FULL REPORT

Brain Injury in Virginia:

State Action Plan 2009-2013







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To view the 2009-2013 Brain Injury in Virginia State Action Plan please visit: www.vadrs.org/VBIAP.htm

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Introduction

The 2009-2013 Brain Injury Action Plan, developed under the leadership of the Virginia Brain Injury Council, serves as a "blueprint" for addressing gaps in services and unmet needs of Virginians with brain injury and their families. Written and telephone surveys and town meetings have been used to elicit feedback for revising and updating the original Statewide TBI Action Plan 1998-2000. The 2009-2013 Brain Injury Action Plan identifies and makes recommendations regarding current (and remaining) gaps in services and resources as determined by Virginia's brain injury community.

The purpose of Virginia's 2009-2013 Brain Injury Action Plan is to serve as a blueprint for the development of a culturally competent, comprehensive, community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of brain injury services and addresses the needs of people with brain injury and their family members / caregivers.

The three broad goals of the **2009-2013 Brain Injury Action Plan** are:

- 1. Expanded Access to Brain Injury Supports and Services Enhance comprehensiveness of services available to all Virginians with brain injury; Expand residential and community-based neurobehavioral treatment options; Expand community living options and appropriate supports to facilitate community integration; and Enhance opportunities to contribute to the community through participation in productive activities.
- 2. Systems Change and Management Develop evidence-based policy and program initiatives to meet the needs of people with brain injury and their family members / caregivers, particularly those representing unserved or underserved populations; and Increase funding for brain injury programs and services to address gaps in service delivery system.
- **3.** Community Impact Provide brain injury information, resources, and education to improve public knowledge and enhance quality of services for people with brain injury and their family members / caregivers.

(See pages 12-14 of this document for more detailed information on these three major goals.)

The 2009-2013 Brain Injury Action Plan will shape the development of a comprehensive service system for Virginians with brain injuries. It will involve collaboration among people with brain injury, family members / caregivers, state agencies, and community partners serving people with brain injury throughout the Commonwealth. The Virginia Brain Injury Council, the advisory group to the Department of Rehabilitative Services, will monitor the implementation of the plan. The Council's vision - that Virginians and their families who experience disability due to brain injury will build a quality of life of their choosing - is reflected in this 2009-2013 Brain Injury Action Plan, which is intended to propel the Commonwealth toward that vision.

Note: For clarity, we chose to consistently use the agency name "Department of Behavioral Health and Developmental Services (DBHDS)" throughout this document, regardless of year being referenced. The name of DBHDS, formerly the Department of Mental Health, Mental Retardation, and Substance Abuse Services, was changed effective 7/1/09.

Background

Definition

As defined in the Code of Virginia, "Brain injury" (§ 37.2-403) means any injury to the brain that occurs after birth...[and] is acquired through traumatic or non-traumatic insults. Non-traumatic insults may include, but are not limited to anoxia, hypoxia, aneurysm, toxic exposure, encephalopathy, surgical interventions, tumor and stroke. Brain injury does not include hereditary, congenital or degenerative brain disorders, or injuries induced by birth trauma."

The definition used by the Brain Injury Association of America (BIAA) and the Brain Injury Association of Virginia (BIAV) is: "A brain injury can be acquired through traumatic or non-traumatic events. A traumatic brain injury (TBI) is an alteration in brain function, or other evidence of brain pathology, caused by an *external force*, including falls and motor vehicle accidents. A non-traumatic brain injury is the result of an *internal source*, as from a stroke or lack of oxygen to the brain."

The brain can be injured in many ways, and a brain injury is referred to by many names. However, all brain injuries are classified according to *when* they occur and the *causes*. Brain damage that occurs before or during the birth process is *congenital* and resulting impairment is considered to be a developmental disability because it happens during the early, developing years of the child. Injury to the brain following birth is *acquired* and can be caused by traumatic or non-traumatic means, or both. *Non-traumatic* brain injuries result from internal causes such as strokes and aneurysms, lack of oxygen or blood to the brain, and exposure to toxic substances. *Traumatic* injuries result from external causes such as blunt force against the skull or the skull hitting against a fixed object, which can occur in car crashes, falls, gunshot wounds, and assaults, including those due to domestic violence and child abuse.

Effects

The range of effects of brain injury may include impairments in physical, cognitive, emotional, and sensory functioning which can affect every area of a survivor's life. Depending upon where the brain has been damaged, and the nature of the injury (traumatic versus non-traumatic), the resulting impairments will vary from person to person. Just as every brain is unique, every brain injury results in a variety of short and long-term effects.

Incidence, Prevalence, and Cost

The most recent census shows Virginia's population at 8,001,024. According to the Centers for Disease Control (CDC), an estimated 1.1% of the population in the U.S. is living with a traumatic brain injury (TBI) related disability. Based on current Virginia census estimates, 181,623 Virginians experience disability as a result of a traumatic brain injury: 88,011 Virginians disabled as a result of TBI (including 21,309 of children aged 1-18), and 93,612 disabled due to stroke.

The costs of injury, both in terms of economic and human impact, are immense: recent estimates put brain injury's annual cost to society at \$60 billion annually.

Services in Virginia

The Brain Injury Services Coordination Unit (BISCU) within the Department of Rehabilitative Services (DRS) manages over \$6 million in programs, contracts, and state/federal grants that provide brain injury services (direct and indirect) throughout the Commonwealth. BISC Unit assists the "lead state agency" in planning and monitoring services that enhance the quality of life and vocational goals of people with acquired brain injury. The BISCU provides information about brain injury to DRS staff and external customers, and assists individuals to obtain DRS services. BISCU also staffs the Commonwealth Neurotrauma Initiative Trust Fund and the Virginia Brain Injury Council, both serving as advisory groups to the DRS Commissioner.

*More information about DRS programs and services can be found in Appendix 1.

Action Plan: History and Process

The Virginia Brain Injury Council (VBIC), established in 1986, serves as the advisory body to a Federal Traumatic Brain Injury (TBI) Act grant awarded to the Department of Rehabilitative Services (DRS), the lead agency in Virginia for the coordination of brain injury services (per Code of Virginia). In 1998, the Department of Rehabilitative Services (DRS) was awarded a two-year Federal TBI Act "Planning Grant" which provided the impetus and funding for a statewide needs and resources assessment. This assessment, completed in 2000, was done by Virginia Commonwealth University's Department of Physical Medicine & Rehabilitation and the Brain Injury Association of Virginia. The assessment formed the basis of the *1998-2000 Statewide Traumatic Brain Injury (TBI) Action Plan*. The 2000 Plan recommended the development of comprehensive services to meet the needs of Virginia's community of people with brain injury, their family members / caregivers, and service providers.

