disABILITY Law Center of Virginia (dLCV)

Report on Deficiencies in Virginia's Adult TBI Services (2015)

Virginia's History on the Development of a Brain Injury Service System

A. Grassroots Advocacy

Since the early 1980s Virginia has been at the national forefront of brain injury advocacy and service development. The **Brain Injury Association of Virginia (BIAV)**, established in 1983, became one of the primary voices in Virginia for persons who sustain a traumatic brain injury (TBI) and their families. TBI's are inflicted by a blow to the head from an external force such as falls, crashes, or sporting incidents. Other forms of brain trauma are acquired and can include stroke, oxygen deficiency, infectious disease or tumors. This report focuses primarily on brain injuries from external trauma, however, the resulting functional limitations from TBI are common to all forms of brain trauma.

With BIAV's advocacy, Virginia was the first state to create a registry to document the incidence of traumatic brain injuries (TBI). The registry, now the Virginia Statewide Trauma Registry, is used as a vehicle to contact traumatic brain injury survivors and their families to provide support and linkage to services. The registry is also used to inform public policy efforts to ensure community integration and quality of life for survivors of brain injury.

> There are 28,000 brain injuries annually in Virginia (JCHC, October 8, 2014[1])

In 2014 VIRGINIA'S JOINT COMMISSION ON HEALTH CARE'S (JCHC) INTERIM REPORT ON BRAIN INJURY SERVICES reported that 28,000 individuals sustained brain injuries annually in Virginia, 1,400 of whom died and 5,000 of whom were hospitalized. With medical advancement, it is far more common now for a person to survive a brain injury regardless of the cause. Many of these individuals have complex needs and face long term disabilities. Building a system infrastructure for this growing population has been the driving focus of advocacy for the last three decades.

[1] *Joint Commission on Health Care Interim Report: Progress in Expanding Access to Brain Injury Services, SJR 80 Presented to the Virginia Brain Injury Council October 14, 2014*

B. Virginia Legislature Recognizes the Problem

In the late 1980s BIAV formed an alliance with similar organizations serving persons with physical and sensory disabilities common to TBI. Armed with Brain Injury Registry data, this advocacy led to the establishment of the **Virginia Disability Commission.** This legislative body is charged with recommending legislative priorities and policies for adoption by the General Assembly. This enables funding and service development for Virginians with physical and sensory disabilities including individuals that sustain TBI. The Commission makes budget recommendations annually that directly affect brain injury services in Virginia.

C. Virginia Commonwealth University Becomes National Model

Virginia has also been the recipient of numerous federal "model systems" grants provided to **Virginia Commonwealth University (VCU) Health System** to research and establish best practices for serving people with brain injury and their families. These grants have been instrumental in spawning state of the art care that has been replicated nationally including trauma care; physical and cognitive rehabilitative care; community integration such as case management, day programs, and supported housing; and support and education of caregivers. These grants have also funded the nationally known **VCU Rehabilitation Research and Training Center (RRTC),** which specializes in providing supported employment and assistive technology for persons with TBI to enable employment and independence.

D. DARS Becomes Lead Agency for TBI

Virginia Department of Aging and Rehabilitative Services (DARS), became the lead state agency in 1989 and is responsible for coordinating public policy and the development of services. DARS receives state funds as well as federal TBI Act funds (Implementation Grants) to support a wide variety of programs and services. They also coordinate periodic needs-assessments to guide and monitor systems change.

The **Virginia Brain Injury Council (VBIC)**, created in 1986, is a statewide, interagency advisory council comprised of consumers (i.e., survivors of brain injury and family members); healthcare professionals; service providers; state agency representatives; and other ad hoc advisory members. The Council promotes accessible, affordable, and appropriate services for Virginians with brain injury and their families by advising DARS and the stakeholder community of ongoing critical needs.

DARS annually administers over $6 million in state appropriations as well as federal grants to fund services designed for persons with brain injury. (SEE APPENDIX I FOR LIST OF PROGRAMS).

