 2004 General Assembly provided additional funding for community-based brain injury services to DRS with the requirement that those receiving funding under the supplement would "submit plans to pursue non-state resources to complement the provisions of general fund support." Many programs are reporting success in attracting non-State dollars. Two clubhouses reported securing more than $50,000 each during 2006 and a case management program raised almost $300,000 in funding. In total, the programs reported securing more than $1 million in non-State funds.

Case Management Accounts for 56 Percent of FY 2007 Spending

Not counting the approximately $1.4 million in CNI grants available annually, the three core services identified by DRS account for 94 percent of the department's FY 2007 brain injury services spending (Figure 6). Case management receives the largest

Figure 6: Majority of DRS Allocation for Brain Injury Services Was for Case Management in FY 2007



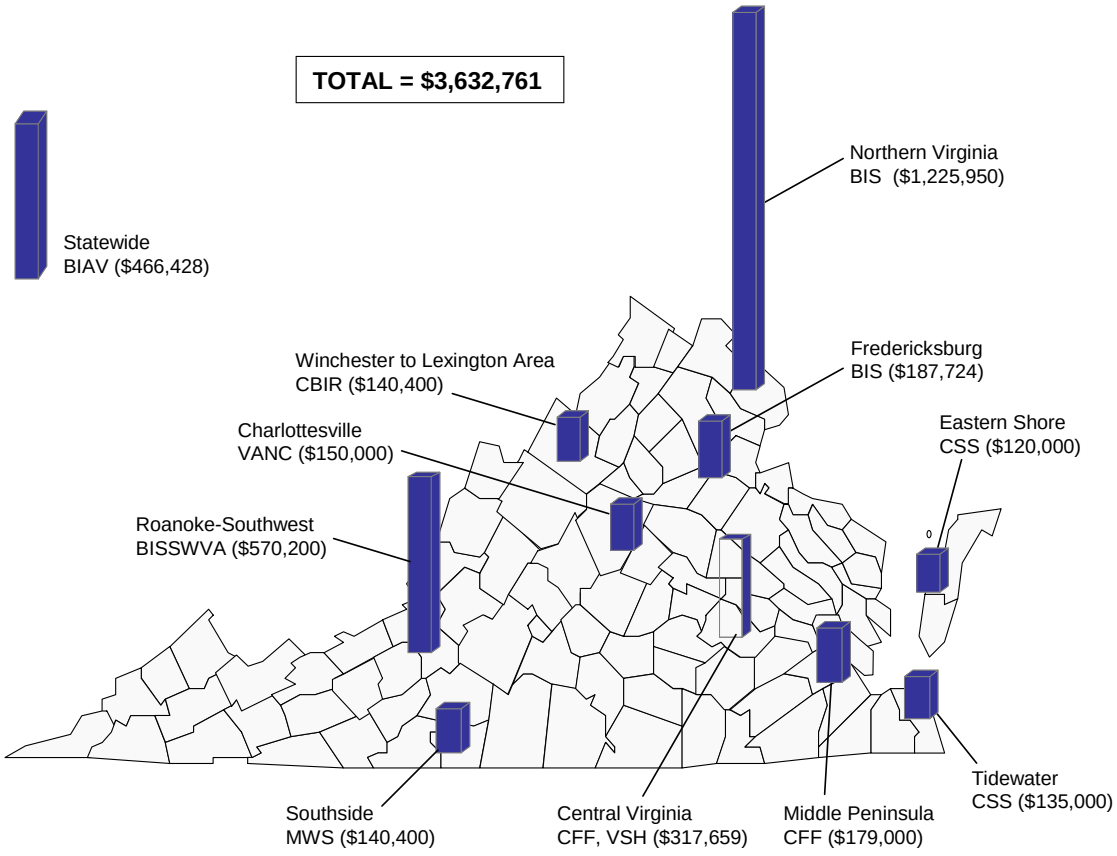
Source: Data from DRS, winter 2007.

percentage (56 percent) of funding (this does not include funding for the case management provided directly by DRS). Clubhouse/day programs (28 percent) and regional resource coordination (10 percent) comprise the department's next two largest FY 2007 allocations. Other services that receive State funding include the registry's operation and personal assistance services.

DRS Obligated $3.6 Million to Nine Providers for Services in FY 2007

In FY 2007, DRS obligated $3.6 million in State and federal funding for contracts with nine brain injury service providers located across the State. Contracted services include case management, clubhouse/day programs, regional resource coordination, and the brain injury registry. Figure 7 indicates the primary location of the

Figure 7: DRS Obligated More than $3.6 Million for Brain Injury Services With Nine Providers in FY 2007



Note: BIAV, Brain Injury Association of Virginia; BIS, Brain Injury Services, Inc.; BISSWVA, Brain Injury Services of Southwest Virginia; CBIR, Crossroads to Brain Injury Recovery; CFF, Community Futures Foundation; CSS, Commonwealth Support Systems, Inc.; MWS, MARC Workshop, Inc; VANC, Virginia Neurocare; VSH, Virginia Supportive Housing.

Source: Analysis of information provided by DRS.

service providers and the allocated amount. Services in Northern Virginia and Fredericksburg received more than $1.4 million (39 percent) of the funding, $570,000 (16 percent) was allocated to serve Roanoke and Southwest Virginia, and statewide activities accounted for another $460,000 (13 percent).

OTHER STATES' COMMUNITY-BASED BRAIN INJURY PROGRAMS

JLARC staff contacted selected surrounding states to identify how they address the needs of their populations with brain injury. State spending directly for community-based brain injury services ranges between zero in Maryland and West Virginia to approximately $6 million in Pennsylvania and South Carolina (Table 6). (These amounts do not include State matching funds for TBI Act grant funding.) The number of brain injury survivors receiving case management services varies between none in West Virginia and 749 in Virginia.

Table 6: Traumatic Brain Injury Programs in Selected States, 2007

State	Approximate State Funding	Number of Individuals Receiving Case Management	Program Description
Kentucky	Data not available	Data not available	Direct services include case management, occupational and speech therapy, prevocational, supported employment, day programs, information and referral, and respite care. Annual per person spending capped at $15,000 and lifetime spending at $60,000. Also funds TBI waiver.
Maryland[a]	Data not available	90	Does not allocate funding for brain injury services. Uses TBI Act grant funding for three resource coordinators who provide case management, one-on-one service coordination, and public outreach. Also funds TBI waiver.
North Carolina	$1,500,000	Data not available	Uses $1 million for personalized individual services, such as transportation, neuropsychological evaluations, and housing assistance. Contracts for case managers, support groups, training and education, a group home, and establishment of a clubhouse.
Pennsylvania	$6,000,000	92	Provides case management, rehabilitation services, neuropsychological evaluations, transportation, life skills, cognitive rehabilitation, and intensive neurobehavioral residential treatment. Annual per person spending is capped at $100,000. Also funds TBI waiver.
South Carolina	$6,000,000	700	Only severely or moderately injured eligible for services. Provides case management, life skills, cognitive rehabilitation, and "drop-in" centers similar to clubhouses. Also funds TBI and spinal cord waiver.
Tennessee	$1,300,000	400	Direct services include case management, education and awareness, summer camps, limited supportive housing, and a TBI registry.
Virginia	**$5,300,000**	**749**	Contracts for case management, seven clubhouse/day programs, public education and outreach, and registry information and referral. Also provides personal care assistance on a limited basis and registry maintenance.
West Virginia[a]	Data not available	0	Does not allocate funding for brain injury services. Uses TBI Act grant funding to contract with the West Virginia University Center for Excellence in Disabilities to provide brain injury training and technical assistance to certain State employees, teachers, and public and private providers and for registry maintenance.

[a] Amount of state match provided under federal TBI Act grant is not known for these states.

Source: State agency staff.

Chapter 3

Access to Brain Injury Services Has Improved but Remains Limited

In Summary

Approximately 1,000 individuals and caregivers benefited from State funding for community-based brain injury services in FY 2007. While substantial State funding increases since 2002 have increased the number of individuals with brain injury accessing services, much of this population lacks access to community-based services. Services are not available in all parts of the State. Where services do exist, there are often waiting lists or other obstacles preventing access. The brain injury services that the State funds were identified through a statewide needs assessment and chosen, in part, in order to serve the largest number of persons with the limited available funds. Services such as intensive neurobehavioral treatment programs, cognitive rehabilitation, supportive housing, and transportation are also needed services, but are not provided by the State. Health insurance limits on the types of services and the number of times covered services can be used also limit access. Traumatic brain injury (TBI) is considered the signature wound of the conflicts in Afghanistan and Iraq, raising concerns about the effect returning service members with TBI could have on the availability of community-based brain injury services as well as whether the State is prepared to address the issue.

Traumatic brain injury affects all aspects of the survivor's life—physical condition, cognition, and behavior. Effectively treating the damage caused by a TBI involves accessing appropriate acute medical, post-acute rehabilitation, and community-based services. In addition, individuals sustaining a TBI may have lifelong service needs. Moreover, as described in a 2007 collection of research articles on brain injury:

> A number of marketplace factors constrain the full development and availability of components of these [service] systems for persons in need, most notably cost, payer support, and availability of resources. These constraints become progressively restrictive for services and supports beyond the acute treatment period.

ACCESS TO STATE-FUNDED SERVICES IS LIMITED BY GEOGRAPHY AND RESOURCES

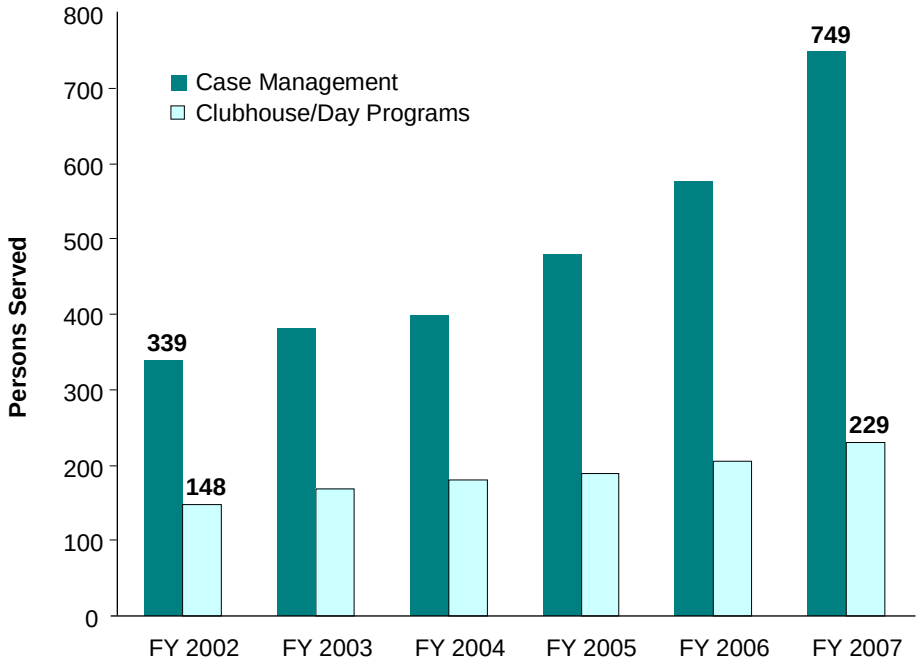
Traumatic brain injuries occur across the State and about 15,000 are reported to the Virginia brain injury registry annually. As a result, availability of community-based services across the State is important. The number of brain injury survivors accessing case management and clubhouse/day programs has increased since FY

2002. However, limited resources make it difficult to have such a wide array of services. In addition, limited resources constrain the capacity of funded service providers to meet the needs of those with brain injury in their area, resulting in waiting lists.

Number of Persons with Brain Injury Being Served Has Increased

The number of brain injury survivors accessing case management or clubhouse/day programs has increased substantially in recent years (Appendix D). The number of individuals receiving case management services more than doubled between FY 2002 and FY 2007 (Figure 8). Much of this increase resulted from legislative appropriations expanding case management services in Northern and Southwest Virginia. The number of individuals participating in clubhouse/day programs rose more than 50 percent over the same period, from 148 to 229. Clubhouse/day programs will likely be available to more persons with brain injury in the future with the recent opening of a new clubhouse in Roanoke.

Figure 8: Increasing Number of Brain Injury Survivors Access Case Management and Clubhouse/Day Programs



Note: Duplication may exist as individuals may access both services. FY 2007 does not include the number of individuals attending clubhouses receiving CNI grant funding.

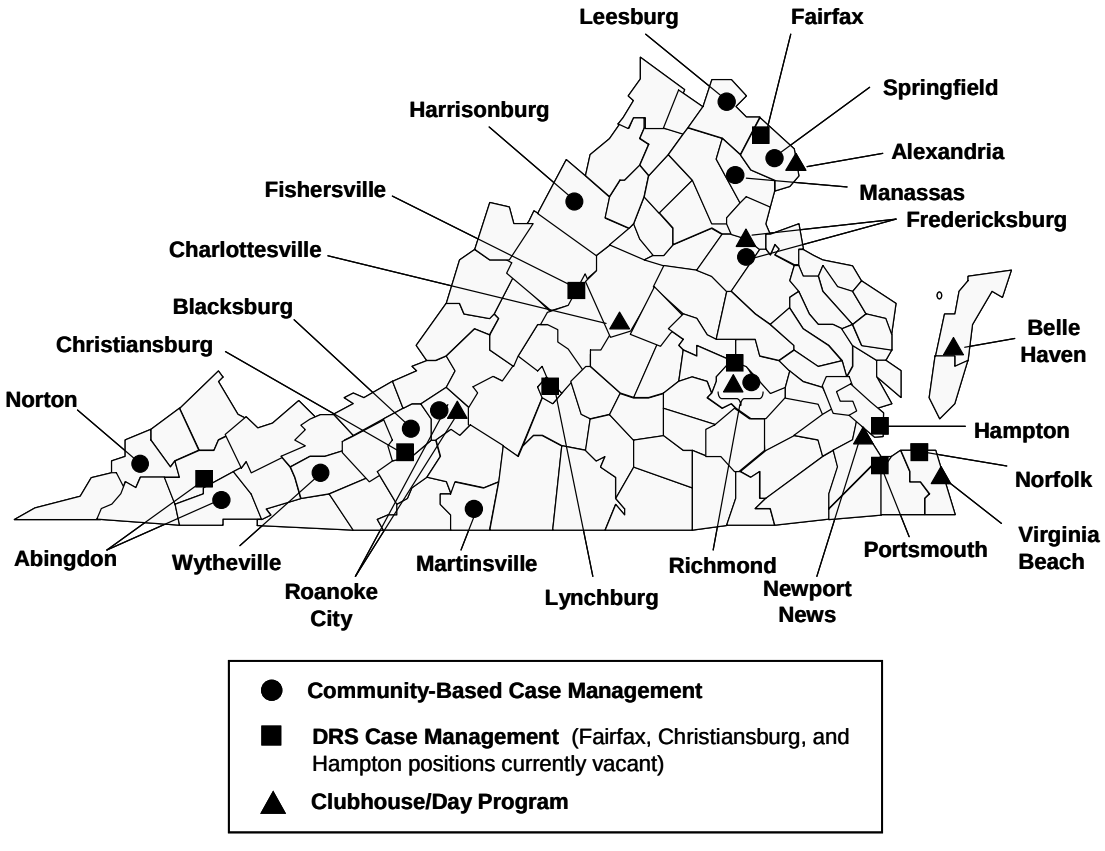
Source: DRS and State-funded brain injury service providers.

Some Parts of Virginia Have Few State-Funded Services

Access to State-funded brain injury services varies significantly by area. Individuals in areas with few services are likely to live great distances from case management and clubhouse/day programs, medical therapists, neuropsychologists, and other health care providers with experience treating brain injury. Awareness of traumatic brain injury and the needs of survivors appears to be limited among health care professionals and educators in these areas. In locations without services, survivors must drive substantial distances to obtain services or go without them.

As indicated in Figure 9, some parts of Virginia, such as the Richmond area, Northern Virginia, and Roanoke have case management programs, clubhouse/day programs, and other services for persons with brain injury in the community. By contrast, individuals in Southside, the Northern Neck, and large parts of the Interstate 81 corridor from Winchester to Lexington have little or no access to community-based services.

Figure 9: Case Management and Clubhouse/Day Programs Are More Available in Urban Areas



Source: DRS.

Individuals in other parts of the State only have limited access to services. Some areas of the State only have one State-funded service. Moreover, persons with brain injury in these parts of the State may have difficulty participating in existing services because of transportation issues. For example, while case management is available in Norton and Abingdon in far Southwest Virginia, long driving times complicate the case managers' ability to meet with their clients. In addition, there are no clubhouse/day programs in that area. In the Tidewater area, there are no brain injury-specific case management programs, although DRS case managers are able to assist some individuals.

DRS' Community Rehabilitation Case Management Services supplements the number of persons receiving contracted case management services. Nine DRS case managers served more than 100 individuals with brain injury in FY 2006. However, access to the DRS case managers is also limited, because these case management positions are also responsible for serving other disability populations. In addition, three of the nine DRS case management positions (in Christiansburg, Hampton, and Northern Virginia) are presently vacant.

DRS and the Brain Injury Association of Virginia identified the need for services in these communities during a series of town hall meetings held in 2005 to update the strategic action plan. The resulting report, based on comments from survivors and their caregivers and others involved with brain injury, found that community-based services were limited in rural areas of the State, including Southwest Virginia and along I-81 in the Shenandoah Valley. Individuals in these and other regions consistently described the lack of services and a resulting sense of isolation. JLARC staff received similar feedback from brain injury service providers and advocates in these regions. Staff were told that Harrisonburg-area hospitals do not have neuropsychologists with brain injury experience, and local educators are reluctant to address the needs of children with brain injuries. Service providers in Roanoke said that a limited number of psychologists and medical therapists are in Southwest Virginia.

Limited access to community-based services can have a substantial impact on brain injury survivors and their caregivers. According to brain injury advocates and researchers, lack of access to needed services often hinders a brain-injured survivor's achievement of independence in the community. Without services, persons may regress, develop more severe problems, or lose the skills they regained during acute rehabilitation. The following case study illustrates how survivors' problems can worsen without services:

Case Study

"Larry," who lives in the Middle Peninsula area, sustained a TBI as a result of being hit by a car. He had no support system except for a teenage daughter. Larry received no services for his injury and slipped in and out of homelessness, became a substance abuser, and was arrested several times. His teenage daughter has been unable to find him any brain injury services.

In some cases, persons with brain injury have had to travel long distances to find services. Advocates and service providers in Harrisonburg told JLARC staff that survivors along the I-81 corridor between Winchester and Lexington often must travel to Charlottesville or Richmond to see medical specialists, relying on family or their case manager for transportation. Likewise, survivors on the Eastern Shore often must travel to Maryland or Virginia Beach for services.

Brain injury survivors and their families have adapted to the shortage of community-based services primarily by relying on informal caregivers. However, these arrangements can adversely impact families. Family members who must provide basic care for loved ones with a brain injury may be limited in their ability to work outside the home, leading to financial difficulties in some cases. Caring for a brain injury survivor can also put family members at risk of clinical depression or anxiety disorders. To alleviate these burdens, some families have sought to place brain injury survivors in long-term care facilities.

Community-Based Providers Report Waiting Lists for Services

Despite the increases in access, only a small percentage of the population with brain injury is being served, and many brain injury survivors still have difficulty accessing services through community-based providers. At least two clubhouse/day programs and two case management programs currently maintain waiting lists for their services. Waiting lists appear most pronounced in urban areas such as Richmond and Northern Virginia. The clubhouse serving the Richmond area reported approximately 20 persons waiting for membership and a wait list of nine months to a year. The primary community-based provider in Northern Virginia has 70 individuals waiting up to a year to access its case management. (Among the four new case management programs, most indicated they would start waiting lists as soon as they reached their maximum case loads.)

Services provided directly by DRS are also in short supply. Currently, ten persons with brain injury are waiting for financial assistance through the Brain Injury Direct Services program, and

four are on a waiting list for personal assistance services. Additionally, the State's disabled population faced waiting lists for DRS-provided case management of 213 in FY 2006 and 150 in FY 2007.

Having to wait for services can have a substantial adverse impact on brain injury survivors. Community-based providers have sought to minimize the impact of service shortages by prioritizing cases on their waiting list. Despite these efforts, brain injury survivors on waiting lists face challenges similar to those facing survivors in underserved communities. These individuals may struggle to maintain their independence in the community, and may be at risk for placement in a long-term care facility. Case managers with one program told JLARC staff that some brain injury survivors on their waiting list developed more serious issues while waiting for services. In other cases, the case manager was no longer able to contact the survivor.

Brain-injured individuals may struggle to maintain their independence in the community, and may be at risk for placement in a long-term care facility.