The goals of the 1998-2000 Statewide TBI Action Plan centered around ten key areas:

- Information/Referral and Advocacy
- Case Management
- Residential Treatment
- Community Living Services
- Employment
- Transportation
- Day Programs/Services
- Social/Recreational/Peer Support
- Individual/Family Supports
- Education/Awareness

DRS received additional federal funding through a TBI Act "Implementation Grant" and in Spring 2005 formed a Steering Committee to oversee the process of updating Virginia's 1998-2000 Action Plan. Representatives from the Virginia Brain Injury Council (VBIC), the Brain Injury Association of Virginia (BIAV), the Commonwealth Neurotrauma Initiative (CNI) Trust Fund Advisory Board, and the Virginia Alliance of Brain Injury Service Providers (VABISP) developed a work plan to carry out this important activity.

The Virginia Brain Injury Council endorsed the Steering Committee's work plan, which involved hosting Brain Injury Town Meetings across the state to which survivors, family members, professionals, and other stakeholders were invited to participate. DRS partnered with the Brain Injury Association of Virginia (BIAV) and with the Virginia Commonwealth University (VCU) Rehabilitation Research & Training Center to conduct the Town Meetings and prepare a report of its findings. The Town Meeting process allowed facilitators to receive feedback on the development of "core" or foundational brain injury services; to identify and prioritize local service needs; and to share information on developing and enhancing services within the local community.

In 2005 the Department of Rehabilitative Services (DRS) hosted several brain injury Town Meetings across the Commonwealth and invited people with brain injury, family members / caregivers,

professionals, and other stakeholders to participate. The Town Meeting process allowed facilitators to receive feedback on the development of "core" or foundational brain injury services; to identify and prioritize local service needs; and to share information on developing and enhancing services within a local community. DRS partnered with the Brain Injury Association of Virginia (BIAV) and with the VCU Rehabilitation Research and Training Center (RRTC) to conduct the Town Meetings and prepare a report of the findings. This process was accomplished through facilitated Town Meetings in five (5) localities across Virginia (Virginia Beach, Abingdon, Harrisonburg, Roanoke, and Alexandria), as well as web-based and paper surveys for those citizens unable to participate in a Town Meeting.

Feedback from these meetings revealed significant progress toward the achievement of many of the goals in the initial *1998-2000 Action Plan*, but also that a tremendous amount of work still needed to be done, particularly in the area of comprehensive service development. The services identified as most critical were case management, clubhouses / day programs, regional resource coordination, residential services, community living supports (including cognitive rehabilitation and mental health / substance abuse services), transportation services, and neurobehavioral treatment and supports.

In 2007, DRS invited Susan Vaughn, Director of Public Policy for the National Association of State Head Injury Administrators (NASHIA), to the January 2007 meeting of the Virginia Brain Injury Council to provide an overview of other states' advisory councils and statewide actions plans. DRS also hired an in-state consultant to review Virginia's progress toward meeting the goals and objectives in the 2000 Statewide TBI Action Plan. Dr. Ann Deaton, a neuropsychologist, utilized the results of a series of statewide town meetings held in 2005; personal interviews with key stakeholders; written surveys of people with brain injury, family members / caregivers, state-funded Brain Injury Services (BIS) Programs, and other professionals to evaluate and report on progress made in achieving the goals of the 1998-2000 Statewide Traumatic Brain Injury (TBI) Action Plan.

The written survey concluded that the past eight years have yielded significant progress in each of the ten key areas identified in the original 2000 plan. Funds appropriated by the Virginia General Assembly in 2004 for brain injury services led to the creation of three "core services" to serve as the foundation of an infrastructure for the delivery of brain injury services. These core services are case management services for adults and children; specialized clubhouses / day programs; and regional resource coordination. (There is additional information on the DRS website on Virginia's three "core" services: Case Management; Clubhouse/Day Programs; and Regional Resource Coordination.)

Since the initial General Assembly allocation of dedicated funding for brain injury services in 1985 (\$250,000), Virginia has seen a remarkable expansion of these services: from one state-funded organization in 1985 to two state-funded programs in 2004 to nine organizations currently operating 12 programs statewide. However, there is widespread agreement among stakeholders that Virginia still lacks a comprehensive service delivery system for people with brain injury. It is critical that survivors have access to treatment, interventions, and community services that improve the quality of their lives and their ability to make a contribution to our communities.

Based on Dr. Deaton's evaluation, DRS and BIAV – with endorsement by the Virginia Brain injury Council - developed a State Action Plan Executive Summary in 2009, as well as a consumer-friendly State Action Plan Booklet with background information and an overview of the Plan's three target areas.

*More information about the results of this survey can be found in Appendix 2.

Recent Developments

Policy initiatives, needs assessments, legislative studies and advocacy efforts conducted over the last five years have led to increased awareness of the silent epidemic of brain injury and have been used to guide in the development of the 2009-2013 Brain Injury Action Plan.

Office of the Secretary of Public Safety 2008 Report on the Incidence of Traumatic Brain Injury in Offender Populations

In an effort to address the lack of information on brain injury prevalence rates among incarcerated populations in Virginia, the Virginia General Assembly passed a House Budget Amendment in 2008 requiring the Secretary of Public Safety to report the incidence of traumatic brain injury in the adult and juvenile offender populations to the chairs of the House Appropriations and Senate Finance committees. A workgroup to oversee the report process was established by the Secretary of Public Safety.

Methods of data collection and availability of data varied between the departments of Juvenile Justice (DJJ) and Corrections (DOC). However, the results of this study indicated that approximately 20% of the incarcerated population may have a history suggestive of TBI. Medical data collected by Juvenile Justice during State Fiscal Year (SFY) 2007 (7/1/2006-6/30/2007) revealed that that 17.2% of the juvenile offender population had received medical attention due to head trauma; psychological information collected during the same period showed that 21.7% of the population had received medical attention due to head trauma. While these data do not establish the prevalence or severity of TBI in this population, they do suggest that close to one in five juveniles committed to DJJ has a history that raises the possibility of TBI, although the percentage of the population that has functionally significant brain injuries as a result of head trauma is unclear.

Data prepared by the Department of Corrections (DOC) revealed that 17.8% of prisoners received at DOC facilities during August 2008 had experienced an injury to the head or brain, and 61.9% of those who had experienced a head injury also had a loss of consciousness. In comparing the two sets of data from the Department of Juvenile Justice and the Department of Corrections, neither definitively establish the prevalence or severity of TBI in this population, but they both document close to one in five inmates has a history that raises the possibility of TBI.

TBI data from locally operated jails and juvenile detention centers are not available in a centralized database. While some of these facilities may collect relevant data, obtaining meaningful data from these facilities will require resources beyond the capability of this work group. Given the lack of resources and information in this area, the 2008 work group recommended that research be undertaken to investigate the prevalence of TBI in Virginia's offender populations and to develop a best practices model for screening, evaluation, and treatment. Furthermore, the work group urged that this effort begin with the population of juveniles committed to Virginia's juvenile correctional centers.

Department of Veterans Services Wounded Warrior Program (VWWP)

The Virginia Department of Veterans Services (DVS) Virginia Wounded Warrior Program (VWWP) was created in 2008 through legislation approved by the Virginia General Assembly and signed into law by Governor Timothy M. Kaine. The Department of Veterans Services (DVS), in cooperation with the Department of Behavioral Health and Developmental Services (DBHDS), and the Department of Rehabilitative Services (DRS), was charged with developing a program to monitor and coordinate mental health and rehabilitative services for Virginia veterans, including Virginia National Guard members and Virginians in the Armed Forces Reserves not in active federal service. The purpose of the program is to ensure that adequate and timely assessment, treatment, and support are available to veterans, service members, and affected family members. The program includes supports to family members affected by the covered military member's service and deployments.