E. dLCV (formerly VOPA) Receives "Protection and Advocacy for Traumatic Brain Injury" Grant

In 2004, Virginia's designated protection and advocacy agency, the **disABILITY Law Center of Virginia** (formally the Virginia Office of Protection and Advocacy), received its first grant under

the TBI Act. Funded by the U.S. Department of Health Resources Services Administration (HRSA), these grants are awarded to facilitate the rights of people with brain injury. States use these grants to provide legal representation, education, and advocacy services for individuals with brain injury.

Summary of Continuing Deficiencies

In 2015, dLCV reviewed numerous reports on TBI to assess the current state of TBI services in Virginia and found the following deficiencies.

A. Core Community-Based Services are Insufficient

Despite three decades of systems advocacy for individuals with brain injury, the needs of Virginians with TBI are often unmet and there remains no clear pathway to services for the individuals who need them. The Centers for Disease Control (CDC) estimates that approximately 2% of Americans are living with the effects of a brain injury. That translates to 166,525 Virginians living with some level of disability resulting from a TBI.

> There are likely 166, 525 Virginians with long term disabilities resulting from a TBI. Based on CDC prevalence rate of TBI in the United States

DARS has repeatedly identified the following community-based services required by this population:

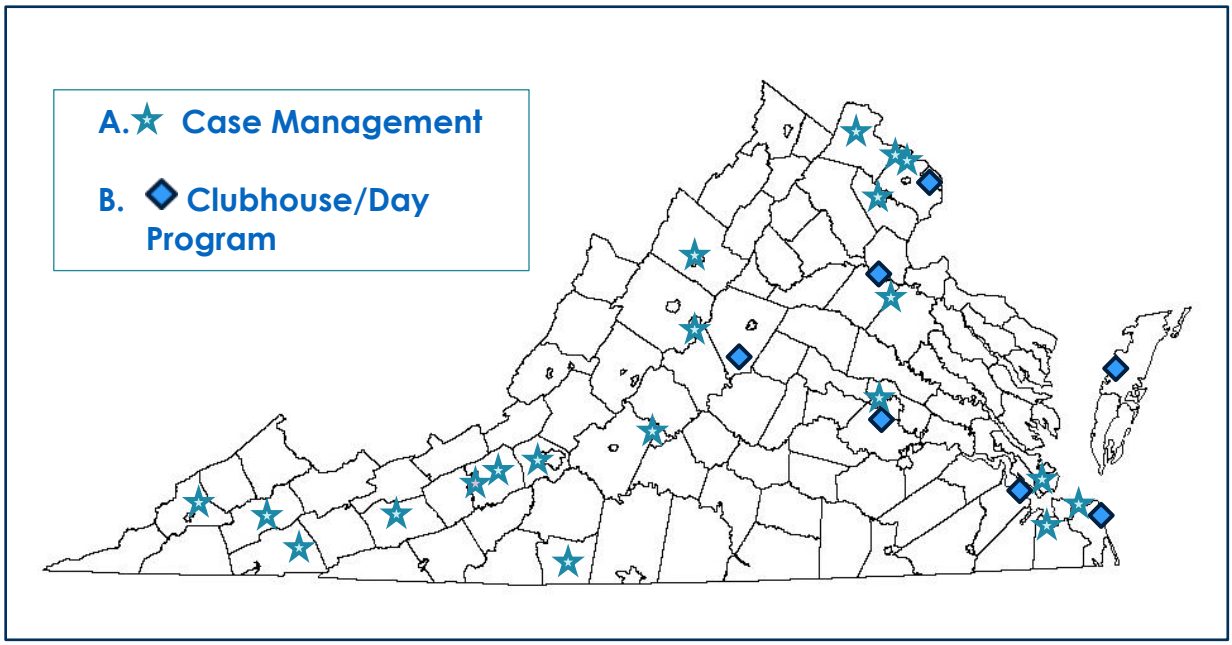
- Information/Referral/Advocacy
- Case Management
- Residential Treatment
- Community Living Services
- Employment
- Transportation, Day Programs
- Social/Recreational/Peer Support
- Individual/Family Supports
- Education/Awareness

In 2007, a study conducted by the Joint Legislative Audit and Review Commission (JLARC, SENATE DOCUMENT NO. 15 2007[2]) found that, though community-based brain injury services have increased, the demand for services far exceeds the availability of services.