Lack of Funding Prevents Persons With Brain Injury From Accessing Available Services

A lack of funding also appears to limit access to brain injury services for some individuals. Case management, clubhouse/day programs, and other programs operated by community-based providers are generally free or available for a nominal fee. However, funding can be a problem for medical services such as rehabilitative therapies and neuropsychological exams. Brain injury survivors may have difficulty accessing such services if their insurance policy does not cover them or if the survivor is uninsured. Paying out-of-pocket for services is not possible for most individuals. According to one case manager, a single neuropsychological exam can cost between $700 to $1,200. Residential treatment programs generally charge several hundred dollars per day for services.

It appears that many brain injury survivors who lack adequate funding go without needed services. In other cases, survivors and caregivers rely on charity care to access services. One case manager told JLARC staff she arranged funding for a neuropsychological exam through the local center for independent living.

ADDITIONAL SERVICE NEEDS HAVE BEEN IDENTIFIED BUT ARE NOT PROVIDED

As previously discussed, more than 150,000 Virginians may have serious functional problems related to a traumatic brain injury. The population may require a long recovery time and access to numerous services. However, State resources are limited in meeting the needs of this population, and only about 1,000 persons are

receiving State-funded community-based case management and clubhouse/day programs services.

According to DRS staff, the choice of core services—case management, clubhouse/day programs, and regional resource coordination—represents efforts to fund programs addressing the largest population with the resources available. As part of the town meetings in 2005, information was presented comparing service costs. Some services identified in the state action plan—residential, employment, and transportation—were deemed too costly while serving too small a population. For example, DRS reported at town meetings held subsequent to the identification of the core services that case management for individuals with brain injury costs between $1,500 and $2,100 per person annually, while residential services cost $8,500 per person annually.

Virginia Lacks Intensive Neurobehavioral Treatment Programs

Persons experiencing severe behavioral issues associated with their TBI, such as violence, aggression, irritability, or other problems with self control, have very few service options in Virginia. Only 20 beds in the State are dedicated to treating persons with severe behavioral issues resulting from their brain injury. DRS staff cite addressing these issues as one of the State's most pressing needs.

Typically, persons with neurobehavioral issues require, in addition to the traditional services associated with a brain injury, the following services provided in an all-encompassing, safe environment:

- 24-hour support and supervision
- access to on-site nursing and medical services
- ongoing behavioral analysis and intervention
- neuropsychological and neuropsychiatric services
- medicine management
- behavioral analysis and planning

Without access to such services, persons with severe issues could receive inappropriate treatment or no treatment at all. These individuals may be placed in a skilled nursing facility that serves a general population; however, few such facilities are equipped to treat such behavioral issues, and it appears that many are reluctant to accept these individuals. In some cases, a brain-injured survivor's behavioral issues may lead to physical violence against themselves or others. These circumstances may result in incarceration in a correctional facility or commitment to a mental

health institution, where the person is unlikely to receive needed services. The following case study highlights a TBI survivor whose inability to access assistance for behavioral problems led to her incarceration:

Case Study

"Jane" sustained her traumatic brain injury from a car accident in the early 1960s and currently resides in subsidized housing in the Tidewater area. Her behavioral issues have resulted in verbal altercations with the police and at least five arrests with overnight stays in the local jail. In addition to her behavioral issues, she also has severe deficits in her ability to plan and her short-term memory.

These individuals may also be taken to a hospital emergency room for stabilization and observation; they may then be involuntarily committed to a local licensed hospital. However, a 1999 report prepared by DRS and the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) recommended prohibiting persons with traumatic brain injuries from admission to State hospitals. DMHMRSAS has subsequently established this recommendation in the department's admissions guidelines for such facilities.

Despite this restriction, persons with a primary diagnosis of a mental health illness and a secondary diagnosis of TBI may still be admitted to a State hospital. If sent to a State hospital under such conditions, the person would be treated for a mental health illness, not a traumatic brain injury. Similarly, if someone has a primary diagnosis of mental retardation and a secondary diagnosis of TBI, they could still be admitted to one of the State's mental retardation training centers. As discussed in Chapter 2, as of August 2007, there were 11 individuals with primary mental health illnesses and a secondary TBI diagnosis and three individuals with a primary diagnosis of mental retardation and a secondary diagnosis of TBI in DMHMRSAS-operated State facilities.

The magnitude of the problem is difficult to calculate due to the uniqueness of each injury and the presenting behavior. A recent draft report by the Virginia Brain Injury Council (VBIC) estimates that thousands of Virginians between the ages of 25 and 65 are living with neurobehavioral problems as a result of acquired brain injury. A significant number of these individuals develop severe neurobehavioral problems, and some of these individuals may require intensive treatment.

Access to intensive neurobehavioral treatment is limited by the availability of providers and the high cost of care. Only 20 beds in the State are available to provide this level of neurobehavioral care

as of September 2007. An additional 20 specialized beds were available for TBI survivors at a skilled nursing home; however, the facility has decided to close its TBI neurobehavioral ward in September 2007. This lack of services was acknowledged by another facility's executive officer, who said that the company decided to open a facility in Virginia after observing that the State was one of the most underserved in the country.

Because of the intensive nature and residential component of the service, costs are high. The VBIC draft report estimates that providing 24-hour neurobehavioral treatment with a high support level costs, on average, $470 per day. In addition, the private facilities tend to focus on workers' compensation and legal settlement cases, while avoiding Medicaid patients. DRS staff have said that the department does not have the financial resources to pay for such treatment. The following case study illustrates how the cost of this service may prevent access to those in need of it and the consequences of not receiving it:

Case Study

"Peter" sustained a traumatic brain injury in 2005 as a result of a motorcycle accident. He and his wife live in the Tidewater area. In February of 2007, Peter's wife was unable to find a case manager who could assist her in accessing residential behavioral services for her husband, whom she described as "violent, delusional, and obsessed" with her. Weeks prior he had been committed to a local psychiatric hospital for the third time. DRS and BIAV were unable to help her secure funding for neurobehavioral treatment. A private, in-state facility was also unable to help her because she could not afford their services. In August, a temporary detention order was issued against Peter for assaulting his wife. At the time, he was admitted to a local psychiatric hospital and placed under suicide watch. Peter's wife was informed by adult protective services that if she is unable to bring her husband home, he will be placed in a shelter.

Supportive and Transitional Housing Programs Are Limited

Interviews and survey results point to an unmet need for housing for persons with brain injury in Virginia. Interviews with survivors, caregivers, case managers, and clubhouse/day program staff cited the lack of supportive or transitional housing options as a significant weakness in the continuum of care for Virginia's brain-injured population. (A similar finding was reported by a 1991 Joint Subcommittee reviewing the needs of Virginians with brain and spinal cord injuries.) Of the 15 case managers working with the adult population who responded to the JLARC staff survey, eight identified housing as an unmet need. Additionally, these case

managers reported helping only 32 of their 443 active clients access supportive or transitional housing programs during FY 2007.

Supportive or transitional housing describes a range of housing situations, from 24-hour supervision to group homes or apartments with limited supervision. The VBIC subcommittee report identifies four types of non-institutional care: residential treatment/group homes where someone can receive various levels of care and support, long-term supported living, supported apartments, and home-based services. The most appropriate housing situation for someone with a TBI depends on the individual's level of functionality. Seven residential facilities for brain injury survivors currently operate in Virginia. Recently, one provider accessed funding from the federal Department of Housing and Urban Development and the Commonwealth Neurotrauma Initiative to establish a residential facility for brain and spinal cord injury survivors in the Richmond metropolitan area. Five persons with brain injury and one individual with a spinal cord injury are currently served through this facility. A second facility with the capacity to serve eight brain injury survivors is being developed.

Access to residential housing is limited partly because of cost. Most private insurance plans do not cover long-term care in a residential setting, and congregate living is not a standard benefit under the State's Medicaid program. In addition, residential services are costly—between $250 and $370 per day—depending on the services accessed, according to the VBIC subcommittee report and housing providers. Care provided in these settings is generally less intense than care in an intensive neurobehavioral setting, and therefore, less costly. Care is often funded through workers' compensation benefits, legal settlements, or the patient. DRS staff have cited the lack of residential options as one factor behind the placement of those with brain injury in nursing homes and psychiatric facilities. The need for residential programs has also led to calls in Virginia for a Medicaid waiver to treat individuals living in, or at risk of entering, long-term care facilities.

According to brain injury survivors and advocates, supportive or transitional housing is an important element in the brain injury continuum of care. It can provide individuals with brain injury the level of support they need based on their functionality, and gives them the opportunity to apply the behavioral and cognitive tools learned in therapy in real-world settings. It also involves these individuals with their community, lessening their isolation. Without access to these programs, individuals with brain injury must rely on family or friends to provide informal care. As the following case study highlights, problems associated with finding the right level of care impact caregivers as well:

Case Study

"Arthur" and his family live in the New River Valley. In 2004, while working on the roof of his home, he slipped and fell face first onto a concrete sidewalk. The fall resulted in an open skull fracture, frontal lobe damage, and permanent blindness in one eye. He was hospitalized for two months. His wife visited several nursing homes but decided he would not receive the care he needed and decided to have him discharged home. In order to care for him, she quit her job. Physical therapy services were obtained for him. The first few months at home were very difficult, and after a period of physical and cognitive improvement, he began regressing and having violent episodes. His wife has been advised that he is very low functioning and probably needs 24-hour care in a nursing facility.

Residence in Long-Term Care Facility May Not Be Appropriate for Some Brain Injury Survivors

There are indications that some brain injury survivors placed in long-term care facilities could live in the community with adequate rehabilitative and support services. In interviews with brain injury advocates and service providers, JLARC staff heard of survivors placed in facilities because community-based services were not available.

Long-term residential care may be necessary for brain injury survivors with the most severe impairments. Individuals who remain in a vegetative state, depend on a ventilator, or have severe physical limitations may require intensive supports to meet their basic needs. However, other persons with less severe brain injury impairments may also be vulnerable to placement in nursing homes or other long-term care facilities. Services in the community can be difficult to obtain, and many such persons rely on family to provide informal care. Placement in a facility may become necessary when caregivers have aged or the emotional and financial burden of providing care has become too great.

As previously discussed, placement can also occur when a person with a brain injury has severe behavioral or mental health issues. In other cases, a brain injury survivor may go directly from a hospital rehabilitation unit to a long-term care facility. If these individuals are discharged from hospital rehabilitation units too soon, they may enter a long-term care facility with a greater level of impairment and a greater need for rehabilitative services for their brain injury. However, needed rehabilitative therapies may not be available in the long-term care facilities, which focus on providing long-term support, not short-term rehabilitative care.

Virginia Medicaid Paid for More Than 450 Brain Injury Survivors to Live in Long-Term Care Facilities Between FY 2004 and FY 2006.

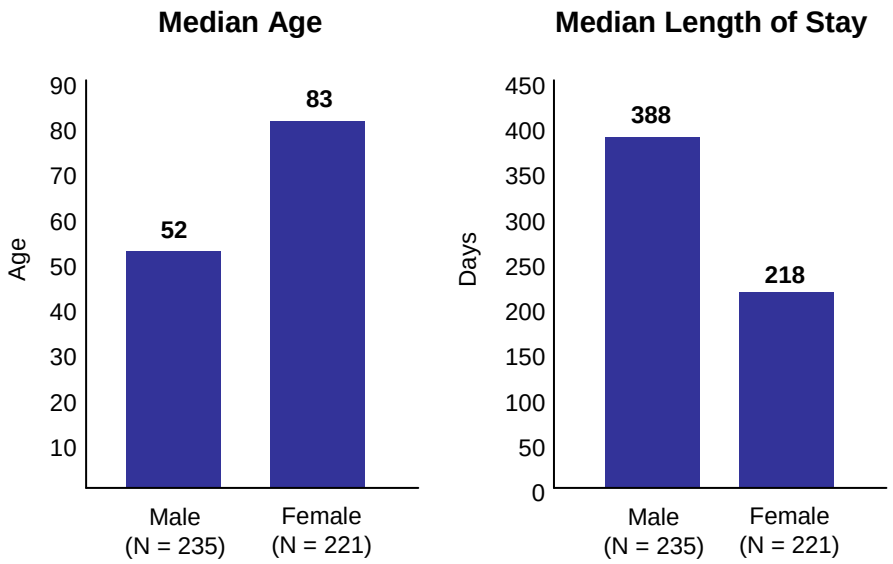
The exact number of brain injury survivors living in long-term care facilities is unknown. Data from DMHMRSAS indicates that 14 brain injury survivors reside in State hospitals and mental retardation training centers as of August 2007. For these individuals, a brain injury has been determined by mental health professionals to be secondary to a mental health diagnosis. Estimates for nursing homes are less precise. During the 2005 General Assembly Session, language in budget amendments to fund a Medicaid brain injury waiver reported that 6,650 persons with brain injury were living in nursing homes. However, this estimate may include individuals with non-traumatic brain injuries resulting from strokes or heart attacks.

A JLARC staff analysis of Medicaid claims data from DMAS identified more than 450 individuals with a traumatic brain injury living in long-term care facilities between FY 2004 and FY 2006. (Approximately 120 additional individuals in long-term care facilities during this period had sustained an anoxic brain injury, which can result from both traumatic and non-traumatic events.) The vast majority of these brain injury survivors—more than 400—spent at least one month in a facility, and approximately half were in a facility 10 months or longer. Most individuals were in skilled nursing or intermediate care facilities; four persons were living in intermediate care facilities for the mentally retarded. The median daily rate paid by DMAS for room and board in these facilities was approximately $102. The data did not permit JLARC staff to determine whether an individual's impairment level required care in a facility or whether living in the community was possible.

Although males and females were almost equally represented, the data suggests that male brain injury survivors in long-term care facilities are younger and stay longer than their female counterparts (Figure 10). The difference in age may reflect findings from the Centers for Disease Control and Prevention (CDC) that TBI rates are generally higher for males at younger ages. Longer stays for males may be driven by their younger ages, or may reflect greater levels of impairment.

The approximately 450 individuals identified by the JLARC analysis are likely a subset of a larger number of brain injury survivors living in long-term care facilities. This estimate does not include those who rely on private insurance or personal resources to pay for nursing home care. In addition, it is likely that an unknown number of individuals also reside in assisted living facilities.

Figure 10: Males With Brain Injury in Long-Term Care Facilities Are Younger and Stay Longer Than Females



Source: Data from the Department of Medical Assistance Services.

Brain Injury Survivors in Long-Term Care Facilities May Not Receive Brain Injury Services. There are indications that persons with brain injuries in long-term care facilities have limited access to State-funded brain injury services and medical therapies. These services could help some brain injury survivors return to the community or, if community reentry is not possible, maximize their independence in a facility. As a result, these individuals may not develop the level of independence that could be attained with greater access to State-funded brain injury services.

One Program Targets Brain Injury Survivors in Nursing Homes

Brain Injury Services, Inc. and INOVA Commonwealth Care Center recently partnered to provide rehabilitative services for brain injury survivors in nursing homes. The goal of the program is to return survivors to the community or increase their independence in the nursing home. Services provided include speech, occupational, and physical therapies, physiatric and psychiatric care, and social services. Funding for the program includes a $150,000 grant from the Commonwealth Neurotrauma Initiative Trust Fund.

Without funding for rehabilitative therapies, survivors in long-term care facilities may not receive services to treat their brain injury. Nursing homes and assisted living facilities have a limited capacity to provide the rehabilitative services that might prepare a person with a brain injury for a return to the community. They may be more accustomed to providing ongoing support for an elderly population than helping younger individuals with brain injuries regain basic living skills. Staff in these facilities may have little or no knowledge of traumatic brain injury, including the behavioral or cognitive problems some survivors experience. High turnover among direct care staff presents an additional problem, requiring persons with brain injury to constantly adjust to new caregivers.

Brain injury service providers do not appear to conduct outreach to nursing homes. While there is no restriction on residents of facili-

ties using State-funded brain injury services in the community, few appear to do so. In the case of clubhouse/day programs, this may reflect functional requirements that likely exclude some severely impaired individuals. For example, clubhouse members must be able to function with minimum supervision and meet their own basic needs. Staff at one clubhouse told JLARC staff more severely impaired individuals require greater supervision and would limit the service capacity of their program.

The impact on persons with brain injury of being placed in a long-term care facility can be substantial. JLARC staff heard anecdotes of individuals who regressed after entering a facility, losing skills they had relearned after their injury. The operator of a residential program for brain injury said some survivors in nursing homes or psychiatric facilities receive medications that address their behavioral problems but exacerbate other effects of a brain injury. An individual with a brain injury in a nursing home may receive limited stimulation and little encouragement to provide for their own needs. Staff with one community-based program conducting outreach to nursing homes described a "learned helplessness" in which brain injury survivors come to expect assistance with tasks they previously performed on their own.

Lack of Cognitive Rehabilitation Therapies Is Frequently Cited

Cognitive rehabilitation therapies (CRTs) include different types of therapies designed to address impairments in memory, planning, organization, and attention that can result from a brain injury. One type of therapy addresses specific cognitive skills such as memory or attention in order to help a person function better at home or in the workplace. A second type focuses on teaching individuals how to perform daily activities such as eating or dressing. CRTs also differ in the extent to which lost skills are taught. *Restorative* therapies employ repetitive tasks, such as computer use, to restore lost cognitive skills. By contrast, *compensatory* therapies help a person compensate for the loss of skills, and generally include cues that remind or guide a person through a task. Cuing strategies may include mnemonic devices, word associations, or assistive technologies such as electronic pagers, personal digital assistants, videotaping, and devices that automatically turn off lights, appliances, or faucets.

Cognitive Rehabilitation Appears To Be Effective, but This Has Not Been Definitively Established. Brain injury survivors and case managers appear to believe CRTs will aid the recovery process. Several survivors told JLARC staff that these therapies could help their memory and make it easier to converse. One survivor credited her two years of CRT with helping her live independently. In a JLARC survey of brain injury case managers, nearly every case

manager with clients receiving CRTs said that these services were effective or somewhat effective.

Some brain injury researchers also believe CRTs are critical to helping survivors regain basic cognitive skills or compensate for permanent impairments. A 2005 review of 87 cognitive rehabilitation studies conducted between 1998 and 2002 concluded that

> [t]here is substantial evidence to support cognitive rehabilitation for people with TBI, including strategy training for mild memory impairment, strategy training for postacute attention deficits, and interventions for functional communication deficits.

However, researchers also recognize that scientific studies demonstrating the effectiveness of CRTs often suffer from methodological limitations. In the 2005 review, researchers noted that it can be difficult to compare results across studies because treatment methods often differ. Moreover, while some studies show cognitive improvements following therapy, few researchers have sought to identify corresponding improvements in a person's ability to function in the community. The review cited the need to "evaluate the effects of cognitive rehabilitation on relevant, functional outcomes."

Health insurers have reached more guarded opinions about the effectiveness of cognitive rehabilitation. One insurer operating in the Commonwealth concluded in a 2006 coverage position paper that CRTs may improve functional outcomes for brain injury survivors, but that the treatment effect may not be strong or more effective than other therapies. The paper added that current research does not permit recommendations for specific interventions or for specific groups of brain injury survivors.

Recent research suggests that compensatory therapies are more likely to benefit brain injury survivors than other therapy approaches. The review of 87 studies published in 2005 found support for compensatory strategies to improve attention, memory, and executive functioning deficits. Effective strategies to improve memory deficits included mnemonic devices and memory notebooks or diaries. In addition, the physician overseeing the rehabilitation unit for the TBI Model System at VCU told JLARC staff that memory notebooks and other compensatory strategies have proven more effective than restorative treatments or repetitive exercises.

Cognitive Rehabilitation Therapies Are Not Available for Most Brain Injury Survivors. Brain injury advocates and clinicians consistently cited the lack of CRTs for persons with brain injury in Virginia.

Advocacy groups have alleged an unwillingness among private insurers to fund treatment for the cognitive impairments resulting from brain injury. Brain injury survivors appear unlikely to receive cognitive therapies following their discharge from the hospital and return to the community. Based on a JLARC survey of brain injury case managers, less than 30 percent of brain injury survivors who received case management services in FY 2007 were able to access CRTs.

There is currently limited State funding for CRTs. DRS does not use brain injury service funds to pay for CRTs, and community-based providers generally do not fund cognitive rehabilitation from accredited neuropsychologists or cognitive therapists. Limited CRTs may be available under the State's Medicaid program. The State plan provides cognitive therapies for individuals in inpatient rehabilitation hospitals. However, services may be terminated if the individual does not show the potential for further improvement, and showing this potential may be difficult for someone with a brain injury. CRTs are also available for brain injury survivors receiving services under the Individual and Family Developmental Disabilities Support waiver.