To improve and expand services to our nation's veterans and service members, VWWP coordinates support services for veterans and members of the National Guard and Reserves who have Post Traumatic Stress Disorder (PTSD) or traumatic brain injuries resulting from service in a combat area. This will be accomplished through local and regional coalitions of Community Services Boards, Brain Injury Services (BIS) Programs, and other public and private service providers offering services across the Commonwealth. Following are examples of the services that may be available through these networks of public and private providers:

- Comprehensive and timely assessment
- Case management
- Outpatient treatment
- · Outreach activities
- Rehabilitative services
- Family support

Rehabilitative Services.

• Linkage to benefits services, housing, employment and educational programs

Neurobehavioral Treatment Needs for People with Acquired Brain Injuries in Virginia
The Virginia Brain Injury Council (VBIC) is a statewide advisory group comprised of
consumers (i.e., survivors of brain injury and family members / caregivers, or representatives
of survivors); licensed, registered, and certified healthcare professionals; an employee or a
current member of the Board of Directors of an organization or program that receives state
general funds to provide brain injury services; an individual affiliated with a hospital or
health care system; individuals not affiliated with any brain injury program; 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 injury and
their families by advising the lead state agency for brain injury, the Department of

In 2007, an ad hoc Council committee was formed in response to a request by the Commissioner of the Virginia Department of Rehabilitative Services for input regarding the

neurobehavioral crisis faced by Virginians with a brain injury, their families, and brain injury service providers. The Neurobehavioral Committee developed a "White Paper" - an authoritative report or guide that addresses specific issues and how to solve them - on neurobehavioral treatment options in Virginia as a basis for discussion and action between the commissioners of the departments of Rehabilitative Services and Behavioral Health and Developmental Services. Members of the Neurobehavioral Committee included brain injury experts from across the state who represent the continuum of care for people with brain injury. A summary of some of the findings and recommendations included in the July 2008 report are:

- Estimates suggest there are more than 250,000 people 18 years and older living in Virginia with brain injury related complications.
- The behavioral and psychiatric complications of brain injury are woefully underaddressed in the Commonwealth; there is a significant unmet need for specialized assessment/treatment programs.
- There is a clear and pressing need for a permanent interagency agreement between the Virginia Departments of Rehabilitative Services; Medical Assistance Services; Juvenile Justice; Corrections; and Behavioral Health and Developmental Services to address this problem in a systematic way at the state level.
- The Department of Medical Assistance Services should aggressively pursue implementation of a Brain Injury Medicaid Waiver, and change state Medicaid policies to cover in-state neurobehavioral programs not designated as skilled nursing programs.
- There should be a focus on three (3) elements of care: residential neurobehavioral programs for people with intense behavioral and support needs; residential community-integrated neurobehavioral group homes for people with moderate to high needs; and community-based supported living programs for those with low intensity needs.
- Neurobehavioral treatment should be included as one of Virginia's "core services" along with community-based case management, clubhouses/day programs, and regional resource coordination. This recommendation has been endorsed by the Virginia Brain Injury Council, the Virginia Alliance of Brain Injury Service Providers, and the Brain Injury Association of Virginia.

*The Executive Summary of this report can be found in Appendix 3.

Joint Legislative Audit and Review Commission (JLARC) Report on BI in Virginia
The 2006 Virginia General Assembly commissioned a study on brain injury in Virginia to be
conducted by the Joint Legislative Audit and Review Commission (JLARC). The study was
to encompass several areas including:

- Causes and prevalence of brain injury in Virginia
- The availability and effectiveness of state-funded brain injury services

- DRS' oversight of state-funded services
- How other states have addressed the needs of people with brain injury

JLARC staff conducted interviews, surveys, and focus groups with people with brain injury, family member / caregivers, and professionals throughout the Commonwealth and released their report in September of 2007. A summary of some of the findings include:

- 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. This number does not include individuals treated at Virginia hospitals that did not report to the registry, individuals whose injuries were not treated, such as abused children, or those seen in physicians' offices or at military facilities, which are not required to report.
- As many as 85,000 Virginians may have long term disabilities resulting from a traumatic brain injury.
- More than 1,000 people with brain injury have been able to access community based services as a result of increases in state funding. In spite of these increases, some areas of Virginia have no services or very limited services available; any existing services are very limited and waiting lists or other obstacles often block access.
- Thousands of people with brain injury suffer from behavioral issues as a result of their injuries; those with severe behavioral issues often end up in long term or correctional facilities. Only 20 beds are available in Virginia to provide the necessary treatment for behavioral issues; all of these are private and insurers are often reluctant to cover behavioral treatment.
- Most insurance plans have limited coverage for brain injury services and coverage often ends too soon. Legal settlements and workers' compensation provide funding sources for some individuals but are not available for all people with brain injury.
- TBI is considered to be the signature wound of the conflicts in Iraq and Afghanistan; however, federal assistance may not adequately meet the needs of these veterans. If they seek state funded services, Virginia's existing community based services may not be able to meet their needs.
- An increase in community-based services could reduce the number of people with brain injury who reside in nursing homes and other long term care facilities. Expanding Virginia's Medicaid Individual, and Family Developmental Disabilities Support Waiver or implementing a TBI specific waiver program could provide assistance for these individuals.

*The full report can be found at http://jlarc.virginia.gov/reports/Rpt360.pdf

2009–2013 Brain Injury Action Plan

The 2009-2013 Brain Injury Action Plan provides an updated work plan for addressing the current gaps in services and resources that have been identified by Virginia's brain injury community. Updating the Plan began in 2006 and continued throughout 2008. To ensure that a wide range of input and experiences are represented in this Plan, input was sought from a variety of people with brain injury, family members / caregivers, professionals, advocates and other stakeholders. The process included written questionnaires (surveys), in-person and telephone interviews, and input from attendees at public meetings of the Virginia Brain Injury Council (VBIC). Finally, existing sources of data were used to develop a plan for a comprehensive system of care for Virginians with brain injury and their family members / caregivers, including the Office of the Secretary of Public Safety 2008 Report on the Incidence of Traumatic Brain Injury in Offender Populations; the Virginia Brain Injury Council's White Paper on the Neurobehavioral Treatment Needs for People with Acquired Brain Injury in Virginia; the Joint Legislative Audit and Review Commission (JLARC) 2007 Report on Brain Injury in Virginia; and the results of the 2005 Town Meetings held across Virginia.

The goals and objectives presented in the work plan reflect the priorities identified through the planning process described in this document. This work plan will guide Virginia's implementation of a comprehensive service delivery system for Virginians with brain injury and their family members / caregivers. Implementation of the Plan will be monitored by the Virginia Brain Injury Council, and will involve collaboration among state agencies, people with brain injury, their family members / caregivers, and organizations serving people with brain injury throughout the Commonwealth.

PURPOSE: The purpose of Virginia's **2009-2013 Brain Injury Action Plan** is to serve as a blueprint for the development of a culturally competent, comprehensive, community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of brain injury services and addresses the needs of people with brain injury and their family members / caregivers.

Strategic Priority Area #1: Access to Expanded Brain Injury Supports and Services Goal 1: Enhance comprehensiveness of services available to all Virginians with brain injury.

Objectives:

- Improve access to case management services across Virginia
- Customize brain injury services according to needs and resources of each community
- Develop targeted resources for Iraqi and Afghanistan veterans in collaboration with the Veterans Administration (VA) system
- Improve the ability of the Juvenile Justice System to meet the needs of juvenile offenders with brain injury within their service system

Goal 2: Expand residential and community-based neurobehavioral treatment options for people with brain injury.

Objectives:

- Develop neurobehavioral treatment programs that offer options across all functional levels regardless of level of independence with Activities of Daily Living (ADL's) or ability to pay.
- Increase access to emergency mental health services within the community mental health system throughout Virginia.

Goal 3: Expand community living options and appropriate supports to facilitate community integration of people with brain injury.

Objectives:

- Promote replication of successful supported housing programs in each region of the state.
- Collaborate with existing transportation services to create effective systems of transportation throughout Virginia.
- Customize services and supports to enable people with brain injury to live in safe, stable, and least restrictive settings of their choosing.

Goal 4: Enhance opportunities to contribute to the community through participation in productive activities.

Objectives:

- Expand network of clubhouse/day programs with case management resources housed within the program to unserved and underserved areas of Virginia.
- Increase capacity of existing clubhouse/day programs and other community-based programs to expand access to programs and services.
- Provide brain injury education and resources for employers, vocational rehabilitation counselors, educators, and employment services providers.

Strategic Priority Area #2: Systems Change and Management

Goal 1: Develop evidence-based policy and program initiatives to meet the needs of people with brain injury and their family members / caregivers, particularly those representing unserved or underserved populations.

Objectives:

- Enhance cooperative relationships among state agencies and organizations to increase capacity to provide appropriate treatment and services.
- Improve the ability of the Virginia Brain Injury Council (VBIC) to advise the Department of Rehabilitative Services regarding appropriate, accessible, and affordable services for Virginians with brain injury.
- Expand the ability to collect and analyze statewide data on the needs of people with brain injury and their family members / caregivers.

Goal 2: Increase funding for brain injury programs and services to address gaps in service delivery system.

Objectives:

- Secure passage of Medicaid Brain Injury Waiver.
- Secure passage of budget amendments to support development and expansion of brain injury programs and services.
- Identify options for increasing funding for post-acute therapies.
- Cultivate public and private sources of funding and partnerships to expand funding options.

Strategic Priority Area #3: Community Impact

Goal 1: Provide brain injury information, resources, and education to improve public knowledge and enhance quality of services for people with brain injury and their family members / caregivers.

Objectives:

- Educate physicians, health care providers, and school communities to recognize and understand the impact of mild brain injury.
- Develop and implement a comprehensive brain injury awareness plan for Virginia legislators.
- Develop and disseminate culturally and linguistically appropriate resource materials about brain injury prevention and treatment.
- Expand educational opportunities for people with brain injury, family members / caregivers, and professionals.
- Strengthen the role of family members / caregivers as advocates for people with brain injury through the development of ombudsman programs and participation on the Virginia Brain Injury Council.

Evaluation of the implementation of the **2009-2013 Brain Injury State Action Plan** will include both a process and an outcome evaluation. This will apply to state agency and agency-contracted staff, project partners, and members of the Virginia Brain Injury Council.

The process evaluation will focus on determining to what extent the plan is being implemented, and what challenges or issues have arisen in its implementation that may affect either continuation of activities or anticipated outcomes. Data for the process evaluation will be obtained from a variety of sources, including existing databases, reports of advisory group meetings, participant lists from training events, and structured surveys and interviews to be developed for the evaluation.

The outcome evaluation will focus on assessing the extent to which the intended goals are being achieved as well as the anticipated or intended impact on the targeted populations. Data for the outcome evaluation will contain the number of people served and goals achieved, activities, policies or processes that are developed, and observable and measurable "milestones" toward the stated targets. The data will be obtained from several different sources, utilizing surveys, structured interviews, and customer satisfaction assessments.

APPENDIX 1: 1998-2000 STATEWIDE TBI ACTION PLAN EVALUATION

In 2007, the Department of Rehabilitative Services (DRS) hired an external consultant, Ann Deaton, Ph.D., to review Virginia's progress toward meeting the goals and objectives in the 2000 Statewide TBI Action Plan. The consultant utilized the results of the 2005 Town Meetings, personal interviews with key stakeholders, and surveys of people with brain injury, family members / caregivers, state-funded brain injury program staff, and other professionals to evaluate and report on progress made on achieving goals of the 1998-2000 Statewide TBI Action Plan and soliciting feedback in the addendum for 2000-2005 State Brain Injury Action Plan.

The distribution of participants involved in the evaluation of the 1998-2000 Statewide TBI Action Plan and the development of the 2009-2013 Brain Injury Action Plan was as follows: people with brain injury (31%), family members / caregivers (24%) and providers (45%) from across the state (10% Shenandoah Valley, 13% Northern Virginia, 16% Southwest Virginia, 27% Eastern Virginia, and 31% Central and Southern Virginia). Despite efforts to collect data that fully represent the needs in the brain injury community in Virginia, it is likely that not all perspectives were captured. The voices of those survivors and family members who have not been able to successfully access resources such as the clubhouse programs or rehabilitative services may not have been fully heard in this process. Providers who are not active within the brain injury community or do not participate in state focused continuing education activities may not have had a voice. It cannot be fully known whether the perspectives of these individuals would substantially differ from the input that was gathered.

Dr. Deaton's report discusses the implementation of the *1998-2000 Statewide TBI Action Plan*, and reviews progress made in each focus area and work that remains unfinished.

Information/Referral and Advocacy

In the area of Information/Referral and Advocacy, stakeholders repeatedly noted the establishment of Regional Resource Coordinators (RRCs) across the state, managed by the Brain Injury Association of Virginia (BIAV) through its Brain Injury Regional Network (BIRN). The Brain Injury Association of Virginia (BIAV) is a statewide organization with headquarters in Richmond, has provided Information and Referral services for over 20 years. Since 2000, BIAV has responded to over 6,000 requests for information and sent over 93,000 outreach mailers to individuals.

Outreach efforts have included community meetings, public awareness and targeted outreach efforts, translations of written materials and presentations into Spanish, participation in and provision of materials at community events, and newspaper, radio, and media visibility. BIAV's Regional Resource Coordinators provide a variety of education and outreach activities in their communities, assist with locating or developing needed services, and develop informal networks that support a survivor's re-entry and community reintegration.