Some community-based providers offer services similar to cognitive therapies. At least one clubhouse help members learn how to use calendars and other devices to improve their memory. Two of the largest community-based providers in Virginia offer life skills training, in which survivors learn compensatory strategies to improve their social skills, manage their finances, and complete other daily tasks. These programs rely in large part on State funding. However, services from community-based providers may not be provided by accredited neuropsychologists or cognitive therapists.

Virginia's Olmstead Task Force

In 1999, the U.S. Supreme Court ruled in *Olmstead v. L.C. and E. W.* that states must provide community-based services for persons with mental disabilities in certain circumstances. Under legislation passed by the 2002 General Assembly, the Olmstead Task Force was convened by the Secretary of Health and Human Resources to implement the recommendations of the *Olmstead* decision. The task force included representatives of State agencies, private stakeholders, and consumers.

Lack of Transportation Prevents Persons With Brain Injury From Accessing Services

The physical and cognitive impairments resulting from traumatic brain injury often limit the ability of survivors to drive or access public transportation. As a result, transportation assistance can be critical to help survivors living in the community access community-based services and remain active. Virginia's Olmstead Task Force concluded in 2003 that "transportation is basic in the integration into and survival in community living for individuals with disabilities. . .". The State's Brain Injury Action Plan also identifies transportation as a priority, calling for the development of statewide options that might include voucher systems, county services, and private companies. The following case studies illustrate the importance of access to transportation services for TBI survivors and their families:

Case Studies

"Ted" sustained his TBI while working as a security guard. He is receiving some worker's compensation benefits but his therapies have been discontinued. According to his case manager, to enable his wife to work, Ted needs access to supervision, and he is a good candidate for a clubhouse. However, he lives in Northern Virginia and has no access to transportation to get him to the clubhouse. As a result, he is unable to access the service and his wife is unable to work.

* * *

"Russell" sustained a TBI as the result of an assault. He has transportation through Metro Access in Northern Virginia. Metro Access provides for shared-ride, curb-to-curb paratransit for persons with disabilities. He obtained a job coach through DRS and because of his access to transportation, works two part-time jobs. He has also lived independently for the past year.

Adequate transportation appears to be a concern for brain injury survivors in both rural and urban parts of the State. In rural communities, limited transportation may severely limit access to community-based services and contribute to a sense of isolation among survivors and caregivers. Persons with brain injuries in rural areas often live far from clubhouse/day programs or rehabilitative therapists. In many cases, public transportation is unavailable or impractical. Members of clubhouses in Roanoke and Charlottesville said local transportation services can be difficult to use and often do not serve the surrounding counties. When these services are available, individuals may spend several hours traveling from their home to a clubhouse.

Transportation may also be problematic in urban areas. Services from cities and counties are often not coordinated, making it difficult for some brain injury survivors to travel relatively short distances. In other cases, a transportation system may not serve an entire metropolitan region. For example, the Community Assisted Ride Enterprise program operated by Greater Richmond Transit Company, the public transit system, serves the City of Richmond and Henrico County, but only certain parts of Chesterfield County and none of Hanover County.

ACCESS TO REHABILITATIVE SERVICES VARIES BY NON-PUBLIC FUNDING SOURCE

Many Virginians rely on private health insurance to pay for the costs of their acute and rehabilitative medical care. In general, health insurance covers most TBI survivors' acute care needs, but

fewer long-term rehabilitative services. In certain circumstances, costs for health care and rehabilitative services may be provided by other sources, such as legal settlements or workers compensation.

Health Insurance Often Does Not Provide for the Long-Term Rehabilitative Needs of Brain Injury Survivors

According to medical doctors, neuropsychologists, and case managers interviewed for this review, insurance providers cover only limited services for persons with brain injuries. Private health insurance appears to offer adequate coverage for emergency and acute medical services needed after a traumatic brain injury. However, concerns exist that the length of hospital stays has been reduced and rehabilitative therapies, such as occupational, physical, and speech, are terminated prematurely for someone with a brain injury under current private health insurance plans. Also, a number of medical doctors, neuropsychologists, and case managers reported that cognitive therapy, residential, and community-based services are not covered at all.

Table 7 illustrates the reduction in average stay in acute and post-acute rehabilitative care for individuals with brain injury since 1996. According to national data, TBI survivors discharged to a post-acute rehabilitation center spent an average of 26 days in acute care and another 28 days in post-acute rehabilitation in 1996. By 2006, length of stay was reduced by almost 30 percent to 20 days in the acute facility and 18 days in the rehabilitation center. In 2006, brain injury patients at Virginia Commonwealth University (VCU) Medical Center spent an average of 13 days in acute care before being admitted to the hospital's rehabilitation center. Limits placed on the length of stay by private insurers have reduced the average stay in VCU Medical Center's post-acute rehabilitation center to 19 days, according to the center's director. More

Table 7: Length of Stay in Rehabilitation Facilities Is Reduced for Persons With Brain Injury

	Average Length of Stay (Days)	
Calendar Year	Acute Care	Post-Acute
1996	26	28
2001	22	22
2006	20	18

Note: Information is for those individuals with brain injury admitted to post-acute rehabilitation facilities. 2006 data comprise 15,600 traumatic brain injury patients.

Source: Data provided by VCU TBI Model System staff as calculated from the Uniform Data System for Medical Rehabilitation.

than 70 percent of those treated in VCU's rehabilitation center were discharged home, not to a sub-acute rehabilitation center or nursing home.

Insurance policies generally will cover rehabilitative services as long as the services are considered "medically necessary." Insurance plans also limit the number of times a service can be obtained and the duration of the service. For someone with a brain injury, these limits can be problematic. First, problems arising from a brain injury include memory, information processing, and behavior—cognitive and emotional problems, not medical problems. Second, some brain injuries result in a lifelong need for services in order to maintain functionality. However, limits on the number of times a service can be accessed fail to recognize the lifelong need. For ex-ample, limiting the number of speech therapy sessions can have adverse effects on the rehabilitation of a person with a brain injury because improved communication helps with social interaction, and practicing communication skills also helps improve cognitive functioning.

JLARC staff reviewed the health plan available to State employees to identify the benefits available to someone who sustains a brain injury. The State's employee health plan is considered to provide more benefits than most private health insurance plans. According to staff at the Department of Human Resource Management, the majority of medical, acute services needed immediately after sustaining a traumatic brain injury are covered. However, it becomes more difficult to receive coverage for services as the treatment needs move away from acute care. Coverage may be limited, conditional, or not available. For example, the number of physical therapy visits per year is limited and prior authorization is required; and cognitive therapy is not covered because this service is considered educational. Also, case management is the only community-based service provided by the State's plan.

Six members of the Virginia Association of Health Plans responded to a series of questions about the extent to which their plans covered certain brain injury services. Speech, occupational, and physical therapies are provided under these plans, and the number of times the service can be accessed is different under each plan. Case management is typically provided. Skilled nursing is also available with the number of visits limited. A limited number of cognitive rehabilitation visits are also available under these plans. However, therapies or services that are deemed long-term care but which might be beneficial to someone with a TBI are not covered, including personal assistance care and life skills services.

Non-Public Funding Sources May Provide for Long-Term Care

In addition to private health insurance, brain injury services may be accessed through other non-public funding. Such sources include workers' compensation, no-fault automobile insurance, legal settlements, and long-term care insurance. Workers' compensation benefits are designed to ensure that employees who are injured or disabled on the job are provided with medical care, rehabilitative services, and monetary compensation, while eliminating the need for litigation. Because these programs focus on returning the injured person to work or a higher level of independence, they may be more likely to provide for longer, more intensive treatment periods.

No-fault automobile insurance plans (available in states such as Michigan and New Jersey) pay for medical care, wage loss, and property damage, regardless of who caused the accident. When legal action is taken, a brain injury survivor may obtain a legal settlement, which can be used to pay for brain injury services. An individual can purchase long-term care insurance, which can pay for long-term services such as assisted living services and respite care. Nonetheless, it is important to recognize that these non-public funding sources are not available to the majority of individuals with brain injury. The availability of such funding sources is dependent on the circumstances in which the brain injury occurs and whether the individual has private insurance.

RETURNING VETERANS WITH TRAUMATIC BRAIN INJURY MAY IMPOSE ADDITIONAL DEMAND ON STATE-FUNDED SERVICES

Traumatic brain injury is considered the signature wound of the wars in Iraq and Afghanistan.

Access to State-funded services for brain injuries may be more difficult if veterans of the wars in Afghanistan and Iraq begin to seek community-based rehabilitative services. Traumatic brain injury is considered the signature wound for veterans of these conflicts. The federal Department of Veterans Affairs (VA) estimates that about 1,800 troops have sustained TBIs, but other estimates are much higher, with some sources estimating that more than half of the combat casualties in these theaters have associated head injuries. Between January 2003 and February 2005, 59 percent of the patients admitted to the Walter Reed Army Medical Center who had been exposed to an explosion were diagnosed with a TBI.

Currently, injured active and inactive military personnel receive acute and post-acute medical and rehabilitative care in several federal settings. The Department of Defense has established eight Defense and Veteran Brain Injury Center (DVBIC) sites to serve active duty service members and veterans with traumatic brain injury through state-of-the-art medical care, innovative clinical research initiatives, and educational programs. Three of the eight

DVBIC sites are located in or close to Virginia, including the Polytrauma Center in the Hunter Holmes McGuire Medical Center in Richmond; the Walter Reed Army Medical Center in Washington, D.C.; and Lakeview Virginia Neurocare (a private rehabilitation facility) in Charlottesville. Retired service members that have been diagnosed with a TBI can also receive medical care through approximately 1,260 VA sites nationwide, including medical centers, hospitals, long-term healthcare facilities, and outpatient clinics. A number of VA healthcare facilities are located in Virginia, including Richmond, Hampton, and Salem. There are also eight outpatient clinics in the Commonwealth.

The federal government is in the process of examining this system of care to address services for brain injury survivors. A Presidential commission has reviewed the care wounded troops receive after they return from combat and offered recommendations for improving the system. Additionally, the U.S. Senate and House of Representatives have both considered proposals to improve veterans' care which would improve the screening process for TBI and require the development of community re-integration plans for wounded troops. Moreover, changes requiring the VA to directly contract with community-based brain injury service providers are also being considered. While funding may bypass the states under this proposal, state licensing agencies could be affected if there is an increase in service provider applications and oversight activities.

The VBIC has expressed serious concern regarding the potential impact of returning veterans on the State's brain injury services. If federal programs do not provide needed services, veterans may access State-administered or contracted services. In addition, active duty personnel may access State services to avoid being labeled as brain-injured. A neuropsychologist stated that active military personnel will seek mental health assistance from sources other than those associated with the VA to avoid labeling. The General Assembly provided an organization in Northern Virginia with $75,000 in non-State agency funding for both FY 2007 and FY 2008 to assist returning veterans with TBI re-integrate with their communities.

Staff at the Virginia Department of Military Affairs indicate that Virginia National Guard service members injured while serving in federal combat would receive service-related healthcare through the VA system. However, some states are not relying on federal action. Citing the federal government's delay in implementing legislation to care for wounded veterans, the State of Illinois announced in June of 2007 that it would begin screening the state's National Guard members for TBIs after they return from Iraq or Afghanistan.

According to Virginia Department of Veterans Services staff, the department has not initiated any specific planning or programming beyond what is already being done to deal with this population. As part of its mission, the department operates 22 benefit services offices where representatives assist veterans and their family members in filing claims for federal veterans benefits. The department may want to consider coordinating with DRS and all other State agencies that may have a role in assisting and providing future services to the State's veterans with brain injury.

Recommendation (1). The Departments of Rehabilitative Services; Veterans Services; Mental Health, Mental Retardation and Substance Abuse Services; and other State entities that could have future responsibility for providing care to the State's returning military service members should develop a plan by July 1, 2008, to address coordination and access to brain injury services by active and retired military personnel.

Chapter 4

Population With Brain Injury Appears to Benefit From State-Funded Services

In Summary

Measuring the effectiveness of State-funded brain injury services is challenging due to the difficulty in controlling for the effect of other services or supports the person may be receiving. While effectiveness may be difficult to evaluate, some DRS-administered services appear to be beneficial. Case management appears to help individuals with brain injury remain in the community, and clubhouse/day programs provide survivors with meaningful opportunities to work on social and vocational skills. Regional resource coordination appears to be meeting its contractual responsibilities, but it is difficult to measure the extent to which public awareness regarding brain injury has improved overall and service availability has increased. Post-injury employment participation rates are also difficult to evaluate. The severity of the injury, pre-injury employment and educational status, and age at injury appear to relate to vocational success. While State-funded programs are meeting contract deliverables, DRS needs to increase its efforts to evaluate program effectiveness.

JLARC staff were directed to evaluate the extent to which State-funded brain injury services are meeting the needs of Virginia's brain injury survivors. State funding for assisting the population with brain injury in accessing local services and returning to work has increased by more than $2.5 million since 2001. As discussed in Chapter 3, despite this increase, unmet needs exist and resource limitations prevent the State from addressing each of those needs. DRS and advocates for people with brain injury have chosen to prioritize support for community-based services that assist the greatest number of persons, not necessarily those persons in greatest need. Measuring the effectiveness of individual services is difficult because each injury is unique and it is difficult to isolate the effects of the service from other events in the person's life.

BRAIN INJURY SURVIVORS APPEAR TO BENEFIT FROM CASE MANAGEMENT AND CLUBHOUSE/DAY PROGRAMS

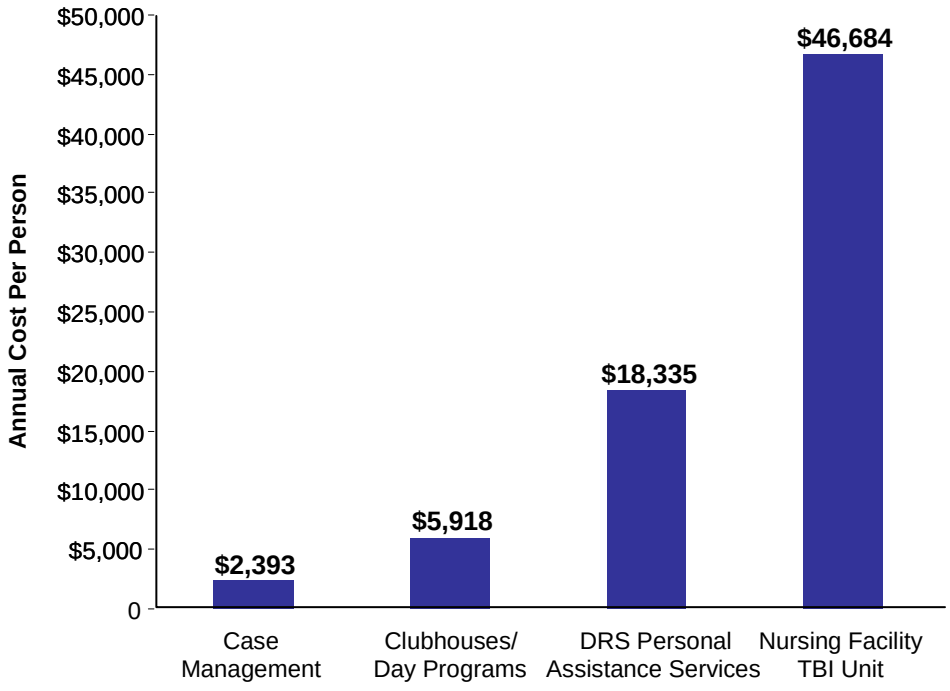
DRS invests 84 percent of State funding for community-based brain injury services in six case management and seven clubhouse/day programs. Brain injury survivors credit their case managers with assisting them with accessing services, while those without case managers indicate a need for assistance in navigating a complicated service system. Members of Virginia's clubhouse/day programs also report high satisfaction with the benefits they receive from attending. Assessments conducted in the late 1990s and in 2005 indicate a need for assistance with accessing services and

programs that promote social and vocational skills. Academic studies in these areas have found it difficult to quantify success because of the number of factors contributing to someone's improvement or lack thereof.

Case Management and Clubhouse/Day Programs Cost Substantially Less than Other Brain Injury Services

As discussed in Chapter 2, the desire to serve the most people with the funding available played a key role in DRS' decision-making process about what services to offer. Because the cost of case management or clubhouse/day programs is substantially lower than certain other brain injury services, more people can be served. Figure 11 compares the annual per capita costs of case management and clubhouse/day programs with other services for brain injury survivors. Data from the two largest case management providers indicates the average annual cost of case management services was approximately $2,400 per person in FY 2007. Data from

Figure 11: Case Managers and Clubhouse/Day Programs Cost Substantially Less Than Other Brain Injury Services in FY 2007



[a] Represents an average of the annual per capita costs for the two largest case management programs in Virginia.

[b] Represents an average of the annual per capita costs for the seven clubhouse/day programs operating in FY 2007.

Source: Data from DRS, DMAS, and State-funded brain injury service providers.

the seven clubhouse/day programs operating in FY 2007 indicate an average annual operating cost of $5,900 per person. By contrast, the annual cost of care in a nursing facility with a dedicated TBI unit was more than $46,000 per person.

Several factors can impact the operating costs of case management and clubhouse/day programs. The cost of case management can depend on caseloads and whether additional services, such as transportation or basic skills training, are provided. Clubhouse/day programs serving more severely impaired individuals may require additional staff, resulting in higher operating costs. Clubhouse/day programs may be able to reduce costs by operating programs jointly or developing relationships with other social service providers. Costs associated with personal assistance care and residential treatment are much higher on an annual basis due to the one-on-one nature of these services and the residential component. DRS is also able to cap State spending on case management and clubhouse/day programs by contracting for these services.

Case Management Appears to Help Brain Injury Survivors Remain in the Community

Traumatic brain injury survivors may require a wide array of services to meet their medical, neuropsychological, residential, vocational, social, transportation, and other needs. However, due to the cognitive deficits caused by a brain injury, most survivors have difficulty assessing their needs and developing a plan for obtaining these services. Moreover, the impact of a brain injury can be subtle, and survivors and caregivers may not recognize the need for services or know where to find them. To address these challenges, DRS has allocated more than half its brain injury funding to assist survivors with navigating federal, State, and local systems of care. Analysis of the State-funded case management programs suggests persons with brain injury are benefiting from case management.

State-Contracted Case Managers Assist More Than 700 Persons With Access to Brain Injury Services. DRS currently contracts with six community-based providers to offer case management. Two providers have been operating for several years, while four began operations within the last year. Currently, 25 case managers serve persons with brain injury through these providers. Caseloads with private case managers range from 25 to 35 clients, with some case managers providing more limited assistance to an additional five to ten individuals. Results from a JLARC survey of State-funded private case managers indicate a ratio of one case manager for every 22 clients with brain injury served. State-contracted case managers provide services to both adult and pediatric clients, but adults constitute the majority of cases.

DRS directly provides case management services to people with severe physical and sensory disabilities, including about 100 persons with brain injury. The Community Rehabilitation Case Management Services (CRCMS) unit operates with nine case managers organized throughout the State. However, positions in Fairfax, Christiansburg, and Hampton are currently vacant, and cases in these regions have been reallocated among the remaining six case managers and the program director. Caseloads range from 35 to 50 clients per manager. CRCMS also provides support coordination services to recipients of Virginia's Individual and Family Developmental Disabilities Support Medicaid waiver.

Brain injury survivors and caregivers indicate that case managers perform four important services:

- providing information about brain injury and the recovery process,
- identifying the rehabilitative and support needs of a brain injury survivor,
- helping to establish goals for rehabilitation, and
- arranging access to rehabilitative and support services in the community.

Case managers meet individually with their clients, typically in the client's home, as well as with caregivers and family if possible, to assess their needs and goals. This information is incorporated into an individual service plan that outlines the individual's (and sometimes the caregiver's) goals, service needs, and the assistance to be provided. The case manager then arranges and coordinates access to brain injury services. Regular contact with the client is maintained, either by phone or in the home of the client.

Limited Evidence Makes It Difficult to Measure Effectiveness. Little evidence is currently available regarding the effectiveness of case management services for brain injury survivors. However, the two longest serving case management programs continue to meet the goals identified in their contracts. For example, in FY 2007, one provider's pediatric program exceeded the number of children it is required to serve and the percentage of individuals' personal goals that must be achieved. The program also achieved accreditation through the Commission on Accreditation of Rehabilitation Facilities for Medical Case Management. The other provider served almost twice as many people as required by the contract. Moreover, annual program audits conducted by Fairfax County of the Northern Virginia program have consistently noted the provider's compliance with the contract.

Available Evidence Suggests Survivors Benefit from Case Management. There is little systematic oversight of case management services, making it difficult to measure effectiveness. However, the available evidence suggests that brain injury survivors are benefiting from State-funded case management programs. The value of case management has been noted by academic researchers and program evaluators. A National Institutes of Health (NIH) Consensus Development Conference on traumatic brain injury in 1998 recommended "case manager programs…to help [persons with brain injury] navigate through the public assistance and medical-rehabilitative care systems." That same year, the Government Accountability Office noted in a review of state traumatic brain injury programs that those most likely to have difficulty accessing services included "individuals without an effective advocate to negotiate the social service system." A 2006 review of the federal TBI Act by the National Academy of Sciences came to a similar conclusion, noting that case management can help survivors and caregivers "navigate through the myriad service systems they require."