With respect to advocacy goals, training has enabled many stakeholders, particularly survivors and family members / caregivers, to understand and realize their roles as advocates.

Advocacy, the act of supporting or arguing in favor of an issue, idea, cause or person, can be done on behalf of one's self, on behalf of another person, or on behalf of a group of people. For example, individuals can learn to become effective advocates for themselves in a variety of situations. They can also speak out on behalf of all survivors of brain injury for improved services and supports. Collective advocacy is the process by which people with a brain injury and others in the brain injury community can organize, formulate, collaborate, reach consensus and articulate for the collective brain injury community's need.

The Brain Injury Association of Virginia's (BIAV) e-mail listserv quickly mobilizes essential advocacy actions. In 2006 and 2007, advocacy efforts resulted in the commissioning of a Joint Legislative Action and Review Committee (JLARC) report to study access to brain injury services in Virginia. Annually, the Virginia Alliance of Brain Injury Service Providers (VABISP) collaborates with the Brain Injury Association of Virginia on the "Brain Injury Awareness Day" at the General Assembly, which includes survivors, family members / caregivers, service providers, professionals, and others. This event is always a success, with new and seasoned advocates from across the Commonwealth meeting with members of General Assembly to increase awareness of the impact of brain injury and the need for adequate funding for brain-injury related services.

BIAV conducts "Advocacy Academies" which have educated over 120 attendees and resulted in written educational materials. The BIAV Policymakers' Guide has been distributed to over 200 elected and appointed policymakers to enhance their understanding of brain injury.

Case Management

One of the services/resources mentioned most often by stakeholders was that of specialized, community-based Case Management for adults and children with acquired brain injury. The JLARC report (2007) noted that people with brain injury benefit from case management services. Numerous individuals with brain injury, family members / caregivers spoke about the benefit of case management, noting the commitment and creativity of case managers in meeting their diverse needs, as well as collaborating with a variety of professional and informal service providers to develop resources. The successes of Case Management included the ability to offer resources to meet financial, vocational, residential, treatment, informational, and leisure / recreational needs.

Having Case Management offered through a Clubhouse was noted as a particularly effective arrangement, as it appeared to maximize the accessibility of survivors to Case Management, and also raised the case managers' awareness of specific needs. In addition, it provides the opportunity for the repetition of critical information that is of unique value to people with brain injury who have significant memory and other cognitive impairments.

Consistent challenges that appeared in the area of Case Management included waiting lists for services and unfilled case manager positions. Professionals stated that case loads are often too heavy to allow for comprehensive case management so that only the urgent needs can be met.

Residential Treatment

Progress in the area of specialized residential programs has been less evident due to the financial cost and the expertise required to operate these programs. Residential treatment options for people with brain injury remain largely unavailable in Virginia, with the 2007 JLARC report noting a total of 20 beds available statewide for what is estimated to be thousands of people with brain injury who have neurobehavioral issues. These services are estimated to cost over \$170,000 annually per person. Resources in this area have increased only slightly with the availability of residential treatment options in Richmond, Virginia Beach, Charlottesville, Blacksburg, and the Shenandoah Valley – unfortunately, all are private and are rarely covered under most insurance or other public financial assistance.

Community Living Services

Specialized brain injury supported living services are provided in Northern Virginia by Brain Injury Services, Inc. (BIS INC) and in Richmond by Virginia Supportive Housing (VSH). BIS INC partners with two organizations that provide supported residential living services. VSH operates two homes in Richmond and provides a dedicated brain injury case manager who works with all of the residents as needed. These resources were described as providing a stable place for people with brain injury to live, thereby enabling them to focus their energies on other aspects of life such as physical and cognitive recovery or employment.

Other creative approaches have included the success of an assisted living option collaboratively developed by three agencies and paid for by Adult Protective Services (APS). This option enabled a survivor to stay safe while moving from an abusive situation to assisted living in the community, resulting in increased community integration for the individual survivor, including the ability to have ongoing therapy and a small income from working in a supported setting several hours each week. In addition to the benefits experienced by the survivor, family members have reported a decrease in their stress levels resulting in a greater capacity for them to provide emotional support to the survivor. This type of creative collaborative effort may offer a best practice that can be replicated in other abusive or potentially abusive situations.

Employment

Only a few stakeholders reported successes in the area of employment over the past seven years, with the exception of the reported successes often found within the clubhouse model.

Vocational rehabilitation options exist across the state and are supported by various programs, as well as by the Department of Rehabilitative Services. According to the JLARC report, DRS data indicate that 54% of the 1000+ clients with traumatic brain injury served in Fiscal Years 2002-2007 have found employment. Supported Employment efforts have been successful for 58% of the more than 470 individuals served in this same time frame. One possibility for the lack of visibility of these successes is that many of these programs and outcomes are taken for granted and that their greatest successes are in returning those with mild brain injuries to employment. Since mild brain injuries occur more frequently than moderate or severe injuries, this accomplishment is substantial and may be overlooked

primarily because of stakeholders' focus on the continuing needs of those not interested in, or able to, return to work.

Transportation

Successes in the area of transportation varied across the state, due to variability in population density and the availability of public transportation options. Use of public transportation is increasingly being encouraged and supported by a variety of providers (including case managers and clubhouse staff), as well as by family members / caregivers. In addition, efforts have been made to locate brain injury service programs in community-based settings, so that service recipients are close to public transportation, as well as employment, shopping, and other community activities.

Informal networks of transportation were reported to be another success. These are often made up of a self-created network of friends, family members / caregivers, or members of a faith-based community who commit to providing transportation to therapy and medical appointments in order to reduce stress on family members.

Utilizing public transportation, or using informal networks such as friends and family members, provides additional social experiences for survivors, and, and enables family members to maintain their employment, which may be the only source of income and insurance benefits.

The provision of transportation by rehabilitation day programs was seen as a benefit that allows for survivor access to needed services, reduces strain on family members, and increases independence of people with brain injury (who can participate in programs without the assistance of family members / caregivers) and, therefore, creating opportunities age-appropriate socialization and emotional coping.

The unique physical, medical, mental/emotional, and neurobehavioral challenges of people with brain injury combine to make transportation a challenge that will continue to require creative efforts in addressing service gaps.

Clubhouses / Day Programs

Virginia has been a national leader in the development of clubhouses for people with brain injury. The six clubhouses across the Commonwealth have been described as one of the most significant and valuable resources developed for Virginians with brain injury. This model enables people with brain injury to experience a work-ordered day with specific, assigned responsibilities and to develop skills for employment in a supportive and therapeutic setting. These skills include following a schedule, producing high quality work outcomes, interacting well with others, problem solving, and developing compensatory strategies for areas of injury-related impairment. These experiences resulted in increased self esteem and confidence as people with brain injury gain greater awareness of their post-injury skills as well as needed accommodations to succeed in community-based competitive work settings. This option (clubhouse model) for a transition was seen as particularly powerful by survivor stakeholders who previously felt the gap was overwhelming.