In addition to these studies, interviews with brain injury survivors and their caregivers provided examples of how case management has benefited consumers. Case managers spend a substantial percentage of their time helping persons with brain injury access needed services. Often this involves helping brain injury survivors apply for Supplemental Security Income, Medicaid, or other benefits and advocating on their behalf as eligibility is determined. The following case study illustrates how one provider helped a brain injury survivor locate needed services:

> ***Case Study***
> *"Andrew" suffered a brain injury in a motor vehicle accident in his early 20s. Although the accident occurred nearly 30 years ago, his brain injury continues to have a significant impact on his life. He has limited concentration, memory, and organizational skills, and struggles to maintain appropriate social boundaries. He was living with his mother, but became homeless when she was hospitalized for an illness. His case manager helped Andrew apply for and receive assistance from the local housing authority. Today, Andrew lives independently in a subsidized apartment complex.*

Case managers have also arranged free services for individuals who lack the funds to pay for care. As the following case study shows, these services are often funded by the organization providing case management:

> ***Case Study***
> *"Sarah" suffered a brain injury in her early 20s when her car collided with a tractor trailer. Several years later, she*

lives with her fiancé while her five-year-old daughter stays with her parents. Sarah suffers from physical pain, anxiety, depression, memory loss, speech problems, and poor organizational skills. She has been unable to work since the accident and has no health insurance. Her case management organization assisted her with an application for charity medical care, and is providing her free transportation to and from medical appointments. To help improve her memory and organizational skills, the organization paid for a personal digital assistant, worth $250, and trained her on its use.

At other times, case managers have assumed a more active role in the daily lives of their clients. Case managers with a new provider told JLARC staff they often function like "substitute mothers," checking on clients, providing basic assistance, and accompanying clients to doctor appointments to take notes for caregivers. However, this level of assistance may not be feasible when caseloads are high or include severely disabled individuals. Staff with this provider said their caseloads are currently below capacity, and this level of assistance will not be possible when caseloads expand.

Brain injury survivors are likely to have difficulty accessing services when assistance from a case manager is not available. This may be because few survivors or caregivers are familiar with the federal, State, and local programs available to them. During town hall meetings conducted by DRS in 2005, brain injury survivors and caregivers from regions without adequate case management services expressed a lack of awareness of the services potentially available in their communities.

JLARC staff heard many positive accounts of case management services during interviews with brain injury survivors and caregivers. One survivor credited her case manager with introducing her to local service providers and inspiring her to improve. She now participates in a clubhouse program, receives life skills training, and has developed relationships with other persons with brain injury. The following account is from a survivor, who worked in a professional setting prior to her injury:

> Recovery from brain injury requires so many different doctors and services at a time when people are exhausted and fatigued and in shock. Case management helps do what the patient or family cannot do. The sheer number of providers that I or others with brain injury need for recovery is huge. I alone have worked [with] a neurologist, an ear, nose, and throat doctor, a physiatrist, an occupational therapist, a physical therapist, a speech and language therapist, a chiropractor, a developmental optometrist, and four rehabilita-

tion hospitals and have received countless medical tests. Case management helps untangle a complex medical system and can help the survivor and their family negotiate this system and find appropriate care.

Several Factors May Limit the Effectiveness of Case Management for Persons With Brain Injury. Case management services for brain injury survivors may be less effective under certain circumstances. Caseloads can have a substantial impact on the effectiveness of case management. Larger caseloads, or caseloads that include more severely impaired survivors, can limit the time a case manager has to work with each client. The CRCMS program administrator said those with neurobehavioral problems can be particularly time-consuming for DRS case managers.

Case management can also be less effective if important needs of a brain injury survivor have not been met. According to staff with community-based providers, survivors are less likely to benefit from case management services if they have chemical dependency issues, lack a support network of friends and family, or do not receive adequate medical treatment for their brain injury.

Finally, in regions where few community-based services are available, case managers are likely to experience difficulty connecting survivors with needed services. Case management positions can be difficult to fill in regions that lack a network of community-based services for brain injury survivors. DRS staff cited this factor in explaining the difficulty filling case management positions in some urban areas.

Academic studies have difficulty quantifying the effectiveness of case management services. Improvements in a persons with brain injury may have several causes. For example, brain injury survivors may receive assistance from caregivers and others. In addition, there appears to be little agreement on what constitutes a successful outcome. A 1999 review of studies evaluating the effectiveness of case management programs for individuals with TBIs noted that researchers often used different outcome measures, including employment outcomes, level of independence, quality of life, and level of family burden. That review could not find clear evidence that case management was effective or ineffective, in part because outcome measures differed and studies could not be meaningfully compared.

Clubhouse/Day Programs Appear to Meet Some Needs of Brain Injury Survivors and Caregivers

A subset of brain injury survivors have severe physical, cognitive, and behavioral impairments that limit their ability to work and

participate in the community. Survivors who live with family can become increasingly isolated and place substantial burdens on informal caregivers. To meet these needs, DRS funds clubhouse/day programs to provide brain injury survivors with meaningful activities in a therapeutic environment. Six clubhouses and two day programs currently serve persons with brain injury in Virginia. Seven of these eight programs received funding from DRS in FY 2007. In practice, clubhouses benefit survivors and caregivers by teaching pre-vocational skills, promoting involvement in the community, and providing respite care. Day programs focus on providing participants with meaningful activities. Such programs do not provide the work-ordered day environment found in clubhouses.

The clubhouse/day support model is used to treat individuals with a wide variety of disabilities, not just brain injury, including individuals with mental retardation and mental illness. The clubhouse model was originally designed to serve individuals with schizophrenia after their discharge from psychiatric hospitals. In addition, the State currently funds day support programs through the Medicaid Individual and Family Developmental Disabilities Support, Mental Retardation, and Day Support waivers.

Clubhouses and Day Programs Use a Consistent Therapeutic Approach. Clubhouses are intended to provide opportunities for brain injury survivors to develop social, work-related, and independent living skills. Programs are based on the basic work-related activities, also known as a work-ordered day, to structure their activities. Members are expected to arrive at a certain time every morning. They work with program staff to operate the clubhouse, and each person is responsible for assigned tasks such as preparing meals, cleaning the facility, ordering supplies, or publishing a regular newsletter. Membership is lifelong and voluntary, though adhering to an attendance schedule is encouraged. Members are generally responsible for their transportation to and from the clubhouse.

Clubhouse programs offer brain injury survivors a variety of structured activities in a typical day, including

- work periods when members can complete their assigned work tasks;
- member-run meetings to receive updates on clubhouse activities, plan upcoming events, and review program rules;
- opportunities to practice proper behavioral interaction with clubhouse staff and other members; and
- volunteer activities in the community.

Brain injury clubhouses generally provide between six and seven hours of structured activities per day. Providers emphasized that brain injury survivors can become easily fatigued, and some members may not be able to attend a full day. Exhibit 1 shows the daily schedule for one clubhouse receiving State funding. Activities are supervised by clubhouse staff, but members play an active role in organizing activities.

In addition to structured activities, clubhouses may provide other services for brain injury survivors. Clubhouse staff become familiar with the needs of members and generally provide limited case management services such as assessing the needs of members, helping them identify goals for improvement, and assisting with applications for public assistance programs. Staff at one clubhouse occasionally check on members to make sure they have taken their medications, remembered an appointment, or arrived home safely. Staff have also provided transportation to and from clubhouse events when members could not arrange their own.

The 1998 NIH Consensus Development Conference recommended the use of clubhouses to help survivors improve their social skills. The authors of a 2007 textbook for brain injury clinicians noted that clubhouses have been a "cost-effective method to promote practical, functional living skills." Virginia has the greatest number of brain injury clubhouses currently operating in the United States. Clubhouses in other states also rely on public funding to serve individuals with brain injury. For example, clubhouses in New Jersey provide cognitive rehabilitation and pre-vocational skills.

Virginia has the greatest number of brain injury clubhouses currently operating in the United States.

The two DRS-funded day programs provide services to persons with brain injury but do not use the work-ordered day structure. Funding was first provided in FY 1999 for a day program in Virginia Beach; that funding was increased in 2001 for a second day program on the Eastern Shore. The day programs do not have an employment focus but provide structured activities in a therapeutic environment for the brain injury survivor and respite care for

Exhibit 1: Typical Clubhouse Schedule

9:00-9:15 AM	Arrive at the clubhouse and socialize with peers and staff.
9:15-9:45 AM	Lead a house meeting for updates on current and upcoming events.
9:45-10:00 AM	Break into small groups to discuss the day's assigned tasks.
10:00-12:00 PM	Work on the daily assigned tasks.
12:00-1:00 PM	Eat lunch.
1:00-3:00 PM	Work on the daily assigned tasks.
3:00-3:30 PM	Socialize with peers and staff.

Source: Clubhouse schedule provided by Community Futures Foundation.

the caregiver. The Virginia Beach day program operates in concert with a sheltered workshop and is able to transition individuals from the day program to the workshop at a member's request.

Available Evidence Suggests Members Benefit from Clubhouse Programs. Although the impact of clubhouse programs on employment success is difficult to measure, evidence from DRS oversight efforts and survey feedback from case managers suggests members are benefiting. Clubhouse programs provide a therapeutic environment for survivors to develop the pre-vocational skills necessary to be successful in the workforce, such as punctuality, interacting with co-workers, and completing tasks. However, few studies document vocational placement as a result of attending a clubhouse/day program.

Clubhouses appear to enjoy broad support as a service for brain injury survivors. According to a JLARC survey of brain injury case managers, nine of 12 case managers who reported having clients in clubhouses rated these programs as effective. In addition, survivors and caregivers interviewed by JLARC staff consistently highlighted three benefits of clubhouse programs: (1) foundation building for entering the workforce, (2) community involvement, and (3) respite for the caregiver. Survivors said that clubhouses help them regain work-related skills and return to employment. One brain injury survivor said clubhouse staff have helped him set vocational goals. He is trying to improve his computer skills, and is responsible for typing the minutes from clubhouse meetings. Staff are also helping him find a volunteer opportunity to further improve his work skills.

In practice, clubhouses appear to be a beneficial method for teaching persons with brain injury pre-vocational skills needed to enter the workplace or a vocational training program. Brain injury survivors with severe impairments often have cognitive and behavioral problems that make it difficult to function in employment or training settings. Program operators and brain injury clinicians emphasized that clubhouses provide structured, supportive environments where brain injury survivors can learn to function productively, improve their social skills, and eliminate behaviors that are not appropriate for the workplace. These pre-vocational skills are necessary if an individual with a brain injury is to complete a vocational training program or maintain paid employment.

As the following case study illustrates, clubhouses address the need for pre-vocational skills partly by providing a setting in which persons with brain injury can work on reducing problematic behaviors:

Case Study

"Mark" suffered a traumatic brain injury as a child. He is now in his 40s, lives at home with his parents, and attends a clubhouse three to four times per week. Mark has struggled to manage his anger since his injury, and often responds to stressful situations by yelling and injuring himself. It can take clubhouse staff up to an hour to calm Mark down when he loses his temper. Staff recognize this behavior will make it difficult to maintain employment or complete a vocational rehabilitation program. They are trying to help him recognize when he is becoming angry and guide him away from the situation causing his behavior or talk with him. Although Mark continues to have angry outbursts, they have become easier to contain since clubhouse staff began working with him.

A VCU Program Provides Job Training In Clubhouses

A program being developed by the TBI Model System at VCU will use clubhouses to improve brain injury survivors work-related skills. The curriculum will focus on skills such as developing a resume and interviewing with a prospective employer. The program was recently piloted at two clubhouses, and staff with the VCU Model System hope to make this training available to clubhouses throughout the State by 2009.

Clubhouses appear to be more accessible for persons who are moderately to severely impaired as a result of their injury than more traditional vocational programs. For example, although the State's Woodrow Wilson Rehabilitation Center works with individuals of varying levels of functional impairment (mild to severe), individuals who can learn and generalize pre-vocational/vocational, cognitive, and independent living skills are likely to be the best and most successful participants in the day and residential programs. WWRC services are typically not appropriate for individuals with severe cognitive, emotional, or behavioral impairments who would have difficulty learning skills in a transitional center and transferring those skills to community settings. By contrast, membership in a clubhouse is lifelong, allowing time to address serious impairments. Clubhouse programs have less restrictive eligibility guidelines, requiring only that persons with brain injury can manage daily activities such as toileting or eating, and do not present a threat to self or others. According to a neuropsychologist with the TBI Model System at Virginia Commonwealth University (VCU), clubhouses are a good option for individuals whose impairments prevent an immediate return to work.

Brain injury survivors and caregivers emphasized the value of clubhouses in keeping survivors involved in the community. One survivor said involvement with a clubhouse has helped her develop relationships with other survivors. She added that cognitive problems make it difficult for her to interact with those who do not have an injury. A caregiver said the local clubhouse has been "life-altering" for her sister who sustained a brain injury, as it has provided her with friends, work, and a "real life."

For some brain injury survivors, membership in a clubhouse may prevent social isolation by helping survivors develop relationships with others. Clubhouse operators and advocates acknowledge that

the most severely impaired members of clubhouses may never be able to maintain paid employment. Without access to clubhouses, these individuals may remain at home, engaged in little productive activity. The following case study demonstrates the social isolation persons with a brain injury can experience when not accessing services.

Case Study

"Roger" suffered a severe brain injury 17 years ago at the age of 19. The injury left him with impaired vision and limited movement on his right side. Roger has struggled with substance abuse problems, and has twice been convicted of driving under the influence. He received vocational rehabilitation through the Woodrow Wilson Rehabilitation Center, but has not been able to maintain steady employment. He currently lives at home in a region of the State that has few community-based services. Without friends or a job, Roger generally sits at home during the day. His mother believes he could be a good member of society with the right help, but worries that it is becoming increasingly difficult to get him involved with family and the community.

Finally, caregivers cited the benefit of clubhouses as a source of respite. Many brain injury survivors live at home and rely on family for basic supports. Caring for a survivor can take an enormous toll on a family. Researchers have found significant levels of stress among families caring for a brain injury survivor. Financial difficulties can result when a caregiver is no longer able to work outside the home. Clubhouses help to alleviate these burdens by providing respite and assistance for caregivers. In some situations, a clubhouse program has enabled a person with a brain injury to spend up to 30 hours per week outside the home. Spouses, parents, and other caregivers can use this time to work or meet other family needs. Clubhouse staff have also been available to help after hours. A caregiver told JLARC staff his son who has a brain injury suffers from seizures, and clubhouse staff are available any time to help.

Effectiveness of Clubhouses Is Limited in Two Ways. Brain injury researchers and advocates have expressed two primary concerns regarding clubhouses for brain injury survivors. First, it has been noted that some members of clubhouses stop progressing toward a higher level of independence. While a clubhouse may continue to provide respite care and social activities for these individuals, it no longer serves a rehabilitative function. One explanation may be that clubhouses are not designed to provide a high level of rehabilitative services. A brain injury clinician told JLARC staff that clubhouses can provide lower cost supervision and respite care, but cannot substitute for medical rehabilitation from trained thera-

pists. Without services such as speech or cognitive rehabilitation, some persons with brain injury will not develop the skills needed to live independently and return to work.

A second concern with the clubhouse approach is that brain injury survivors will struggle to apply skills learned in the clubhouse to real-world environments such as the home or workplace. A researcher in the vocational rehabilitation field told JLARC staff there is little evidence that survivors attending clubhouses can make this transition. To date, no scientific studies have examined the effectiveness of clubhouses in helping brain injury survivors return to work or live more independently in the community. Persons with brain injury interviewed by JLARC staff also noted that transferring skills from one environment to another can be difficult.

EFFECTIVENESS OF REGIONAL RESOURCE COORDINATION IS UNCERTAIN

Because TBIs involve cognitive functions, such as processing information and short-term memory, the needs of brain injury survivors often go unnoticed. Public education and awareness of the issue are important for helping survivors access services. The federal government recognizes this need in the TBI Act grant program by funding State efforts to improve understanding and develop services. DRS contracts with the Brain Injury Association of Virginia (BIAV) to provide education, outreach, public awareness, and advocacy through a number of regional resource coordinators located in underserved areas.

Like the other two State-funded services, the efficacy of regional resource coordination efforts is difficult to measure. Informing the public about the issue is a large undertaking. Individuals access information in many different ways, and retention of that information depends on a host of factors. Decisions by brain injury service providers to locate in specific areas also depend on many factors. Evaluating the efforts of an individual regional resource coordinator to inform the public and increase the number of providers would involve accounting for all such factors. At the same time, regional resource coordinators appear to enjoy the support of their communities and are meeting their program deliverables.

Regional Resource Coordinators Focus on Building Capacity in Underserved Areas

DRS developed the third component of its service "footprint"—regional resource coordination—in response to feedback from survivors and caregivers that brain injury was poorly understood in many communities. The department contracts with BIAV to place

regional coordinators in underserved communities. Currently, there are four coordinators in the State (Table 8). Coordinators have three primary responsibilities:

- building awareness and understanding of traumatic brain injury among survivors, caregivers, educators, law enforcement officials, and others through education seminars;
- assessing the unmet needs of a community by identifying persons with brain injury and their service needs; and
- building the service capacity of a community by recruiting local providers and promoting coalitions of providers.

State funding for regional resource coordinators has totaled almost $1 million since 2002 (Table 9). In addition to State General Funds, DRS also uses $100,000 in federal TBI Act grant funding and about $30,000 in State matching funds for these services.

Table 8: Regional Resource Coordinator Locations and Dates of Service

Current Location / Service Area	Dates of Service
Hampton Roads	February 2002 to present
Middle Peninsula, Northern Neck, Fredericksburg	February 2003 to present
Staunton – Winchester	March 2007 to present
Roanoke – Farmville	March 2007 to present
Previous Location / Service Area	**Dates of Service**
Roanoke, Martinsville, Danville	February 2002 to August 2006
Charlottesville – Harrisonburg	August 2002 to January 2005
Lee, Scott, Wise Counties and City of Norton	August 2002 to December 2003 April 2004 to December 2005

Source: Brain Injury Association of Virginia.

Table 9: State Funding for Regional Resource Coordination Totals Almost $1 Million Since 2002

Fiscal Year	State Funding
2002	$146,416
2003	142,690
2004	146,691
2005	152,200
2006	150,000
2007	254,196
Total	**$992,193**

Note: Funding in years 2002 through 2004 provided through Commonwealth Neurotrauma Initiative Trust Fund and awarded on a November to October timeframe. Funding in years 2005 through 2007 represents State General Funds.

Source: DRS, Brain Injury Services Programs: FY '02-'07 State General Fund Allocations, 2007.

Effectiveness of Regional Resource Coordination Is Difficult to Assess

The effectiveness of regional resource coordination is difficult to measure given the program goals. Coordinators are meeting their contractual goals, for the most part, of providing information to the public and medical community about brain injury. However, the extent to which these activities have resulted in measurable outcomes is difficult to evaluate.

The needs assessment conducted for DRS in 1998 identified information, referral, advocacy, and education as major service areas needing development. The Virginia Brain Injury Council endorsed the need to develop these areas in the 2000 Action Plan, and the regional resource coordinator positions were created to carry out this function. Comments provided during statewide town meetings in 2005 reiterated support for the work of resource coordinators.

In 2006, DRS implemented a performance measurement system (Scorecard) to rate the effectiveness of brain injury service providers regarding the service areas identified in the 2000 Action Plan (referred to as "community impact goals"). BIAV was rated as exceeding expectations in meeting the community impact goals for all of FY 2007.

Table 10 identifies the four community impact goals DRS established. Programs must achieve 20 percent or more of their stated goal to provide educational, outreach, public awareness, and advocacy activities for a specified number of people by the target date to be rated as exceeding expectations.

Table 10: Community Impact Goals Established in DRS' Scorecard Performance Measurement System

Goal	Program Description
Education	Conducts or sponsors presentations, workshops, and/or conferences designed to expand or improve services.
Outreach	Develops or expands support groups; forms relationships and builds coalitions with community partners; identifies and facilitates development of and referral to community resources; develops or improves access to written and online information.
Public Awareness	Develops, conducts, sponsors, or participates in activities that increase the community's general knowledge of brain injury (print / broadcast activities, health fairs, awareness events, etc).
Advocacy	Develops and provides information, training, and resources that assist survivors, caregivers and others to become effective self and systems advocates.

Source: DRS Scorecard Measurement System (http://www.vadrs.org/cbs/outcomes/) accessed August 12, 2007.

Comments made during the 2005 town hall meetings reflect mixed views regarding effectiveness on the part of the regional resource coordinators in place at the time. Consumer support existed for the coordinators in the Virginia Beach and Gloucester town meetings, particularly Gloucester, where maintaining support for the coordinator was identified as the number one funding priority. Participants pointed to attendance at the town meeting and the creation of a satellite Center for Independent Living in Hartsfield as a result of the coordinator's efforts. Conversely, comments made at the Abingdon meeting stressed a lack of knowledge of available services and how to access information, although a regional resource coordinator was operating in Lee, Wise, and Scott Counties, and the City of Norton.

While regional resource coordinators are conducting activities that should increase public awareness, their ability to develop resources is less clear. Efforts by the Roanoke coordinator led to the expansion of a vocational workshop in Martinsville for persons with mental illness to include persons with brain injury. Subsequently, the program added case management for the population with brain injury in that area. The coordinator in Virginia Beach was instrumental in developing a program to help the domestic violence shelters in that area screen abused women for TBI. The coordinator serving the Shenandoah Valley is planning a symposium that would bring together primary care physicians, special education providers, and others to discuss how to meet the needs of brain injury survivors in the region.

Annual progress reports indicate coordinators are meeting the deliverables in the DRS contract. For example, in meeting the 2007 public education goals in the contract, the coordinators operating prior to March 2007 provided specialized materials to at least 20 persons, conducted at least four presentations or workshops for professionals, and jointly provided at least one major conference.

Regional resource coordinators fill a need identified by the federal TBI grant program to promote public awareness and consumer advocacy. In fact, federal TBI Act funding accounts for about 28 percent of the funding provided for regional resource coordination. Nonetheless, there are few other examples of the coordinators directly contributing to an increase in the number of providers and the capacity of existing providers. It is also challenging to determine if the public education efforts are working, considering that this issue was first identified in 2000 and lack of awareness is still considered a problem, especially among those in the medical community. The lack of development of providers may be at least partly due to factors beyond the coordinators' control. Providers may be reluctant to enter a new area without knowing if the size of

the population will support the business. They may also be less likely to serve an area if they are unsure how they are going to be paid for their services.

Furthermore, areas such as metropolitan Richmond, Northern Virginia, and parts of Southwest Virginia appear to have developed a system of brain injury services without the assistance of a dedicated regional coordinator. One brain injury advocate told JLARC staff that services have generally developed through the efforts of caregivers and advocates rather than a regional coordinator.

Given the difficulty with measuring the effectiveness of the regional resource coordinators and the other competing needs for funding, DRS should continue to closely monitor and evaluate their performance. The department may want to ensure that the contract objectives are sufficient to allow DRS to determine whether objectives are being met. Through its contracting function, the department should retain the opportunity in the future to reorganize the coordinator positions to areas of the State that remain underserved.

EMPLOYMENT RATES AFTER INJURY ARE LOW

In addition to the financial benefits of employment, engaging persons with TBI in work-related activities provides therapeutic and physical benefits, according to research in the area. Employment requires a person with a brain injury to work on their cognitive functions, such as organization, thought processing, and behavior control, that are damaged as a result of the injury.

Research Suggests Mixed Results Regarding Employment Success of TBI Survivors

While a number of employment studies of the traumatic brain injured population have been conducted, few universal findings have emerged. For example, the National Academy of Sciences' 2006 report *Evaluating the HRSA Traumatic Brain Injury Program* found "no definitive estimates of employment post-TBI" but also reported that numerous studies suggest high unemployment rates among the severely impaired. Factors associated with measuring employment success include severity of injury, pre-injury employment history, family and caregiver support, and employment length. In addition, studies that have been conducted tend not to follow the employment patterns of persons with brain injury over time to determine their ability to maintain employment or the quality of the employment they obtain.

Still, some statistics are available. Findings from one research study reported post-injury employment rates for the severely impaired at 38 percent two years after injury. Employment rates for persons who sustained moderate or mild injuries were better (66 percent and 80 percent two years post-injury, respectively). One academic study of employment rates of persons with severe functional impairments who participated in a vocational rehabilitation program reported rates ranging from 50 to 80 percent for the initial job placement. However, employment rates of subsequent placements, which are considered by vocational rehabilitation researchers to be the norm, fell to 50 to 60 percent. Survivors may be more likely to find work the longer the period of time from their injury. A VCU TBI Model System study examined employment rates of 186 adults with severe functional issues after their injury who had been employed prior to their injury. The study reported that 32 percent had found work one year after their injury. That figure increased to 36 percent in the second year and 42 percent in the third year after injury.

Employment Rates Vary for TBI Survivors Receiving DRS Employment Training

DRS offers vocational rehabilitation services through several programs. These include the federal-State vocational rehabilitation program, supported employment, and short-term job-coaching. Additionally, the Woodrow Wilson Rehabilitation Center assesses the functional capacity of persons with brain injury and creates an individualized plan of the person's vocational potential. Table 11 identifies the number of brain-injured survivors who applied for assistance through one of these work-related programs. Not everyone with a brain injury who applies may benefit from such assistance.

Vocational Rehabilitation Program Assists Those Ready for Work. Between 2002 and 2007, DRS served an average of more than 176 persons with a traumatic brain injury annually through the de-

Table 11: Number of Persons With Brain Injury Served by DRS Work Programs Between FY 2002 and FY 2007

	Fiscal Year					
Program	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**
Vocational Rehabilitation	771	757	631	576	570	540
Supported Employment	218	235	209	169	193	223
Job Coach Training	43	50	34	26	38	24
Woodrow Wilson Rehabilitation Center	81	64	54	50	66	65

Source: DRS.

partment's vocational rehabilitation program. The program helps people get ready for, find, and keep a job. However, a person must be eligible to work based on DRS-established criteria. Therefore, not every person with a brain injury who applies for DRS-provided vocational rehabilitation will be eligible.

Between FY 2002 and FY 2007, DRS successfully placed 575 of 1,057 (54 percent) vocational rehabilitation clients with brain injury (Table 12). Successful closure rates during that time range from 49 to 65 percent. Figures reported by 11 other states between 2002 and 2006 showed success rates ranging from 19 percent to 85 percent. According to a researcher, state-by-state comparisons are difficult because states may measure different outcomes and different populations.

Limited responses to consumer satisfaction surveys conducted by DRS during October 2003 and September 2006 reveal that between 64 percent and 94 percent of TBI survivors who participated in vocational rehabilitation were satisfied or greatly satisfied with their experience. However, three of the 13 respondents to the JLARC staff survey of case managers indicated that vocational rehabilitation, including supported employment, was ineffective, and eight others said that it was only somewhat effective. During FY 2002 through FY 2006, the per capita cost of providing vocational rehabilitation services to persons with traumatic brain injury was approximately $2,000.

Table 12: Successfully Closed Vocational Rehabilitation Cases for Persons With TBI in Virginia

State Fiscal Year	Number of TBI Cases Successfully Closed[a]	Number of TBI Cases Closed After Receiving Services[a]	Percentage
2002	99	192	51.6%
2003	111	223	49.8
2004	102	188	54.3
2005	70	144	48.6
2006	96	160	60.0
2007	97	150	64.5
Total	**575**	**1,057**	**54.4**

Note: Figures are based on the federal rehabilitation rate, which is calculated by dividing the number of clients accepted for vocational rehabilitation services who obtained employment by the sum of those who obtained employment and those for whom an individualized plan for employment (IPE) was initiated but did not obtain employment. The rate does not include persons not accepted for vocational rehabilitation services or cases closed prior to IPE initiation.

[a] May include individuals who received multiple vocational rehabilitation services in the same year or in multiple years.

Source: DRS.

Supported Employment May Assist Those with More Severe Injuries. Between FY 2002 and FY 2006, DRS served an average of 78 persons with TBI annually through supported employment. Supported employment involves a job coach working with the survivor to identify the jobs the person can do given his or her injury and level of functionality. The supported employment method places people in a position and has them learn the job as they go with assistance from a job coach. Initially, the job coach will be at the worksite every day with the brain injury survivor. After an acclimation period, the coach will spend less time with the person. Supported employment success depends on well-trained staff that can assess the needs of the survivor and the business. Individuals with more substantial injuries can benefit from supported employment because of the one-on-one nature of the assistance and the interaction of the job coach with the employer.

Table 13 identifies the number of successfully closed supported employment cases since 2002. As the table illustrates, 58 percent of TBI survivors who received supported employment had their cases successfully closed by DRS. Studies suggest that supported employment is the most successful method of assisting persons with traumatic brain injuries acquire and maintain employment and was added as a federal vocational rehabilitation option in 1986. Up-front costs associated with supported employment can be expensive when compared with vocational rehabilitation. A study of 59 survivors who received supported employment between 1985 and 1999 reported average costs for supported employment to be approximately $8,600 per person, most of which was spent in the first year. The study also found participant earnings for the 14-year time period totaled more than $26,000, on average, per person.

Table 13: Successfully Closed Supportive Employment Cases for Persons With TBI in Virginia

State Fiscal Year	Number of TBI Cases Successfully Closed[a]	Number of TBI Cases Closed After Receiving Services[a]	Percentage
2002	45	77	58.4%
2003	47	85	55.3
2004	52	87	59.8
2005	33	63	52.4
2006	46	75	61.3
2007	48	81	59.3
Total	**271**	**468**	**57.9**

[a] May include individuals who received multiple supported employment services in the same year or in multiple years.

Source: DRS.

According to DRS staff, funding issues affect the long-term success of supported employment for persons with brain injuries. Under federal law, supported employment cannot be initiated unless funding is available for follow-along supports. For persons with mental retardation, this money is provided by the local community services board. Follow-along money for persons with physical injuries, like brain injury, is provided through a limited amount of State-funded Supported Employment for Individuals with Physical Disabilities and Long-Term Employment Support Services. If a person need additional support, DRS can also provide funding from the department.

DRS FOCUSES MORE ON CONTRACT OVERSIGHT THAN ON PROGRAM EFFECTIVENESS

As discussed in Chapter 1, State funding of brain injury services began in FY 1990 with a $250,000 General Fund appropriation to Fairfax County, requiring the county to contract with a non-profit for "the development of a program in Northern Virginia to provide integrated community-based services for the traumatically brain injured population." Today, State General Fund appropriations provide for more than $3.6 million annually and the number of contracted providers has grown to nine. Ensuring that State funding is appropriately and effectively used is DRS' responsibility.

Based on JLARC staff's review of each provider's 2006 and 2007 annual reports, the State-contracted programs appear to be meeting their contract requirements. For example, the regional resource coordinators met the contract's educational goal by providing specialized brain injury materials to a minimum of 20 professionals each year, conducting a minimum of four presentations or workshops for professionals, and collectively holding at least one major conference annually.

However, in discussions with DRS staff, it was indicated that greater program evaluation was an area of need. The last major series of program audits was conducted in 2004 by an independent evaluator, and few problems were identified. Programmatic oversight of the brain injury programs is currently being conducted through vendor self-evaluations as part of the Scorecard reporting system. While the Scorecard appears to be a positive step in determining program effectiveness, all programs are currently rated as exceeding the established objectives. DRS staff anticipate the need to revise the established goals to be more realistic.

Additionally, DRS staff indicated that the Brain Injury and Spinal Cord Injury Services unit may be implementing a new case management system to which all State-contracted case managers will have to report. According to the unit manager, the system will cre-

ate uniform reporting requirements, making it possible for DRS staff to review individual cases and evaluate the case managers. While it appears this will be useful in measuring effectiveness down to the individual level, questions remain regarding to what extent DRS staff will have time to adequately review this information. Currently, there are only two full-time positions assigned to the unit. The manager is responsible for contract oversight and management of the federal TBI grant, as well as several DRS-related activities. The specialist assistant is assigned to manage the CNI Trust Fund program and provide some assistance to the manager. According to the manager, it is challenging to manage the program at this staffing level. Considering the limited resources and the difficulty in measuring effectiveness of certain services, the department should consider contracting for a limited number of program evaluations annually.

Recommendation (2). The Department of Rehabilitative Services should perform or contract with a third party to annually perform program evaluations of at least two State-contracted brain injury service providers.

In August 2006, DRS' Internal Audit Division reviewed the unit and found that management has policies and procedures to provide good control over State and federal funding. The audit focused on the unit's contract contents and grant awards and the appropriate use of State and federal funds between July 1, 2005, and March 31, 2006. Nonetheless, the report recommended

- requiring all State-funded brain injury programs to achieve accreditation through the Commission on Accreditation for Rehabilitation Facilities or the International Center for Clubhouse Development, and
- requiring all future contracts to include language requiring each program to submit both an annual independent audit and a control self-assessment by December 31 of each year.

However, the requirement for submitting annual audits was not included in the contract modifications developed for FY 2008 funding, according to the unit manager. Doing so would not require additional work on the part of the providers, who all appear to be undergoing annual audits. Requiring submission of the annual financial audit reports could provide another layer of oversight for the department. The unit should review these documents and share them with the department's Internal Audit Division to ensure State and federal funds are appropriately used.

Recommendation (3). The Department of Rehabilitative Services' (DRS) Brain Injury and Spinal Cord Injury Services unit should include language in all State-funded contracts with brain injury service programs requiring each program to submit the annual independent audit that is conducted of each program. DRS should review these documents and share them with the department's Internal Audit Division to ensure appropriate use of State and federal funds.

Chapter 5

Identification of Brain Injury Survivors Needs Improvement

In Summary

Virginia's brain injury registry is not operating effectively. Database issues are preventing at least two Level I Trauma Centers from reporting to the registry. While some hospitals are unable to share information they collect with the registry, they are providing the same information to the Virginia Statewide Trauma Registry (VSTR). The General Assembly may want to consider eliminating statutory language requiring hospitals to report to the brain injury registry while amending VSTR's reporting requirements to specifically include brain injury-related information. A workgroup should be established to identify data elements needed to operate an effective registry and modifications to current hospital reporting requirements needed in order to ensure appropriate reporting occurs.

Currently, 37 states, including Virginia, operate trauma registries that collect data on brain injuries. Most of these states collect information on brain injuries as part of broader efforts to collect information on trauma injuries in general, but 17 states have registries devoted solely to measuring the incidence of brain injuries. Since 1984, Virginia has had a brain injury registry that has been used to collect and maintain information on the number and causes of brain injury in the State.

STATE REGISTRY DOES NOT ADEQUATELY IDENTIFY AND INFORM VIRGINIA'S POPULATION WITH BRAIN INJURY

Virginia's brain injury registry was established to "facilitate the provision of appropriate rehabilitative services by [DRS] and other state agencies to help" brain injury survivors by (1) identifying those diagnosed with a traumatic brain injury, and (2) providing assistance in obtaining services to persons with a TBI diagnosis and their caregivers. The statute also requires DRS to use the information for program and fiscal planning.

Individuals Are Reported to the Registry and Mailed Information About Brain Injury Services

All hospitals are required to report to DRS within 30 days of the injury the following information about each person treated for a brain injury: (1) name, (2) age, (3) place of residence, and (4) cause

of injury. DRS requires that the following seven types of brain injuries be reported:

- anoxic brain damage resulting from a traumatic event such as electrocution, near-drowning, or near-suffocation;
- fracture of the skull vault or base;
- other and multiple skull fractures;
- intracranial injury;
- unspecified head injuries;
- shaken infant syndrome; and
- brain trauma resulting from unknown reasons.

(JLARC staff are not considering anoxic brain damage from a non-traumatic event in this review.) Information is supposed to be reported concerning all patients who are treated and released from emergency departments, admitted to a hospital for inpatient treatment, transferred into or out of a hospital, or die on the way to a hospital or during treatment.

Currently, reporting to the registry can occur in one of two ways. Hospitals can use the DRS universal reporting form (Appendix E). The form includes all statutorily required information, including the seven types of brain injury diagnoses. The form cites the *Code of Virginia* section requiring completion of the form, as well as instructions on its completion, a contact phone number, and a mailing address. In addition, DRS permits hospitals to report by sending the department electronic spreadsheets containing the required information. Generally, this is only done by the hospitals treating large numbers of trauma patients. Hospitals can transmit the data by email or by sending DRS a CD-ROM.

Once the patient and injury information is collected by DRS, one part-time employee enters the data into the registry. The employee may also provide data verification if the information clearly appears to be inaccurate. The department then prints patient address labels and provides them to the Brain Injury Association of Virginia (BIAV), with whom DRS contracts to administer the outreach and the information and referral activities.

As part of the outreach function, BIAV sends a packet of information to each individual using the patient labels. The packet contains information about brain injuries, BIAV's contact information, and a self-addressed, postage-paid response card that the recipient can use to request more information from the association. BIAV is also responsible for providing each hospital in the State with technical assistance on what information to report, how to report it,

when it needs to be reported, and why it is important that traumatic brain injury information be reported to the registry.

Not All Persons Diagnosed With a TBI Are Being Reported to the Registry

Problems exist with all aspects of the registry. Identification of brain injuries is problematic. Unlike problems associated with a physical injury, such as a broken arm, the cognitive or behavioral problems associated with a brain injury are not always evident. JLARC staff were also told by two psychologists who specialize in traumatic brain injury that TBIs are overlooked or misdiagnosed by many physicians. In addition, a neurobehavioral psychologist noted that TBI effects may manifest themselves weeks or months after the injury.

Reporting issues also plague the effectiveness of the registry. Several major trauma facilities have suspended reporting to the registry. For example, INOVA Fairfax Hospital and the UVA Medical Center typically do not report TBI information to the registry despite being Level I Trauma Centers. Both hospitals operate electronic data systems that produce the required information; however, because of formatting issues, DRS is unable to load the hospitals' data into the registry without a substantial recoding effort. As a result, data from these hospitals is not included in the registry.

Because of these data issues, around 2000, DRS began exploring opportunities to integrate the registry with VDH's Virginia Statewide Trauma Registry (VSTR) that was under development. Hospitals are also required to report all trauma injuries, including TBIs, to the VSTR. At the time, DRS staff directed BIAV staff to tell the Level I Trauma Centers to suspend reporting to the registry until the registry and VSTR were integrated. As will be discussed later in this section, integration has not yet occurred. While DRS says that discussion with VDH is ongoing (staff from the two departments last met in May), the Level I Trauma Centers have never been told to reinstate their registry reporting.

The department's decision to suspend the reporting requirement for some hospitals raises several concerns. As a result of the suspension, the registry does not have complete information on the number of Virginians with brain injury. In addition, the suspension creates an inconsistency among hospitals, with some still required to report to the registry and others excused from reporting. Finally, DRS does not have the authority to excuse hospitals from complying with a statutory requirement.

The decision to suspend reporting highlights a broader concern as to whether the registry's current database platform is sufficient to support the requirements addressed in the *Code of Virginia*. The database used for the registry cannot accommodate data transfers because of the formats used by the major hospitals to record patient-level data. Under existing circumstances, either the hospitals with electronic data reporting systems will need to manually enter potentially thousands of TBI cases into a format DRS can use, or DRS staff will have to manually enter hospital data into the registry.

Additionally, DRS has little enforcement authority to compel hospitals to report. For their part, hospitals have complained about the lack of funding to assist them in reporting in a timely manner, and have noted that their priority is caring for patients.

Current data verification attempts are weak as well. In reviewing the registry data, JLARC staff found several instances in which the birth date was identified as occurring after the date of injury, or the date of injury was clearly incorrect. According to DRS staff, their ability to follow up with the reporting facility on such errors is very limited given the department's available resources.

Persons Identified by Registry May Not Be Getting Information and Referral Assistance

In addition to the identification and reporting problems, the information and referral function also appears to be ineffective. Both DRS and BIAV acknowledge a low response rate to the information packets mailed out by BIAV. Table 14 identifies the number of outreach mailers sent during 2005 through 2007, resulting contacts, and the response rates, which are less than two percent annually. To address these low rates, at the beginning of 2007 DRS contracted with BIAV to conduct a limited survey identifying how persons currently receiving services learned of those services. Service referrals from family and friends were identified most often, followed by hospitals and case managers. BIAV points out in the report of the survey findings that it receives a large number of calls

Table 14: Contacts Related Directly to Outreach Mailers, FY 2005-FY 2007

Fiscal Year	Mailers Sent	Direct Contacts	Percentage
2005	14,759	254	1.7 %
2006	19,180	262	1.4
2007	18,719	260	1.4
Total	**52,658**	**776**	**1.5**

Source: Brain Injury Association of Virginia.

from family and friends. Additionally, the report points out that the survey respondents may have difficulty recalling how they initially identified services because an average of 12 years had elapsed since the respondents' injuries.