The clubhouse model encourages members to participate in the day-to-day operation of the clubhouse, thereby supporting and strengthening cognitive, social, vocational, recreational, and daily living skills. Several members noted the powerful experience of being able to give back to their communities through volunteer work arranged by the clubhouse. Despite the fact that many of the programs have waiting lists, not all members attend daily or for extended periods of time, so that openings do occur periodically (e.g., when a member returns to work full time).

Social/Recreational/Peer Support

Successful approaches to providing social and recreational options for people with brain injuries were identified as clubhouses and day programs, local recreation and parks departments, community-based groups, annual camps, and informal networks of family members / caregivers and friends. Some of these options offer regular social outlets and recreational outings, while others offer an annual opportunity for people with brain injury to meet and interact with other survivors of brain injury. Social and recreational opportunities for survivors give family members needed respite from intensive care giving responsibilities.

In addition, other models for providing social and recreational activities for survivors included a partnership that enabled university students to provide an art-based recreational experience. Another example involved a Richmond area faith community that connected a survivor with a therapeutic horseback riding center; this resource provided post-acute opportunities for the person's physical recovery while also offering an appropriate leisure and social opportunity. Sharing these best practices across the Commonwealth can offer models for new programs and resources.

Individual/Family Supports

One of the resources repeatedly noted by family members / caregivers and people with brain injury during this plan development effort, as well as in the 2005 Town Meetings, was that of free support groups across the state. Many of these support groups began with assistance from the Brain Injury Association of Virginia (BIAV); several others were initiated and/or operated by service providers in areas where no BIAV support group existed or the existing support group was struggling. These groups offer ongoing support to people with brain injury and family members / caregivers that include information on resources, services, and supports; emotional support; and social and recreational/leisure activities. Since the groups are local, they provide insight and recommendations for specific resources which other members of their community have used successfully. In addition, support groups have served effectively for dissemination of information and outreach efforts requiring collaboration such as the statewide legislative advocacy activities.

Faith-based communities and informal networks of family, friends, and community members were often cited as primary supports that enabled people with brain injury and their family members / caregivers to cope with the immediate impact of a brain injury and to successfully reenter the community. These networks provide a variety of services including transportation, social and recreational outlets, sharing of information, identification of resources, and emotional support for people with brain injury and their family members / caregivers.

Other family supports targeted in the 2000 Action Plan included respite and personal assistance services. Stakeholders reported that these services have been available to them on an individual basis. It requires considerable awareness and perseverance, along with the support of a Case Manager and/or Regional Resource Coordinator to put this type of support in place. Personal assistance services are estimated by DRS to cost more than \$18,000 per person (JLARC, 2007).

Education/Awareness

Educational materials have been provided to people with brain injury, family members / caregivers, and professionals across the state in the form of specialized written materials, and workshops/seminars/conferences across Virginia. Groups targeted by these efforts have included emergency personnel, veterans' groups, legal professionals, educators, medical and rehabilitative professionals, criminal justice professionals, legislators, employers, educators, free clinics, domestic violence workers, and nursing home staff, as well as others.

Virtual and web-based technology and access has become increasingly available over the years since the 2000 Action Plan. A variety of these technologies include listservs, teleconferencing, and interactive web sites. These resources have increased the speed of communication and access to information, but are also seen by some as too impersonal.

Conclusions:

The successes that are based on the original 1998-1000 Statewide TBI Action Plan and revealed in the 2005 evaluation appear to be the result of a collaborative vision, focused effort on the issues, and an active approach to strategizing next steps. In discussing these accomplishments – including what is "right" with Virginia's systems of care and resources - many stakeholders were surprised to realize how far the Commonwealth has progressed in attempting to meet the needs of our citizens with brain injury. It was noted that the state's Hospital Trauma Centers continue to be an excellent and critically important aspect of care that has remained consistently strong. The community-based resources that are available following acute medical treatment and rehabilitation have also improved. Specific positives were noted in regard to case management, the clubhouse/day program models, and regional resource coordination: Case Management is critical to accessing an often complicated and convoluted service system; Clubhouse / Day Programs provide community-based opportunities for socialization, independence, and reacquisition of skills; and Regional Resource Coordination facilitates access to information, resources, and service development.

Despite the improvements, access to services that enable successful community reintegration continued to be the greatest concern to stakeholders attending the Town Meetings. There was universal agreement that there is an ongoing need for an accessible, affordable, and appropriate system of comprehensive services. For all stakeholders, the importance of integrated and individualized services was crucial. The customization of services depends upon the unique needs of each survivor as well as the resources of each community. For brain injury survivors and their families, supports and services that improve the quality of their lives, and their ability to contribute to their communities, are paramount. There is a

widely held perspective that available resources, financial and otherwise, remain inadequate to meet the existing needs of Virginians with brain injury.

APPENDIX 2: "WHITE PAPER" ON THE NEUROBEHAVIORAL TREATMENT NEEDS OF PEOPLE WITH ACQUIRED BRAIN INJURIES IN VIRGINIA

Executive Summary

THE NEED FOR APPROPRIATE, ACCESSIBLE, AFFORDABLE TREATMENT:

- Estimates suggest there are more than 250,000 people 18 years and older living in Virginia with brain injury related complications.
- There are only 20 beds available in Virginia providing neurobehavioral treatment; these are privately owned and not reimbursed by Medicaid or private insurance.
- The behavioral and psychiatric complications of brain injury are woefully underaddressed in the Commonwealth: there is a significant unmet need for specialized assessment/treatment programs.
- Families are being torn apart as Virginians with brain injury are sent out of state at exorbitant costs to receive treatment for neurobehavioral complications.
- Problems range in severity from a small percentage of very complicated cases that require very intensive care and treatment to those that can be addressed in community settings.
- A number of people with post-acute neurobehavioral challenges in acute psychiatric hospitals, state mental health institutions, skilled nursing facilities, and adult and juvenile correctional systems could be more effectively treated in community-integrated residential neurobehavioral programs.
- There is a clear need to expand the continuum of services for people with neurobehavioral problems.
- Education on evidence-based best practices for current and future providers of neurobehavioral treatment programs must be provided across a continuum of care.
- The development of standards, oversight mechanisms, and treatment and outcome accountability are needed to address the neurobehavioral problems of people with brain injury.
- The unmet behavioral needs of people with brain injury are directly related to mental health reform initiatives currently occurring in Virginia.
- Services occurring in the vacuum of a facility are compromised without community based services to support people with brain injury after discharge.

- The 2007 Joint Legislative Audit and Review Commission report, *Access to State Funded Brain Injury Services*, concluded that:
 - o Thousands of survivors suffer from behavioral issues as a result of their injuries;
 - Those with severe behavioral issues often end up receiving treatment out of state, and many more are inappropriately placed in long term care or correctional facilities:
 - An increase in community-based services would reduce the number of survivors who reside in nursing homes and other long term care facilities;
 - o Implementing a TBI specific waiver program could provide assistance for these individuals.