DRS Does Not Use Information Collected by the Registry for Planning Purposes

Although required by the *Code of Virginia,* the department does not appear to use data from the registry to allocate brain injury funding in Virginia. DRS staff indicated that because of data accuracy issues, registry data is mostly used to answer questions, such as how many persons in a specific region may have a TBI. However, planning is particularly important with regard to locating services in a geographically diverse state like Virginia, where the prevalence of brain injury survivors may differ substantially. For example, JLARC staff were told by advocates in Southwest Virginia that, according to their estimates, close to five percent of the region's population has sustained a TBI, more than twice the rate of CDC's national estimate. The advocates were able to use their estimate in part to get earmarked funding increases for case management services there.

DRS Does Not Coordinate Identification With Virginia Statewide Trauma Registry

While DRS acknowledges the registry's problems, the department has not taken advantage of potentially useful information being collected by the VSTR. VDH is statutorily required to collect and maintain traumatic injury data if the injury results in hospital admission. To fulfill this requirement, VDH created the VSTR to provide a database of patients injured in the Commonwealth and admitted to hospitals in Virginia or surrounding states. DRS could use this data to supplement what it receives through the brain injury registry.

Even though DRS has been working with VDH for almost a decade to link the State's brain injury and trauma registries, it appears that little progress has been made. Two years ago, VDH implemented a web-based, electronic version of the VSTR that had been in development since 1997. During development, VDH and DRS staff worked to integrate the registry's data needs into the VSTR's design, but were not successful. Integration may not be feasible at the present time. VDH staff said that with the web-based version of VSTR functioning, it would be an enormous undertaking to add DRS system requirements.

In addition to the technical challenges, differences in reporting requirements also hampered efforts to integrate the registries. First,

reporting to the VSTR is only required once every six months as opposed to within 30 days for the brain injury registry. VDH established the six-month deadline after complaints from hospitals that they could not report the data in less than four or five months. (According to health care professionals and advocates, the 30-day reporting requirement is necessary because it is important to provide information and referral quickly to someone with a brain injury.) Second, only hospital admissions are required to be reported to the VSTR, whereas emergency rooms and hospitals must report any TBIs to the registry. Furthermore, VDH has the benefit of being able to compel trauma centers to report to VSTR by using the potential loss of trauma funding as an incentive. There is no similar incentive available to DRS for compelling hospital reporting.

PROBLEMS WITH BRAIN INJURY REGISTRY SUGGEST NEEDED IMPROVEMENTS

Recognition of the need to improve the existing registry is not new. In 2001, the Joint Commission on Health Care (JCHC) released a report presenting a series of options to improve registry operations.

Trauma Registry Could Be Used to Collect Brain Injury Information

As discussed previously, various factors prevent the brain injury registry from operating effectively, including the inability of DRS to access the patient-level information being collected by the Level I Trauma Centers. As a result, the registry does not comprehensively collect brain injury information as intended. Additionally, hospitals must report the same information to two separate data systems, each with unique reporting requirements. In light of these challenges, the General Assembly may wish to consider amending the *Code of Virginia* to eliminate the requirement that hospitals report to the brain injury registry, and instead require hospitals to report brain injury information to the Virginia Statewide Trauma Registry, and that DRS convene a work group to identify the information needed to accomplish these changes.

Recommendation (4). The General Assembly may wish to consider amending §32.1-116.1 of the *Code of Virginia* to require (1) all licensed hospitals rendering emergency medical services to report to the Virginia Statewide Trauma Registry (VSTR) patient-level information on all persons diagnosed with a brain and/or spinal cord injury, sustained other than through disease, using the VSTR's reporting requirements, and (2) the Virginia Department of Health to transmit such information to the Department of Rehabilitative Services.

Recommendation (5). The General Assembly may wish to consider amending §51.5-11 of the *Code of Virginia* to eliminate the statutory language requiring hospital reporting to the brain injury registry. The General Assembly may also wish to consider amending the *Code of Virginia* to direct the Department of Rehabilitative Services to obtain the brain and/or spinal cord injury data collected by the Virginia Statewide Trauma Registry.

Recommendation (6). The Department of Rehabilitative Services should convene a work group consisting of the department, the Virginia Department of Health, brain and spinal cord injury stakeholders, and others as needed to identify the appropriate data elements needed from the Virginia Statewide Trauma Registry and the most appropriate electronic format for transmitting that information. The work group's recommendations should be reported to the House Health, Welfare, and Institutions and Senate Education and Health committees prior to the 2008 General Assembly Session.

The department should require State-funded brain-injury service providers to submit the names and relevant information of individuals with brain injury who request their services, and the department should add such names to the registry, if not already included. In addition to obtaining information from the VSTR and brain injury service providers, DRS should take steps to integrate personal information that is being gathered by other entities. DRS should consider developing agreements to collect brain injury-related data that may be collected by other agencies, such as the Department of Mental Health, Mental Retardation and Substance Abuse Services. The 40 local community services boards may also be able to provide useful information.

Recommendation (7). The Department of Rehabilitative Services should require all State-funded brain injury service programs to provide the department with the information required by §51.5-11(B) of the *Code of Virginia*. The information should be reported each time a provider is contacted or makes contact with a new person with brain injury.

Current Information and Referral Process Should Be Eliminated

Between 2005 and 2007, fewer than two percent of the outreach mailers sent to persons identified on the registry resulted in requests for additional information. Given the low response rate, DRS should discontinue the current effort aimed at providing information to brain injury survivors after the current contract expires in 2009.

DRS may want to consider exploring alternative methods of providing information to brain injury survivors. The department could

seek to improve the effectiveness of its information and referral function by contacting those reported to the registry and their caregivers through different means and at different times than under current practice. The State could also consider limiting follow-up contacts to those persons diagnosed with a severe or moderate traumatic brain injury. DRS could also try to increase awareness among medical care staff and involve them in providing information to survivors, especially during the acute care phase. Additionally, DRS may want to consider undertaking a public awareness campaign. In its 2001 report, the JCHC suggested increasing DRS funding for the department to undertake such a campaign that could address the importance of reporting brain injuries; however, no cost estimate was provided.

Information Should Be Used for Planning Purposes

More comprehensive and accurate patient-level data could assist the department's decision-making with regard to planning and programming services in the future. The *Code of Virginia* requires DRS to use the data for effective program, policy, and fiscal planning. However, DRS staff cite the fact that not all hospitals are reporting to the registry and the concerns surrounding the accuracy of the information as reasons for not using the data for such purposes. Because information reported to VSTR should be more comprehensive and accurate than data reported to the brain injury registry, DRS should integrate such information into the department's planning function. Information concerning survivors' injury severity and geographic location could assist the department in determining the types and locations of services needed in the future.

Recommendation (8). The Department of Rehabilitative Services should integrate the brain injury information it collects into the department's program, policy, and fiscal planning.

Chapter 6

Improving Access to Community-Based Brain Injury Services

In Summary

The extent to which Virginia provides services for the State's population with brain-injury is a policy choice. This report has identified unmet needs among various segments of this population. For example, the availability of residential treatment programs for persons with severe neurobehavioral issues is limited. Persons with severe impairments who are at risk for entering or are in a nursing home may not be able to access services to treat their brain injury. Other services for persons with brain injury, such as cognitive rehabilitation therapy and supportive housing, are also lacking or limited. Virginia may be able to address some of the needs of these severely impaired individuals through reallocation of existing resources or by use of Medicaid waivers.

Since initially receiving funding in 1998, DRS has made a reasonably good effort to address the needs of as many persons with brain injury as resources have allowed. Case management and clubhouse/day programs served more than 1,000 people in FY 2007, an increase of more than 50 percent since FY 2002, and survivors and caregivers also appear to benefit from such services. Large numbers of people are being contacted by the regional resource coordinators and the brain injury registry. However, there remain substantial unmet needs for brain-injured survivors. The extent to which the State provides community-based brain injury services is a policy choice. However, if additional resources are identified, the State may want to address some of these unmet needs.

SERVICES FOR PERSONS WITH SEVERE NEUROBEHAVIORAL ISSUES ARE NEEDED

Earlier chapters of this report identify issues with service availability for all persons with brain injury. Given limited resources, the State may want to consider addressing the needs of those with severe behavioral issues first if additional resources are allocated to this population. This segment of the population with brain injury is most likely to be at risk of placement in a skilled nursing home, local jail, local licensed hospital, or State prison or to not receive any services at all. There is virtually no system of care in the community for people with behavioral problems who do not have the financial resources to pay for private care. A Virginia Brain Injury Council (VBIC) subcommittee comprised of a panel of neuro-

psychologists in the State estimates that thousands of persons with TBI may have neurobehavioral problems, and some of these individuals may require intensive treatment. However, there are only 20 specialized neurobehavioral beds dedicated to providing intensive residential treatment in Virginia, and costs are estimated at about $470 per day.

State Should Consider Funding Intensive Behavioral Treatment Services

According to DRS staff, neuropsychologists, brain injury advocates, and others interviewed by JLARC staff, the lack of a residential behavioral treatment option for persons with brain injury with severe behavioral issues is a major unmet need. Behaviors that can cause serious concern include aggression or violence toward others, threats of violence, self-injury, and property destruction. A 2006 paper by the National Association of State Head Injury Administrators states that it is these behavioral challenges that cause family and caregivers concern and result in the individual being seen by professionals or service agencies. Treating these behavioral problems could allow the person to receive other therapies and be integrated back into the community.

Typically, these individuals will eventually require State or local services, whether through detention in a local jail or State prison, or even out-of-state placement in a Medicaid-funded nursing home or commitment to a licensed local hospital. Information supplied by DMHMRSAS indicates that at least 14 persons with mental health or mental retardation diagnoses and a co-occurring TBI diagnosis reside in State facilities—11 in four mental health hospitals and three in a mental retardation training center. Treatment costs for these individuals are approximately $120,000 for the length of their stay.

According to the Department of Medical Assistance (DMAS), Medicaid-eligible patients are sometimes eligible for placement in out-of-state neurological treatment facilities if placement in one of the State's existing nursing homes cannot be arranged. In the last few years, the Commonwealth has paid for two out-of-state placements, at a cost of $362 per day per person. No data exists for those in jails or prison, but some researchers have suggested that one-third of the inmate population nationwide could have a brain injury. Persons with severe behavioral issues may also be inappropriately placed in a nursing home where their behavior is a problem for the other residents and staff and where they are unlikely to receive appropriate services.

The following case study illustrates the problems someone with these issues can have trying to access services:

Case Study

After being discharged from a rehabilitation hospital following a traumatic brain injury, "Robert" was moved to a nursing facility. However, he had to be removed from the facility because he could not be contained and there was no lockdown facility available. He was admitted into the Alzheimer's unit of another facility that placed him in a lockdown unit. Eventually, he was able to pick the locks and escape from this facility. Robert currently resides in the only nursing home in Virginia with a dedicated section for traumatic brain injuries that accepts Medicaid funding. However, his family was informed that the brain injury unit in the nursing home will close in September. They have sought funding support from DRS to send him to a private facility closer to them, but have been told none is available.

While resources for providing intensive neurobehavioral treatment are limited, funding designed to help persons transition out of the State hospitals and into long-term community-based services has been used by community service boards (CSBs) to move at least two people into the State's private neurobehavioral facilities. Discharge Assistance Project (DAP) funding is a State-funded regional initiative to facilitate patient reductions within the State hospital system. DAP funds are allocated to CSBs or regional consortiums of CSBs which can then use the funding to find community-based services for individuals with disabilities. According to DMHMRSAS staff and others, this source of funding is only available when all other treatment options have failed. The following case study highlights an example where DAP funding resulted in someone with a brain injury receiving appropriate care.

Case Study

"Bill" suffered a traumatic brain injury as the result of a motorcycle accident at the age of 17. As a result of his injury, he behaves inappropriately around others. His inappropriate behavior has prevented him from finding stable housing, causing him to live in a variety of situations, including with family, an adult day care facility, mental health facilities, and prison. With the help of State DAP funding, he now resides in a privately operated residential treatment program. As a result of the specialized care, his functioning has improved and he is permitted to leave the facility and go into the community with staff supervision.

Calls for establishing intensive neurobehavioral treatment settings are not new. A 1999 DMHMRSAS report to the General Assembly recommended developing secure residential programs for long-term and short-term treatment and rehabilitation of persons with

severe behavioral issues. The report further recommended pursuing funding for such care through a TBI waiver through the State Medicaid program. The report also recommended establishing a pilot program at Woodrow Wilson Rehabilitation Center (WWRC) and Western State Hospital to improve training of staff to ensure more comprehensive treatment of TBI survivors in State psychiatric hospitals. However, this pilot program was not implemented. In 2004, because of a lack of resources, WWRC decided against establishing a pilot program for a small unit dedicated to treating those with severe behavioral needs.

A VBIC subcommittee recently drafted a report identifying a four-stage system of treatment for persons with behavioral issues. The four stages address all needs, from acute medical and psychiatric care to long-term supported living and supported home-based services. The draft recommends establishment of a pilot program for treating persons needing intensive 24-hour support as well as residential treatment/group home programs for those requiring 24-hour supervision with moderate support needs. The subcommittee identified these as the two groups with the greatest unmet needs among the 25- to 65-year-old population with brain injury because they are not served by primary educational programs or Medicare.

Limited Resources for Funding Some Neurobehavioral Treatment Slots Are Available Through the CNI Trust Fund

The Commonwealth Neurotrauma Initiative (CNI) Trust Fund produces revenues of about $1.4 million annually for a combination of research and community-based services grant funding (Table 15). Currently, the CNI Trust Fund has $4 million in obligated grants through 2010. The VBIC subcommittee report estimates it costs $470 per day to treat someone with severe behavioral issues in a secure, 24-hour facility, or $171,550 per person per year. Therefore, $1.4 million would allow approximately eight persons to receive care in such facilities for a full year or 16 persons for six months. The subcommittee's report recommends funding a $1.6 million pilot program to serve 20 persons for six-month increments.

Reallocating funding from the grant program to direct services for intensive treatment would provide some funding to address the unmet needs of the most underserved of the population with brain injury. While funding only eight to 16 slots may appear small, treating this segment of the population will result in persons who may be a danger to themselves or others receiving appropriate services and support in safe and secure settings.

Table 15: Annual Revenues of the Commonwealth Neurotrauma Initiative Trust Fund, 2002 - 2007

Fiscal Year	Revenue
2002	$ 1,532,621
2003	$ 1,490,065
2004	$ 1,419,435
2005	$ 1,410,458
2006	$ 1,271,965
2007	$ 1,328,700
Annual Average (2002-2007)	**$ 1,408,874**

Source: DRS.

Disadvantages to changing the mission of the CNI Trust Fund and its current functions should be considered. First, the amount of funding available is small, and its collection depends on the continued reckless driving habits of Virginians. Second, grant funding for community-based services helps a disproportionate amount of people relative to the funding provided. Many existing case management programs, clubhouse/day programs and the regional resource coordination effort received such grant funding. Third, discoveries made using research grants could help Virginians and persons with brain injury across the country.

There have also been discussions regarding whether a portion of DAP funding should be dedicated to TBI as a way to provide a source of funding for treating those with the most severe behavioral issues. Brain injury advocates have asked for an equal amount of funding used to treat persons with a brain injury to be set aside for a specific, State-operated brain injury facility. DMHMRSAS has been reluctant to do this, however, because beds allocated for TBI survivors would result in a reduction in the number of beds available to treat the general population, thereby limiting treatment options for persons with other conditions.

State Should Consider Contracting With Existing Providers

While only 20 intensive neurobehavioral beds are available in Virginia, the State may wish to consider developing agreements with the facility operating these beds for treating this population. By contracting directly with the facility, the State would not need to build a new facility or eliminate hospital beds available to the general public. Additionally, DMHMRSAS already licenses the existing residential brain-injury facilities so new regulations would not be needed, although amendments may be required. Such an arrangement also has the potential to encourage expansion of such services within existing facilities as well as creation of new providers.

ADDITIONAL STATE RESOURCES COULD ADDRESS EXISTING SERVICE NEEDS

While addressing the needs of those with severe neurobehavioral problems should be the State's first priority, unmet needs exist among other segments of the population with brain injury as well. If extra resources were available, this population could continue to benefit from expansion of case management and clubhouse programs.

Additional resources could also be used to meet other needs. The ability of persons with brain injury to access cognitive rehabilitative therapies to assist them with organizing their activities and compensating for functions lost as a result of their brain injury appears limited. As discussed previously, important services such as residential housing, neurobehavioral care, and personal assistance services are not available to most brain injury survivors in Virginia. Without access to these services, individuals with severe impairments must rely on family in the home to provide care and may be forced to enter long-term care facilities. A brain injury clinician and researcher with VCU's TBI Model System cited these conditions in suggesting that brain injury survivors move to another state for services following the acute phase of recovery.

MEDICAID PROGRAM COULD BE ONE OPTION TO EXPAND ACCESS TO NEEDED SERVICES

Medicaid home- and community-based (HCB) waivers are designed to enable severely disabled persons to remain in the community. HCB waivers are authorized under Section 1915(c) of the federal Social Security Act. This provision allows states to offer HCB services through their Medicaid programs by waiving federal requirements that services be made available to all qualifying individuals. Under an HCB waiver, states have the authority to limit services to a specific disabled group or region of the state. Federal regulations require that states limit waiver services to individuals who are living in, or at risk of entering a hospital, nursing facility, or Intermediate Care Facility for the Mentally Retarded (ICF/MR).

Waiver Programs May Enable Persons With Severe Brain Injury to Remain in the Community

One option to improve access to community-based services for persons with severe brain injury is through the use of Medicaid HCB waivers. Waivers offer two primary advantages as a method of providing additional brain injury services. First, the State can control costs through a waiver by limiting available services, the eligible population, or through other means. Also the State shares the cost of providing waiver services with the federal government. Sec-

ond, an HCB waiver would target more severely impaired individuals living in, or at risk of entering, long-term care facilities. A Medicaid waiver has the potential to reduce the number of brain injury survivors in long-term care facilities by providing residential housing assistance, neurobehavioral care, and other brain injury services not widely available in Virginia.

TBI Waiver Could Serve Unique Needs of Severely Impaired

Person with brain injury who have severe functional problems have the greatest amount of service needs. Implementing a specific TBI waiver would permit the State to identify the population it wishes to serve and target services to that population. Previous cost estimates of State funding for a TBI waiver were approximately $6.2 to $7.5 million annually.

As of 2007, 24 states were operating waivers for TBI survivors (Table 16). These waivers varied widely in terms of cost and the number of individuals served, with New Hampshire having the highest per capita expenditures ($81,815) and Mississippi the lowest ($8,193). Other states may serve persons with brain injury through waivers for other disabled groups. For example, Georgia allocates 30 TBI slots under its Independent Care waiver.

If a brain injury waiver is implemented, Virginia would have to determine which segment of the population with brain injury to serve. States can target certain disabled groups by using waiver eligibility criteria and specifying the long-term care institution waiver recipients are at risk of entering. At least three segments of the population could be targeted (these segments are not mutually exclusive and, as such, an individual with brain injury could be served under more than one):

- Persons with brain injury at risk of entering nursing homes and intermediate care facilities. Services for this population are generally long-term in nature. Waiver recipients would likely include individuals in long-term care facilities as well as survivors in the community but at risk of entering a facility.
- Persons with brain injury in hospital rehabilitation units. Services could be provided for a limited time, allowing survivors to shorten their stay in a rehabilitation unit and return to the community. Under this option, waiver recipients would have sustained their brain injuries more recently, and may have a greater need for rehabilitative services.
- Persons with brain injury who have severe neurobehavioral problems. In 2003, the Virginia Olmstead Task Force rec-

Table 16: Twenty-Four States Administer Traumatic Brain Injury Medicaid Waivers

State	Target Population	Unique Waiver Recipients	Total Annual Expenditures[a] (In Thousands)	Annual Per Capita Expenditures
Colorado	TBI	404	$8,338	$20,638
Connecticut	TBI	193	12,278	63,618
Florida	TBI & SCI	200	2,918	14,592
Idaho	TBI	19	1,054	55,489
Illinois	TBI	1,641	15,885	9,680
Indiana	TBI	170	3,210	18,885
Iowa	TBI	501	6,294	12,564
Kansas	TBI	180	4,944	27,465
Kentucky	TBI	91	3,841	42,214
Maryland[b]	TBI	30	--	--
Massachusetts	TBI	32	1,305	40,779
Minnesota	TBI	895	33,964	37,949
Mississippi	TBI & SCI	326	2,671	8,193
Nebraska	TBI	10	273	27,297
New Hampshire	TBI	76	6,218	81,815
New Jersey	TBI	241	14,674	60,890
New York	TBI	1,157	49,444	42,734
North Dakota	TBI	30	791	26,360
Pennsylvania[b]	TBI	325	--	--
South Carolina	TBI & SCI	478	11,181	23,391
Utah	TBI	84	2,221	26,444
Vermont	TBI	48	2,402	50,038
Wisconsin	TBI	302	17,756	58,795
Wyoming	TBI	68	2,016	29,641

Notes: Data for 2003. "--" indicates data was not available. SCI, Spinal cord injury. Other states also may serve brain injury survivors with non-TBI waivers.

[a] Expenditures include federal and state contributions.

[b] Data for 2007.

Source: *Medicaid 1915(c) Home and Community-Based Service Programs: Data Update*, Kaiser Commission on Medicaid and the Uninsured, December 2006; *Guide to State Government Brain Injury Policies, Funding and Services*, National Association of State Head Injury Administrators, Second Edition, 2005; U.S. Centers for Medicare and Medicaid Services.

ommended developing a brain injury waiver for individuals with "significant behavioral issues," including emergency and short-term services for this population. Eligibility for this type of waiver could be limited to survivors at risk of institutionalization.

An additional step for a state implementing an HCB waiver is ensuring that the waiver is cost-effective. Federal regulations require that waivers be budget-neutral, meaning states must ensure that the average per capita cost of an HCB waiver does not exceed the average per capita cost of care in the alternative institution. States can use a variety of strategies to limit the per capita cost of a waiver, including limits on the amount of services, dollar limits on

the value of benefits, the exclusion of more costly services, and prior authorization of services.

Limits on the amount of services available are used with current HCB waivers in Virginia. However, according to DMAS staff, these limits are designed to ensure that services are clinically appropriate rather than to limit the costs. Statutory changes in 2005 require DMHMRSAS to license providers of residential services for persons with brain injury, and these regulations have been implemented. According to DMAS staff, additional regulations may be required for providers of other brain injury services.

Benefits and Possible Challenges to Implementing a TBI Waiver. The primary advantage to developing a TBI waiver is that waiver services could be offered to a larger segment of the population with brain injury. While services under the Individual and Family Developmental Disabilities Support (DD) waiver are limited to individuals who suffered their brain injury before age 22 and are at risk of entering an ICF-MR, a TBI waiver would be available to individuals of all age groups as long as they are at risk for placement in a nursing home. The State would also have greater authority to determine the segment of the population with brain injury it would serve under a waiver.

A second advantage to implementing a TBI waiver is that the State would have flexibility in determining the services provided for waiver recipients. A menu of services could be developed to address the unmet needs of TBI survivors in Virginia. These services could be designed to meet the needs of a specific segment of this population. For example, a waiver serving individuals from hospital rehabilitation units might provide more generous rehabilitative services than a waiver targeting individuals who have had their injuries for a long time.

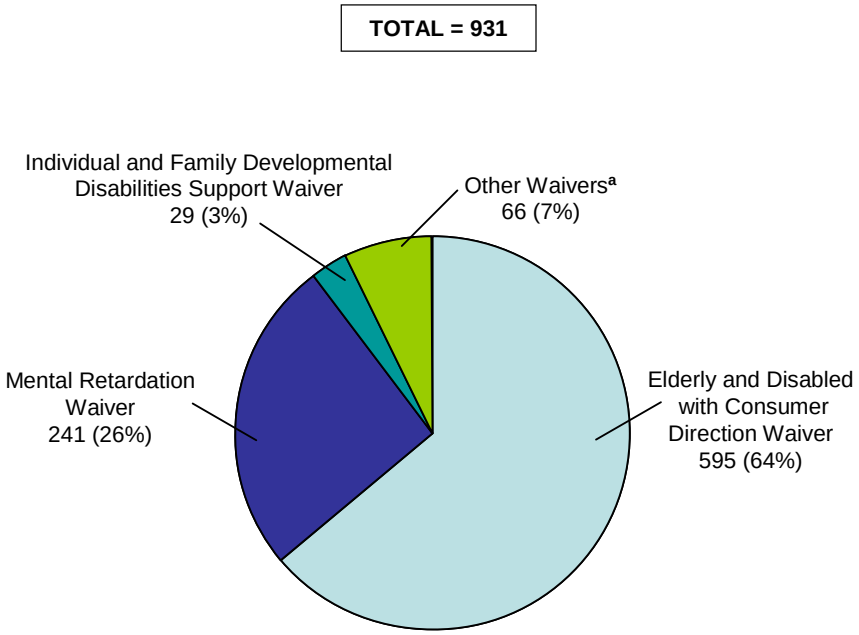
The primary challenge to implementing a TBI waiver is the potential cost to the State. The General Assembly appropriated $3.4 million to DRS for community-based brain injury services in FY 2007. A new waiver would substantially increase this level of funding. In 2005 and 2006, the General Assembly considered budget amendments that would have allocated between $6.2 and $7.5 million in State General Funds for 200 waiver slots. The cost of serving TBI survivors under a waiver will likely be higher in the future. For example, brain injury advocates have recommended providing personal care and congregate residential services through a brain injury waiver. The 2006 Appropriation Act increased reimbursement rates for personal care services through HCB waivers by three percent. Reimbursement rates for congregate residential services provided through the Mental Retardation (MR) waiver were increased by ten percent.

Expansion of Developmental Disabilities Waiver Could Also Improve Access to Services

Another way to provide additional services for severely impaired TBI survivors is to expand the use of one or more waivers currently operating in Virginia. Some survivors have been able to access services through the State's existing HCB waivers. Data from DMAS indicate that 931 TBI survivors accessed a HCB waiver between FY 2004 and FY 2006. Nearly 90 percent of these individuals used the Elderly and Disabled with Consumer Direction (EDCD) and MR waivers (Figure 12). JLARC staff were unable to determine from the data whether these individuals received services specifically for a TBI. In addition, DMAS staff caution that numbers of waiver recipients fluctuate widely and may be different over other time periods.

According to DMAS staff, the DD waiver is most likely to meet the needs of persons with brain injury. The DD waiver serves disabled persons age six and older who have conditions such as autism, cerebral palsy, or brain injury. Waiver recipients must meet the criteria for placement in an ICF/MR, but cannot have a diagnosis of mental retardation. According to federal regulations, a TBI sur-

Figure 12: More Than 900 Persons With Brain Injury Accessed Services Using HCB Waivers During FY 2004 Through FY 2006



[a] Other waivers include the Technology Assisted waiver, AIDS waiver, Day Support waiver, and the Consumer-Directed Personal Attendant Services waiver.

Source: Data from the Department of Medical Assistance Services.

vivor must have suffered his or her brain injury before age 22 in order to meet ICF/MR criteria and qualify for waiver services. The DD waiver already serves a limited number of survivors, with 29 persons receiving services through the DD waiver between FY 2004 and FY 2006. According to DMAS staff, of the 455 DD waiver slots funded for FY 2007, 41 TBI survivors were enrolled in the DD waiver as of July 2007. An additional 114 survivors were on the waiting list for waiver services. Like other counts of waiver recipients, these numbers are subject to wide variation over time.

The DD waiver could be expanded to better serve brain injury survivors in one of two ways, or both. First, the State could add additional services to the DD waiver. The waiver currently funds most of the services identified by brain injury clinicians and advocates as critical to keeping survivors in the community. These services include

- in-home residential supports,
- respite care,
- skilled nursing,
- crisis stabilization and supervision,
- pre-vocational and supported employment services,
- day support programs,
- environmental modifications, and
- assistive technology.

However, persons with brain injury are not able to access residential housing assistance, neurobehavioral services, cognitive rehabilitation therapies, or non-medical transportation through the DD waiver. Without these services, some TBI survivors with severe impairments will remain at risk of entering a long-term care facility. Some survivors are not capable of living alone and do not have family or friends who can provide live-in assistance. Others have behavioral and cognitive impairments that make it difficult for caregivers to provide adequate care.

The second option for expanding access to the DD waiver would involve adding new slots designated for persons with brain injury. According to DMAS staff, serving additional survivors with the current number of slots would be difficult because the waiting list for DD waiver services is approximately 700. Alternatively, the State could designate a certain number of existing slots in the DD waiver for brain injury survivors. However, this would effectively reduce the number of waiver slots available to otherwise eligible individuals without a traumatic brain injury. DMAS staff state that they would have to explore the feasibility of adding new slots

for persons with brain injury. In addition, adding new slots or additional services to the DD waiver would require approval from the Centers for Medicare and Medicaid Services (CMS), the federal agency overseeing the Medicaid program.

Benefits and Possible Challenges of Expanding the Individual and Family Developmental Disabilities Support Waiver. The primary benefit of expanding access to brain injury services through the DD waiver is that few changes would be needed to better meet the needs of brain injury survivors. The DD waiver already provides many of the services these persons need to remain in the community. Those who do not require residential housing services, cognitive rehabilitation therapies, or transportation are likely to receive adequate assistance from the DD waiver. And, as long as a brain injury occurred before age 22, persons with severe impairments are likely to meet the functional criteria for waiver eligibility.

There are three primary challenges to expanding access to brain injury services through the DD waiver. First, individuals who sustained a brain injury after age 22 would not be eligible for waiver services. This would prevent a substantial percentage of persons with brain injury from receiving waiver services. According to estimates from the Centers for Disease Control and Prevention, nearly half of all TBIs in the United States occur among persons over the age of 25.

A second challenge to using the DD waiver is that services would not be available to persons with brain injury living in, or at risk of entering, nursing homes. Eligibility for the DD waiver is based on eligibility for placement in an ICF-MR. This would exclude a substantial number of brain injury survivors because it appears that most institutionalized survivors live in nursing homes, while relatively few live in ICF-MRs.

A final challenge is that adding services to the DD waiver could add substantially to the cost of the waiver. Services such as residential housing assistance and neurobehavioral care can be costly to provide, and most likely would be made available to all DD waiver recipients, including those without a traumatic brain injury. According to DMAS staff and Medicaid officials in other states, adding new services to the DD waiver but limiting them to persons with brain injury would be complicated in practice. This approach risks creating a "waiver within a waiver," and would be difficult to administer and may not be approved by CMS.

POLICY CHOICES GUIDE PROVISION OF COMMUNITY-BASED BRAIN INJURY SERVICES

The extent to which the State provides community-based brain injury services is a policy choice. This report has identified unmet brain injury service needs as well as access issues for existing services. If additional resources are available for brain injury services, the State may want to first address the needs of those with the most severe functional disabilities, such as severe neurobehavioral problems and those at risk for placement in nursing homes or already in nursing homes. Currently, needed services for such persons are limited. Expansion of Virginia's Medicaid waiver program could aid the State's most severely impaired individuals with brain injury. Beyond these immediate needs, persons with brain injury could benefit from expansion of case management and clubhouse programs and the introduction of additional services, including supportive housing, transportation, and personal assistance. Without access to these services, individuals with severe impairments must rely on family or other caregivers for assistance and may be forced to enter long-term care facilities.

List of Recommendations: Access to State-Funded Brain Injury Services in Virginia

1. The Departments of Rehabilitative Services; Veterans Services; Mental Health, Mental Retardation and Substance Abuse Services; and other State entities that could have future responsibility for providing care to the State's returning military service members should develop a plan by July 1, 2008, to address coordination and access to brain injury services by active and retired military personnel.

2. The Department of Rehabilitative Services should perform or contract with a third party to annually perform program evaluations of at least two State-contracted brain injury service providers.

3. The Department of Rehabilitative Services' (DRS) Brain Injury and Spinal Cord Injury Services unit should include language in all State-funded contracts with brain injury service programs requiring each program to submit the annual independent audit that is conducted of each program. DRS should review these documents and share them with the department's Internal Audit Division to ensure appropriate use of State and federal funds.

4. The General Assembly may wish to consider amending §32.1-116.1 of the *Code of Virginia* to require (1) all licensed hospitals rendering emergency medical services to report to the Virginia Statewide Trauma Registry (VSTR) patient-level information on all persons diagnosed with a brain and/or spinal cord injury, sustained other than through disease, using the VSTR's reporting requirements, and (2) the Virginia Department of Health to transmit such information to the Department of Rehabilitative Services.

5. The General Assembly may wish to consider amending §51.5-11 of the *Code of Virginia* to eliminate the statutory language requiring hospital reporting to the brain injury registry. The General Assembly may also wish to consider amending the *Code of Virginia* to direct the Department of Rehabilitative Services to obtain the brain and/or spinal cord injury data collected by the Virginia Statewide Trauma Registry.

6. The Department of Rehabilitative Services should convene a work group consisting of the department, the Virginia Department of Health, brain and spinal cord injury stakeholders, and others as needed to identify the appropriate data elements needed from the Virginia Statewide Trauma Registry and the most appropriate electronic format for transmitting that information. The work group's recommendations should be reported to the House Health, Welfare, and Institutions and Senate Education and Health committees prior to the 2008 General Assembly Session.

7. The Department of Rehabilitative Services should require all State-funded brain injury service programs to provide the department with the information required by §51.5-11(B) of the *Code of Virginia*. The information should be reported each time a provider is contacted or makes contact with a new person with brain injury.

8. The Department of Rehabilitative Services should integrate the brain injury information it collects into the department's program, policy, and fiscal planning.

Appendix A

Study Mandate

Item 21F, 2006 Appropriation Act

F. The Joint Legislative Audit and Review Commission (JLARC) shall report on access to brain injury services in the Commonwealth. The report shall include, but not be limited to, the causes and prevalence of brain injuries, the array of community-based medical and/or rehabilitative services available in Virginia for treating individuals with brain injuries, the extent to which private insurance pays for brain injury services, and how other states have addressed the needs of individuals with brain injuries for community services. The report shall also examine funding provided through the Department of Rehabilitative Services to provide a continuum of community based brain injury services across the Commonwealth, including how efficiently and effectively funding is allocated and expended to meet service needs. JLARC shall submit a final report by October 1, 2007.

Appendix B

Research Activities and Methods

Key research activities and methods for this study included

- structured interviews,
- group interviews with brain injury survivors and caregivers,
- site visits to brain injury service providers,
- a survey of community-based brain injury case managers,
- data collection and analysis,
- case studies,
- document reviews,
- review of academic literature, and
- attendance at meetings and conferences.

STRUCTURED INTERVIEWS

JLARC staff conducted structured interviews with staff at the following State entities to better understand the system of public services for brain-injured persons in Virginia as well as how agencies view their role regarding brain injury survivors and coordinate with other agencies:

- DRS Brain Injury and Spinal Cord Injury Services unit and the Community Rehabilitation Case Management Services unit,
- Brain Injury Services unit at the Woodrow Wilson Rehabilitation Center (WWRC),
- Virginia Department of Medical Assistance Services,
- Virginia Department of Corrections,
- Virginia Department of Education,
- Virginia Department of Veterans Services,
- Virginia Department of Human Resource Management,
- Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services.

JLARC staff also conducted group interviews with brain injury survivors and caregivers regarding the availability and effectiveness of community-based services in Virginia. Such interviews were held in Roanoke, Charlottesville, and Northern Virginia, and included a total of 23 participants. In addition, staff interviewed most of the brain injury service providers currently receiving State funds to better understand the services they provide and brain-injured population they serve. Finally, staff interviewed brain injury clinicians and researchers regarding the effectiveness of State-funded brain injury services and best practices for treating brain-injured persons in community settings.

SITE VISITS TO BRAIN INJURY SERVICE PROVIDERS

JLARC staff visited brain injury service providers to better understand the services they provide and the brain-injured population they serve. Staff toured brain injury clubhouses in Richmond, Roanoke, and Charlottesville; residential treatment programs in Richmond and Blacksburg; the inpatient rehabilitation unit at the VCU Traumatic Brain Injury Model System; and the Brain Injury Services Unit at WWRC.

SURVEY OF BRAIN INJURY CASE MANAGERS

JLARC staff surveyed case managers with community-based providers receiving State funds to better understand the effectiveness and availability of brain injury services. Case managers were asked to assess the functional level of their brain-injured clients, rate the effectiveness of brain injury services, and identify needed services that were available and not available to their clients. In addition, case managers were asked to identify the funding source for services accessed by their clients and the reasons needed services were not accessed.

Staff surveyed 25 case managers with the six community-based organizations receiving State funds to provide case management services. Twenty-two case managers returned a survey for a response rate of 88 percent (see Table 15).

DATA COLLECTION AND ANALYSIS

JLARC staff collected and analyzed data on brain-injured persons reported to two State data collection registries as well as Medicaid data on services accessed. This data was collected from DRS, VDH, and DMAS.

Table 15: JLARC Staff Survey of Community-Based Case Management Providers

Provider	Number of Case Managers Surveyed	Number of Survey Responses Received
Brain Injury Services, Inc.	11	8
Brain Injury Services of Southwest Virginia	9	9
Community Futures Foundation, Inc.	1	1
Crossroads to Brain Injury Recovery, Inc.	2	2
MARC Workshop, Inc.	1	1
Virginia Supportive Housing	1	1
Totals	**25**	**22**

Virginia Central Registry for Brain Injury and Spinal Cord Injury

JLARC staff obtained from DRS a copy of the data contained in the Virginia Central Registry for Brain Injury and Spinal Cord Injury. The data was used to determine the frequency of traumatic brain injuries in the State between 2002 and 2007. According to DRS, data added to the registry during 2002 and after was likely to be more accurate due to an effort by the department to improve hospital reporting.

Virginia Statewide Trauma Registry

JLARC staff obtained from VDH a copy of the data contained in the Virginia Statewide Trauma Registry (VSTR). The data was used to compare against the brain injury registry to identify anyone listed in the VSTR with a traumatic brain injury but not identified in the registry. To perform this analysis, JLARC created an unduplicated dataset with each individual's name, birth date, and a unique identifier for anyone reported to the VSTR in 2006.

State Medicaid Claims Data

JLARC staff analyzed data provided by DMAS for Medicaid claims submitted during the FY 2004–FY 2006 period. Staff used the claims data to identify the number of brain injury survivors who received services through home and community-based (HCB) waivers, the number who lived in long-term care facilities, and the total number who accessed Medicaid-funded services during this period. Diagnostic codes from the Virginia Central Registry were used to identify individuals with a traumatic brain injury diagnosis. The

data did not permit JLARC staff to determine whether a person received services for their brain injury or for another medical condition.

Data from DMAS included reimbursement claims for the following services:

- outpatient services,
- hospital inpatient care,
- prescription drugs,
- dental care, and
- patient-pays for Medicare.

JLARC staff used claims for outpatient services, inpatient care, and Medicare patient-pays to identify brain injury survivors enrolled in HCB waivers. Claims for inpatient services were used to identify survivors in skilled nursing facilities, intermediate care facilities (ICFs), and ICFs for the mentally retarded. Staff did not use claims for dental services or prescription drugs when determining the total number of brain-injured persons who received Medicaid-funded services.

CASE STUDIES

JLARC staff requested case studies from community-based service providers to better understand the needs of brain injury survivors and caregivers. Staff used case studies to supplement and validate findings regarding the availability and effectiveness of brain injury services. Case studies also provided insight into the experiences of survivors and caregivers, the effectiveness of certain community-based services, and the difficulty accessing services in underserved communities.

DOCUMENT REVIEWS

JLARC staff reviewed the contracts of the nine State-contracted brain injury service providers. In addition, JLARC staff also reviewed the FY 2006 and FY 2007 annual reports of the six providers in operation prior to FY 2007. (Funding was not provided to three programs until March of FY 2007, and therefore, there was little for these providers to report.) The contracts were used to identify the agreed-upon deliverables for each provider and the annual reports were reviewed to identify the extent to which these deliverables were achieved. JLARC staff also requested a copy of each service provider's most recent independent financial audit to review the findings and recommendations. The financial audits conducted by the DRS internal auditor of the Brain Injury and Spi-

nal Cord Injury Services unit and a provider of clubhouse/day programs were also reviewed. JLARC staff also reviewed the findings and recommendations of several program evaluations conducted for DRS by a private consultant in 2004, as well as the findings and recommendations of a program audit conducted by Fairfax County in 2006.

REVIEW OF PROFESSIONAL LITERATURE

JLARC staff conducted literature reviews to supplement findings regarding the effectiveness of the following brain injury services:

- clubhouse/day programs,
- case management,
- vocational rehabilitation, and
- cognitive rehabilitation therapies.

Staff also reviewed selected literature regarding the incidence and prevalence of traumatic brain injury, other states' programs for brain-injured persons, and the use of Medicaid waivers to serve the brain-injured population. Priority was given to critical reviews of previously published literature and to more recent research. Finally, staff consulted a medical textbook for brain injury clinicians to better understand the medical and rehabilitative needs of brain-injured persons.

ATTENDANCE AT MEETINGS

JLARC staff attended the April and July meetings of the Virginia Brain Injury Council, a statewide interagency commission responsible for advising DRS on improving access to brain injury services in Virginia. Staff also attended a July meeting of the Virginia Alliance for Brain Injury Service Providers and the June meeting of the CNI Advisory Board at which grants for brain and spinal cord injury research were awarded. Finally, staff attended a support group meeting for brain injury survivors and caregivers in the Gloucester area.