THE NEED FOR INTERAGENCY COLLABORATION:

- Improved identification of brain injury using validated screening tools and increased access to appropriate services is a priority that should begin in the Executive Branch at the Secretariat level.
- There is a clear and pressing need for a permanent interagency agreement between the Virginia Departments of Rehabilitative Services, Medical Assistance Services, Juvenile Justice, Corrections and Behavioral Health and Developmental Services to address this problem in a statewide, systematic way.
- The Department of Behavioral Health and Developmental Services in conjunction with the Departments of Rehabilitative Services and Medical Assistance Services should review current licensing requirements for non-Medicaid residential facilities to ensure best practices and to develop new regulations across all levels of neurobehavioral care. This includes the use of objective acuity measures for behavioral risk factors to better identify least restrictive environments and to measure progress and outcomes.
- The Departments of Rehabilitative Services, Medical Assistance Services and Behavioral Health and Developmental Services should emphasize the expansion of community-based neurobehavioral treatment services for people with brain injury as a central component of the Olmstead Community Integration discussions.
- The Department of Medical Assistance Services should aggressively pursue implementation of a Home and Community Based Brain Injury waiver.
- There should be a change in state Medicaid policies to cover in-state neurobehavioral programs not designated as skilled nursing programs.

MODELS OF SERVICE DELIVERY:

- A comprehensive, holistic, neuropsychological/neuropsychiatric, system of care approach is the model system of best practices for neurobehavioral care.
- Supported living programs require greater availability, a greater neurobehavioral focus, and better coordination.

- Access to appropriate and necessary services should be a basic human right available to those people with brain injury who lack coverage through the provisions of the Individuals with Disabilities Education Act, Medicaid, Medicare, private insurance, the Department of Defense or the Department of Veterans Affairs.
- There should be a focus on three elements of care: residential neurobehavioral programs for people with intense behavioral and support needs; residential community-integrated neurobehavioral group homes for people with moderate to high needs; and community-based supported living programs.
- Neurobehavioral treatment should be incorporated into Virginia's core brain injury services of community based case management, clubhouses/day programs and resource coordination which has been endorsed by the Virginia Brain Injury Council, the Virginia Alliance of Brain Injury Service Providers & the Brain Injury Association of Virginia.

DEFINITIONS OF LEVELS OF CARE / ESTIMATED COSTS:

- Intensive residential treatment: 24 hour support and supervision, active neurobehavioral treatment and rehabilitation, and medication trials in a safe environment: \$470/day
- Community-integrated group homes: *24-hour supervision for those with moderate support needs and risk factors:* \$370/day
- Supported living programs:

24-hour on-site services	\$250/day
Daily, but less than 24-hour supports	\$140/day
Supports provided 2-3 times / week	\$55/day

FUNDING FOR A DEMONSTRATION PROJECT:

- There should be a three-tiered model of neurobehavioral services and supports: intensive residential treatment, community-integrated group homes, and community based supported living programs.
- Some of these needs could be met through reallocation of state funds currently being spent on out-of-state and inappropriate in-state placements.
- The implementation of a brain injury waiver would enhance the system of care and draw down federal funds currently not available to Virginia.
- The Commonwealth Neurotrauma Initiative should consider developing a request for proposals with input from the Departments of Rehabilitative Services, Medical Assistance Services and Behavioral Health and Developmental Services, the Virginia Brain Injury Council, the Virginia Alliance of Brain Injury Service Providers, and the Brain Injury Association of Virginia for a small neurobehavioral pilot project to generate outcome data that could serve to drive future neurobehavioral funding decisions.

- If the proposal is fully funded, funds should be distributed across the system of care. If not fully funded, it is recommended that guidance be provided by the Neurobehavioral Committee of the VBIC.
- One hundred individuals could be served through a demonstration project; the numbers may be reflected as:

Intensive residential treatment: 10 people x \$470/day x 26 weeks \$855,400

Community-integrated group homes: 20 people x \$370/day x 365 days \$2,701,000

Community-based supported living programs: 70 people x 365 days \$4,423,800 24-hour on-site services: 35 people x \$250/day x 52 weeks= \$3,193,750 Daily (less than 24-hour) support: 17 people x \$140/day x 52 weeks= \$868,700 Weekly (2-3 times /week) supports: 18 people x \$55/day x 52 weeks= \$361,350

TOTAL COST: \$7,980,200



State-Administered Services

The following services and programs are administered directly by the Department of Rehabilitative Services (DRS):

Brain Injury Services Coordination Unit (BISCU) within the Department of Rehabilitative Services (DRS) manages programs and services for people with brain injury and assists the "lead state agency" in planning and monitoring services that enhance the quality of life and vocational goals of people with acquired brain injury. The BISCU provides information about brain injury to DRS staff and external customers, and assists individuals to obtain DRS services. BISCU also staffs the Virginia Brain Injury Council, which serves as the advisory group to the DRS Commissioner, and also staffs the Commonwealth Neurotrauma Initiative (CNI) Trust Fund.

- *Brain Injury Direct Services (BIDS) Fund* provides short-term specialized services, assistive technology, and other equipment / goods to help individuals live more independently and move forward in their recovery. Since the BIDS Fund is limited and can be accessed only if no other funding source is available, it is recommended to contact DRS prior to applying for funds. The BIDS Fund does *not* pay for inpatient medical rehabilitation or any type of residential services. Individuals must be at least one year post-injury and must meet disability and financial criteria.
- Commonwealth Neurotrauma Initiative (CNI) Trust Fund was established legislatively in 1997 for the purpose of "improving the treatment and care of Virginians with traumatic spinal cord or brain injuries." The Trust Fund Advisory Board disburses funds to Virginia-based organizations, institutions, and researchers through a competitive grant process administered by DRS. Grant funds of \$5,000 to \$150,000 per year for up to three years are awarded in rotating cycles for Option A: Research; and Option B: Community Based Services. Although programs are short-term, direct services to consumers may be available in specific areas through the grant program.
- Federal Traumatic Brain Injury (TBI) Act grant funding was awarded to the Virginia Department of Rehabilitative Services for 2009-2013. "Closing the Gap" focuses on expanding and strengthening the State's infrastructure for the delivery of brain injury services through a variety of activities and work with targeted populations. There are two DRS subcontracts to assist in carrying out the grant activities: the primary contractor is the

Brain Injury Association of Virginia (BIAV); Virginia Commonwealth University is also contracted to work with the Department of Juvenile Justice to identify and provide treatment options for youth entering the correctional system. The Federal grant is a systems change grant and does not provide direct services to consumer.

Centers for Independent Living (CILs) provide services statewide that promote the independence, productivity, and leadership of people with disabilities. CILs are operated by people with disabilities who assist others to take charge of their own lives. CILs work with individuals and communities to remove barriers to independence. Services include information / referral, peer counseling, independent living skills training, and individual / systems advocacy. There are 16 CILs and four satellite CILS located throughout Virginia.

Community Rehabilitation Case Management Services (CRCMS) Program provides case management / service coordination for individuals with central nervous system and other severe functional disabilities (including brain injury). Rehabilitation Specialists assist in identifying individual needs and resources to increase independent living and community integration.

Personal Assistance Services for People with Brain Injury (PAS/BI) provides personal assistance to people with significant functional limitations due to a physical disability caused by a brain injury and who are ineligible for attendant services through other sources. The consumer, or a consumer-designated representative, manages all aspects of employing a personal assistant. Services may include assistance getting in/out of bed, dressing, bathing, meal preparation, and housework. Priority is given to individuals at risk of institutional placement.

Vocational Rehabilitation (VR) Program is the federal/state funded program within the Department of Rehabilitative Services (DRS) that offers employment-related assistance to people with disabilities, including people with brain injuries. Individuals who meet disability and financial eligibility criteria work with a Vocational Rehabilitation Counselor to jointly develop an Individualized Plan for Employment (IPE) that identifies an employment goal, as well as services or training to achieve that goal. Services include evaluation of skills and abilities; help determining an employment goal; counseling and guidance; vocational training; and job seeking / job placement services.

Woodrow Wilson Rehabilitation Center (WWRC) is a state-funded rehabilitation facility operated by the Department of Rehabilitative Services (DRS) that offers an array of residential and outpatient services ranging from a comprehensive rehabilitation therapy program to vocational training to short-term assessment. In addition to receiving regular WWRC services, eligible individuals with acquired brain injury may receive supplemental specialized services through WWRC's Brain Injury Services Department such as counseling / guidance; neuropsychological assessment and therapy; vocational evaluation / training; cognitive rehabilitation services; independent living / community re-entry skills; and physical, occupational, and speech / language therapies. Specialized case management services may also be available to individuals with brain injury who attend WWRC programs.

State-Contracted Programs/Services

The following organizations receive Commonwealth of Virginia state general funds to provide programs / services through contracts managed by the Department of Rehabilitative Services:

Brain Injury Association of Virginia (BIAV) provides statewide information and referral services to people with brain injury, family members, and professionals. BIAV services include a toll-free help-line, an information clearinghouse and resource library, referrals to brain injury-specific and general community resources, a statewide network of support groups, systems advocacy, educational events, and an adult camp for survivors. BIAV also has Regional Resource Coordinators in five areas of the state who provide local information/referral, education, public awareness and resource development.

Brain Injury Services, Inc. (**BIS INC**) provides case management services, supported living, volunteer placement, information and referral, and two clubhouse programs for people with brain injuries in **Northern Virginia** and **Fredericksburg** areas. BIS INC operates ADAPT clubhouse in **Fairfax** and Westwood Clubhouse in **Fredericksburg**. Clubhouse members are actively involved in the daily operation of the clubhouse through a "work-ordered day" which leads to improved work skills and behaviors that support community and vocational re-entry.

Brain Injury Services of Southwest Virginia (BISSWVA) provides case management services, community support services (life skills training), volunteer placement, and information and referral for people with brain injury in the LENOWISCO, Cumberland Plateau, Mount Rogers, New River Valley, and Roanoke Valley-Alleghany areas.

Community Futures Foundation, Inc. (CFF) operates two clubhouse programs and provides information and referral for people with brain injuries in the Greater Richmond and Newport News areas: The Mill House is in Richmond and Denbigh House is in Newport News. Clubhouse members are actively involved in daily operations of the clubhouse through a "work-ordered day" which leads to improved work skills and behaviors that support community and vocational re-entry. Limited case management and volunteer placement are available for clubhouse members. CFF offers Clubhouse-based Employee Development Services (EDS) which provides a structured and in-depth assessment of an individual's work-related skills and abilities. Case management services are also available in the Greater Richmond area.

Crossroads to Brain Injury Recovery (CBIR) provides case management services, community support services (life skills training), volunteer placement, and information and referral for individuals with brain injury in the Greater Shenandoah Valley to include the counties of Rockbridge, Augusta, Bath, Highland, and Rockingham; and the cities of Harrisonburg, Lexington, Buena Vista, Waynesboro, and Staunton. Crossroads' main office is located in Harrisonburg on the James Madison University Campus in Blue Ridge Hall. The organization has a satellite office at Woodrow Wilson Rehabilitation Center in Fishersville.

Mary Buckley Foundation, Inc. (MBF) operates a clubhouse program and a day program, and provides information and referral to people with brain injuries on the Eastern Shore and in the Virginia Beach area: No Limits is a day program on the Eastern Shore, and Beacon House is a clubhouse program in Virginia Beach. Day programs provide individuals with brain injury the opportunity to participate in structured activities in a supportive, therapeutic environment. Activities may include vocational tasks, community outings, computer training, and social/recreational activities. Clubhouse members are actively involved in the daily operation of the clubhouse through a "work-ordered day" which leads to improved work skills and behaviors that support community and vocational re-entry. Limited case management and volunteer placement are available for members who attend the two programs.

MWS Brain Injury Services (MWS BIS) provides case management services, community support services (life skills training), volunteer placement, and information and referral for individuals with brain injury residing in the counties of Henry, Patrick, and Pittsylvania, as well as the cities of Martinsville, Danville, and the town of Stuart.

Virginia NeuroCare (VANC) operates High Street Clubhouse and provides information and referral to people with brain injuries in the **Charlottesville** area. Clubhouse members are actively involved in the daily operation of the clubhouse through a "work-ordered day" which leads to improved work skills and behaviors that support community and vocational re-entry. Limited case management and volunteer placement are available for clubhouse members.

Virginia Supportive Housing (VSH) provides case management services and information and referral to residents of two community homes for people with brain injury in the **Richmond** metropolitan area: Independence House, which houses six individuals, is located in the Fulton Hill community, and Bliley Manor, which houses eight individuals, is located in the Southside of Richmond. Limited follow-up case management is available to individuals who have moved on to more independent residential settings.

Private Brain Injury Programs and Non-Brain Injury Resources

In addition to the state-administered and state-funded programs/services for people with brain injury listed in this Appendix, there are other services that can be found in some areas of the state: private providers of brain injury services and state/local providers of services to people with disabilities. However, no single community offers the full spectrum of services — including both state and non-state resources - from emergency room treatment to the least restrictive living environment. In fact, many communities do not have any of the services or supports that are critical for people with brain injury.

There are a number of private programs in Virginia that have expertise in serving individuals with brain injury. These include hospital-based inpatient and outpatient rehabilitation, and community-based services that provide medical treatment, community living supports, vocational services, psychological services / supports, and residential services. Unfortunately, most of these programs only accept private insurance or private pay and are beyond the reach of most families in need of these services who have Medicaid only or no insurance at all.

There are also public and private services for people with disabilities. However, while there may be programs in a particular area that serve people with disabilities, the programs are often not accessible to people with brain injury due to eligibility criteria, or they are not effective in meeting the unique challenges and needs of people with brain injury.

Services not traditionally reimbursed by insurance are often the last to be developed, although they are usually the most critical in the long-term rehabilitation and community living of someone who has sustained a brain injury. The continuum of care for people with brain injury can be difficult to navigate and is often severely limited by financial resources. The Virginia Department of Rehabilitative Services (DRS) and the Brain Injury Association of Virginia (BIAV) can provide referral to agencies with information about professionals and programs statewide to assist survivors and families in finding appropriate services that meet their needs.