JLARC staff attended one conference and one seminar for brain injury service providers during the study. Staff attended a two-day conference on best practices for treating brain injury survivors in the community, sponsored by Brain Injury Services, Inc., the National Resource Center for Traumatic Brain Injury, and the VCU Traumatic Brain Injury Model System. Conference faculty included brain injury researchers, clinicians, and service providers as well as staff from DRS. Finally, staff attended a seminar organized by DRS for State-funded brain injury service providers.

Appendix C

Services in Virginia for People With Brain Injury

Administered by DRS
Brain Injury Direct Services Fund – Provides short-term specialized services, assistive technology, and other equipment or goods to help individuals live more independently and move forward in their recovery. The BIDS Fund does not pay for inpatient medical rehabilitation or any other residential services.
Centers for Independent Living – Comprised of 16 facilities throughout the State run by disabled persons that provide information and referral, peer counseling, and individual life skills training.
Commonwealth Neurotrauma Initiative Trust Fund – Established legislatively in 1997 for the purpose of "improving the treatment and care of Virginians with traumatic spinal cord or brain injuries." Grants are awarded in rotating years for research and community-based services.
Federal Traumatic Brain Injury Act – DRS oversees the grant award through a contract with the Brain Injury Association of Virginia. Funding is used to maintain and strengthen existing brain injury infrastructures and increase community advocacy.
Personal Assistance Services for People with Brain Injury – Provides personal assistance with dressing, bathing, and housework to physically disabled persons who are ineligible for these services under other programs.
Woodrow Wilson Rehabilitation Center – State-funded rehabilitation center located in Fishersville providing rehabilitation therapy and vocational training. The Center also includes a brain injury services program that includes neuropsychological assessments and therapies, cognitive rehabilitation services, and other programs.
Virginia Central Registry for Brain Injury and Spinal Cord Injury – Database is required under the *Code of Virginia* to track and provide outreach to persons treated for a brain injury.
Vocational Rehabilitation Program – State and federally funded program that offers employment-related assistance to persons with disabilities, including brain injuries.
State-Contracted Services
Brain Injury Association of Virginia – Provides statewide information and support to people with a brain injury, family members and professionals. Conducts mailings and provides information based on the State registry.
Brain Injury Services, Inc. – Provides information and referral, case management, supported living, volunteer placement, and clubhouse programs for persons in Northern Virginia with brain injuries.
Brain Injury Services of Southwest Virginia – Provides information and referral, case management, life skills services, and volunteer placement for persons in Southwest Virginia with brain injuries.

State-Contracted Services
Commonwealth Support Systems, Inc. – Operates day programs in Virginia Beach and Belle Haven at which brain injured persons participate in a structured environment through vocational tasks, community outings, computer training, and social activities.
Community Futures Foundation, Inc. – Operates clubhouses in Richmond and Newport News providing members with a work-ordered day focused on improving work skills and emotional behavior. Case management, life skills management, and volunteer placement are also provided.
Crossroads to Brain Injury Recovery, Inc. – Provides information and referral, case management, life skills services, and volunteer placement for persons with a brain injury in the Greater Shenandoah Valley.
MARC Workshop, Inc. – Provides information and referral, case management, life skills services, and volunteer placement for persons in parts of Southside Virginia with a brain injury.
Virginia Neurocare – Operates a clubhouse in Charlottesville providing members with a work-ordered day focused on improving work skills and emotional behavior.
Virginia Supportive Housing – Manages two residential facilities in Richmond and provides residents with case management.
Source: DRS, *Services for People with Brain Injury in Virginia*, Feb. 2007. Available at http://www.vadrs.org/formscabinet/

Appendix D Number of Persons Served by Brain Injury Services in Virginia

	FY 2002	FY 2003	FY 2004	FY 2005	FY 2006	FY 2007
Case Management						
Brain Injury Services, Inc.	339[b]	371[b]	359[b]	390[b]	394	424
Brain Injury Services of Southwest Virginia	0	10[b]	39[b]	91	182	271
Crossroads to Brain Injury Recovery, Inc.	NSFA					17
MARC Workshop, Inc.	NSFA					19
Virginia Supportive Housing	NSFA					6
Community Futures Foundation, Inc.	NSFA					12
Clubhouses/Day Programs						
ADAPT Clubhouse	34	37	48	40	36	33
Denbigh House Clubhouse	NSFA			18	26	30
High Street Clubhouse	26[b]	22[b]	30[b]	30	27	27
Mill House Clubhouse	43[b]	51[b]	52[b]	45	42	41
No Limits Day Program	15	16	12	15	17	19
SEEK Day Program	30	30	25	20	34	40
Westwood Clubhouse	NSFA	12	14	16	23	39
Regional Resource Coordination						
Persons Receiving Individual Assistance	NSFA	NSFA	NSFA	300	200	509
Persons Attending Support Groups	NSFA	NSFA	NSFA	200	100	437
DEPARTMENT OF REHABILITATIVE SERVICES						
Brain Injury & Spinal Cord Injury Services Unit of Community-Based Services Division						
Brain Injury Direct Services Fund[a]	24	14	11	26	18	30
Community Rehabilitation Case Management Services Unit of CBS Division						
CRCMS Program	77	108	111	106	106	NS
Personal Assistance Services Unit of Community-Based Services Division						
Personal Assistance Services	11	9	9	8	7	6
Woodrow Wilson Rehabilitation Center						
WWRC Brain Injury Services Program	81	64	54	50	66	65
State Vocational Rehabilitation Program (Field Rehabilitation Services)						
Vocational Rehabilitation Services	771	757	631	576	570	540
Supported Employment Services	218	235	209	169	193	223
Job Coach Training Services	43	50	34	26	38	24

Note: NSFA, No State funding allocated during this period; NS, Not submitted. Numbers may include persons with non-traumatic or non-acquired brain injuries. An eighth clubhouse received Commonwealth Neurotrauma Initiative Trust funding for FY 2007 and served 15 individuals.

[a] Used to provide funds for short-term, specialized services, assistive technology, and other discretionary uses.

[b] Includes persons served through Commonwealth Neurotrauma Initiative Trust funds.

Source: Information provided to JLARC staff by DRS and service programs.

Appendix E

DRS Hospital Reporting Form

Revised 3/2004

DEPARTMENT OF REHABILITATIVE SERVICES

COMMONWEALTH OF VIRGINIA
Virginia Central Registry for Brain Injury & Spinal Cord Injury

Section 51.5-11 of the Code of Virginia mandates that the Department (*of Rehabilitative Services*)… establish and maintain a central registry of persons who sustain spinal cord injury…and brain injury. Every hospital…shall report to the Department…any person sustaining brain injury and…spinal cord injury.

PLEASE PRINT CLEARLY AND LEGIBLY!

1. HOSPITAL MEDICAL RECORDS # _____ SS# ___ - ___ - ____

Name _____ Date of Birth ___/___/___
last First Middle mo. day year

Address _____ Telephone ( )

City _____ State _____ Zip Code _____

2. DATE OF INJURY ___/___/___ (mo. day year) **3.** Male ☐ Female ☐

4. CAUSE OF INJURY (*check one*)

Motor vehicle	☐	Sports/recreation	☐	Diving	☐	Motorcycle	☐
Gunshot	☐	Bicycle	☐	Fall	☐	Pedestrian	☐
Assault	☐	Other/Unknown (*specify*)					

5. INITIAL CONDITION OF PATIENT (*check all that apply*)

Was patient unconscious? Yes ☐ No ☐ Unknown ☐

If yes, how long? ☐ Less than 1 hour ☐ Over 1 hour, less than 24 ☐ More than 24 hours**
☐ Unknown **If unconscious for more than 24 hours, how many days?

Glasgow Coma Score: ☐ 3-8 (severe) ☐ 9-12 (moderate) ☐ 13-15 (mild) ☐ unknown
(*use lowest known score*)

6. PATIENT DIAGNOSES ICD- 9 Codes (*check all that apply*)

BRAIN INJURY		SPINAL CORD INJURY	
348.1	☐ Anoxic Brain Damage	806.0 - 806.19 or 952.0 - 952.09	☐ Cervical
800 - 801.9	☐ Fracture of Skull	806.20 - 806.39 or 952.10 - 952.19	☐ Thoracic
803 - 804.9	☐ Other/Multiple Skull Fractures	806.4, 806.5 or 952.2	☐ Lumbar
850 - 854.1	☐ Intracranial Injury	806.60 - 806.79 or 952.3 - 952.4	☐ Sacral/Coccyx
959.01	☐ Head Injury, Unspecified	952.8	☐ Multiple Sites
995.55	☐ Shaken Infant Syndrome	806.8, 806.9 or 952.9	☐ Unspecified Sites
Unknown	☐		

7. DISPOSITION (*check only ONE*)

☐ Seen in our Emergency Department *only* (*treated and released* OR *treated and transferred*)
Date of Treatment in ER: ___/___/___
Date of Discharge from ER: ___/___/___

☐ Admitted to our Hospital?
Date of Admission to Hospital: ___/___/___
Date of Discharge from Hospital: ___/___/___

Discharged to: (*complete for **ALL** patients*)
☐ home
☐ other facility _____ (*specify*)
☐ deceased _____ (*date*)
☐ unknown

8. FORM COMPLETED BY (*fill out completely*)

I certify that this form is filled out completely and accurately to the best of my knowledge.

Name _____ _____
please print *signature*

Today's date ___/___/___ (mo. day year) Hospital _____

VIRGINIA CENTRAL REGISTRY for BRAIN INJURY & SPINAL CORD INJURY

THE VIRGINIA CENTRAL REGISTRY SERVES SEVERAL PURPOSES:

- It provides the means for the Brain Injury Association of Virginia (BIAV) and for Woodrow Wilson Rehabilitation Center (WWRC) to contact and offer timely assistance to all Virginians who sustain brain injuries and/or spinal cord injuries.
- It provides statewide statistics regarding the incidence of brain and spinal cord injury.
- It provides information to the Department of Rehabilitative Services (DRS) and other agencies and organizations that is useful in planning and delivering statewide brain injury and spinal cord injury services.

WHO SHOULD BE REPORTED? Patients who are treated for trauma and/or have any of the following ICD-9 codes should be reported to the ***Virginia Central Registry for Brain Injury & Spinal Cord Injury***:

Brain Injury ICD-9 Code Categories*:

348.1	Anoxic brain damage*
800.0 - 801.9	Fracture of skull
803.0 - 804.9	Other and unqualified and multiple skull fractures
850.0 - 854.1	Intracranial injury
959.01	Head injury - unspecified
995.55	Shaken Infant Syndrome

**Anoxia caused by cardiac arrest, medical-surgical procedures, or a disease process should not be reported. Strokes should not be reported.*

Spinal Cord Injury ICD-9 Code Categories*

Cervical	806.0 - 806.19 952.00 - 952.09	Fracture of vertebral column w/SCI SCI w/out spinal bone injury
Thoracic	806.20 - 806.39 952.10 - 952.19	Fracture of vertebral column w/SCI SCI w/out spinal bone injury
Lumbar	806.4, 806.5 952.2	Fracture of vertebral column w/SCI SCI w/out spinal bone injury
Sacral/Coccyx	806.60 - 806.79 952.3, 952.4	Fracture of vertebral column w/SCI SCI w/out spinal bone injury
Multiple Sites	952.8	SCI w/out spinal bone injury
Unspecified	806.8, 806.9 952.9	Unspecified site of SCI Unspecified site of SCI w/out spinal bone injury

**Spinal and related neurological problems that are congenital or the sole consequence of a disease process should not be reported.*

Report all patients who are treated in your emergency room and released, admitted to your hospital for inpatient treatment, transferred into or out of your hospital for treatment, declared "Dead On Arrival" at your hospital, and patients who expire during treatment at your hospital (whether due to these specified injuries or other reasons).

WHEN COMPLETING SIDE ONE OF THIS FORM, REMEMBER THE FOLLOWING:

- Please PRINT clearly and legibly!
- Include the Social Security number. If it is not available anywhere in hospital records, note that on the form.
- Indicate all diagnoses that are applicable for this patient.
- Complete all sections, even if only checking off "don't know" or "unavailable".
- Forms should be submitted within 30 days of identifying a patient with brain injury, and within 7 days of identifying a patient with spinal cord injury.
- Include the name and hospital of the person filling out the report; fill in the date that the form is completed.

WHEN IN DOUBT, PLEASE REPORT THE PATIENT... OR CALL:

The Brain Injury Association of Virginia at 804-355-5748 or e-mail info@biav.net with your questions and concerns.

RETURN COMPLETED REPORTING FORMS TO:

Virginia Central Registry for Brain Injury & Spinal Cord Injury
P. O. Box K300, Richmond, VA 23288-0300
Toll Free Number 1-800-552-5019

Please note that you can access this reporting form via Internet at http://www.vadrs.org/formscabinet

Appendix F

Agency Responses

As a part of the extensive validation process, State agencies and other entities involved in a JLARC assessment effort are given the opportunity to comment on an exposure draft of the report. Appropriate technical corrections resulting from comments provided by these entities have been made in this version of the report. This appendix includes written responses from the Departments of Rehabilitative Services, Health, and Medical Assistance Services.

AUG 31 2007

COMMONWEALTH of VIRGINIA

James A. Rothrock, M.S., L.P.C.
COMMISSIONER

Department Of Rehabilitative Services
8004 FRANKLIN FARMS DRIVE
RICHMOND, VIRGINIA 23229

VOICE: (804) 662-7000
TTY: (804) 662-9040
VOICE - TOLL FREE: 800-552-5019
TTY - TOLL FREE: 800-464-9950
FAX: (804) 662-9532
EMAIL: drs@drs.virginia.gov

August 30, 2007

Philip A. Leone
Joint Legislative Audit & Review Commission
General Assembly Building, Suite 1100
Richmond, Virginia 23219

Dear Mr. Leone:

First let me take the opportunity to express to you, and particularly Mr. Messick, our collective thanks and appreciation for taking the time to conduct such a thorough review of the Brain Injury services operated in and through our agency and/or found within the Commonwealth in general.

I have had the opportunity to review your report and am in basic agreement with your findings. Your report commends our attention to the following and I heartily concur with the:

- Need for additional programming in the area of Neurobehavioral Care;
- Importance of DRS increasing our role as a monitoring entity to go beyond contract reviews and approach more substantive program evaluation;
- Review of the Registry process to improve the manner in which Brain Injury survivors are informed about the services they need that we do have in our Commonwealth;
- Assessment of how the Commonwealth Neurotrauma Initiative Fund can be used to support Neurobehavioral programming.

Although we are confident in our management of these funds during the "start up" phase—the last few years that have marked an historic growth in funds for Brain Injury—we also fully recognize our responsibility to assure solid stewardship of these funds. We are already reviewing allocation protocols that would allow us to get the funds to our partners, but at the same time, allow us to expand our program evaluation efforts.

I look forward to your meeting in September, where I can personally address these findings and again thank you for your efforts that will improve our Commonwealth's capacity to respond to the ever increasing needs of this important population.

With best regards, I am

Sincerely,

James A. Rothrock

SEP 07 2007

COMMONWEALTH of VIRGINIA

Robert B. Stroube, M.D. M.P.H
State Health Commissioner

Gary R. Brown
Director

P. Scott Winston
Assistant Director

Department of Health
Office of Emergency Medical Services

109 Governor Street Suite UB-55
Richmond, VA 23219
1-800-523-6019 (VA only)
804-864-7600
FAX: 804-864-7580

August 27, 2007

To: Philip A. Leone, Director
Joint Legislative Audit and Review Commission (JLARC)

From: Paul M. Sharpe, Trauma/Critical Care Coordinator

Through: Gary R. Brown, Director
Robert B. Stroube, M.D., M.P.H., State Health Commissioner

Re: Response to Exposure Draft; Access to State-Funded Brain Injury Services in Virginia

Mr. Leone;

Thank you for the opportunity to review and provide comment on the Exposure Draft of The JLARC report "Access to State-Funded Brain Injury Services in Virginia." Due to the time constraints, the focus of this response will be on chapter five "Identification of Brain Injury Survivors Needs Improvement" and limited to clarifying factual matters and responding to the recommendations made by JLARC. Chapter five discusses the Virginia Statewide Trauma Registry (VSTR) and its potential uses with Department of Rehabilitative Services (DRS) outreach to citizens in the Commonwealth potentially in need of DRS services.

During follow up discussions between the OEMS and JLARC staff, clarifying language was proposed that would provide for recommendations, that in summary, would allow data that is currently being submitted to the Brain and Spinal Cord Injury Registry and the VSTR to be submitted only to the VSTR. In many instances these patients are being submitted twice by hospitals resulting in a duplication of effort. With the recommendation including that data being collected for brain injury, spinal cord injury, and traumatic injury is submitted using the VSTR reporting requirements, VDH/OEMS fully supports the integration of these databases.

Understanding that the DRS will need to have access to patient identifiable information to perform outreach, as well as, access to data for program assessment and planning, OEMS will begin performing quality assessments in preparation of potentially combining these services in the future.

Again, thank you for the opportunity to provide comment on this important matter. Please feel free to contact us if you have any further questions.

COMMONWEALTH of VIRGINIA

Department of Medical Assistance Services

PATRICK W. FINNERTY
DIRECTOR

SUITE 1300
600 EAST BROAD STREET
RICHMOND, VA 23219
804/786-7933
800/343-0634 (TDD)
www.dmas.virginia.gov

August 30, 2007

Mr. Philip A. Leone
Director
Joint Legislative Audit and Review Commission
Suite 1100, General Assembly Building, Capital Square
Richmond, VA 23219

Phil

Dear Mr. Leone:

Thank you for the opportunity to review and comment on the exposure draft of the report titled *Access to State-Funded Brain Injury Services in Virginia*. I commend you and your staff's effort in its broad examination of the issues surrounding brain injury services in the Commonwealth.

As the report clearly indicates, the Department of Medical Assistance Services (DMAS) already plays a major role in the financing of healthcare on behalf of many brain-injured individuals through institutional placements and through our home and community-based waiver programs. We would agree that the Medicaid program in Virginia could potentially be modified to increase the number of brain-injured recipients served through the program, and could potentially provide these individuals with more specialized services. As you are certainly aware, any Medicaid program modifications for brain injured recipients, whether through modifications to existing waivers or through a new waiver, would require federal approval and would require additional state and federal funding. These factors would likely drive the design of any specific program addressing brain-injured individuals.

Obviously, DMAS has not had the opportunity to verify current brain-injured recipient counts nor initiate any analysis of waiver design options expressed in the draft report within the allotted time for review of this draft report. However, DMAS stands ready to work with all interested parties to further explore whatever options the Governor and General Assembly believe appropriate in response to this report. Again, thank you for the opportunity to comment on the draft report.

Sincerely,

Patrick W. Finnerty
Director

PWF/sf

cc: The Honorable Marilyn B. Tavenner, Secretary of Health and Human Resources

JLARC Staff

Executive Staff

Philip A. Leone, Director
Glen S. Tittermary, Deputy Director

Division Chiefs

Robert B. Rotz, Senior Division Chief
Harold E. Greer III, Division Chief

Section Managers

Patricia S. Bishop, Fiscal & Administrative Services
Gregory J. Rest, Research Methods
Walter L. Smiley, Fiscal Analysis

Project Leaders

Aris W. Bearse
Justin C. Brown
Ashley S. Colvin
Martha L. Erwin
Eric H. Messick
Nathalie Molliet-Ribet
Kimberly A. Sarte

Project Staff

Janice G. Baab
Jamie S. Bitz
Jennifer K. Breidenbaugh
Eileen T. Fleck
Mark R. Gribbin
Paula C. Lambert
Bradley B. Marsh
Ellen J. Miller
Stefanie R. Papps
Jason W. Powell
Pinki N. Shah
Tracey R. Smith
Elisabeth M. Thomson
Christine D. Wolfe

Administrative and Research Support Staff

Joan M. Irby
Betsy M. Jackson

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345. VRS Biennial Status and Semi-Annual Investment Report No. 27
346. Evaluation of Children's Residential Services Delivered Through the Comprehensive Services Act
347. Virginia Compared to the Other States
348. Review of State Spending (2006 Update)
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2007 Reports

352. Follow-Up Report: Custody Relinquishment and the Comprehensive Services Act
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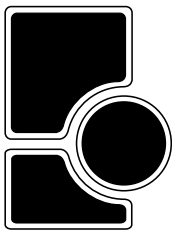
358. Evaluation of Senate Bill 931: Mandated Coverage of Prosthetic Devices

These reports are available on the JLARC website at http://jlarc.state.va.us



Joint Legislative Audit and Review Commission
Suite 1100
General Assembly Building
Capitol Square
Richmond, Virginia 23219
804-786-1258 Fax 804-371-0101
http://jlarc.state.va.us