> Geography and service availability still limit access, and some needed services are not available. For example, 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-

[2] *http://jlarc.virginia.gov/reports/Rpt360.pdf*

based services a concern made more pressing by the number of military service members returning with TBIs. (JLARC, SENATE DOCUMENT NO. 15 2007)



DATA SOURCE: DARS 2014 ANNUAL REPORT OF STATE FUNDED BRAIN INJURY SERVICES AND JLARC SENATE DOCUMENT NO. 15, 2007

By 2014, DARS funding provided direct services to an estimated 4000 individuals with brain injury (2,500 received case management, clubhouse/day programs, resource coordination, supported living, and support groups; 1,500 received consultation and information and referral). Many are also served through the DARS vocational rehabilitation program which includes supported employment. While system capacity for existing programs has increased since 2007, no new programs were created since the JLARC Study in 2007 (DARS 2014 ANNUAL REPORT OF STATE-FUNDED BRAIN INJURY SERVICES).

> Approximately 4000 Virginians disabled by TBI received DARS funded TBI services in 2014. (Based on DARS 2014 Annual Report of State-Funded Brain Injury Services Programs)

With less than 4,000 Virginians receiving TBI-designed direct services, it is evident that DARS community-based service funds are reaching only a fraction of adults with TBI. THE DARS 2009-2013 STATE ACTION PLAN stressed the need to expand services throughout Virginia at all levels of care—from trauma/acute care to community. The report gave special attention to recent war veterans with TBIs and those with neurobehavioral treatment needs (which often include these war veterans) as well as juvenile offenders and those with co-occurring mental health and substance abuse issues.

Due to common behavioral and psychiatric complications of brain injury, the latest DARS State Action Plan advocates for a permanent interagency collaboration between DARS, Department of Medical Assistance (DMAS), Department of Behavioral Health and Developmental Services (DBHDS), Department of Juvenile Justice (DJJ), and Department of Corrections (DOC). They further advocated that DMAS should aggressively pursue implementation of a Brain Injury Medicaid Waiver and change state Medicaid policies to cover in-state neurobehavioral programs not designated as a skilled nursing program.

B. Long Road Ahead to Access Medicaid Waivers

In 2014, the **Joint Commission on Health Care (JCHC)** was mandated by the Virginia General Assembly to review progress in implementing recommendations from the 2007 JLARC Study. Portia Cole, PhD, Senior Policy Analyst with the JCHC, presented the interim report's preliminary findings to the Virginia Brain Injury Council at their October 14, 2014 meeting. According to the report, nearly 500 individuals with brain injury were institutionalized in state facilities and nursing homes. She stated that:

> Virginia is out of compliance with Olmstead, and vulnerable to further legal action without a plan that enables individuals with brain injury to transition from institutions to communities

This interim report reiterates Virginia's current lack of a Medicaid waiver for those who sustain a brain injury after the age of 22. In addition, it documents a significant waiting list for the Developmental Disabilities Waiver for those who sustained a brain injury prior to age 22. BIAV has reported anecdotally that many of these children reside in pediatric skilled nursing facilities. The report recommended that TBI be included in the initiative to redesign Medicaid. Dr. Cole stressed the need to communicate to legislators the cost/benefit of providing services upfront and in the community in order to avoid state hospitals, prison placement, and other restrictive and ill-suited environments.

As a step forward, the **2015 Virginia General Assembly** responded to long-standing brain injury advocacy efforts by approving the following legislation:

In its Medicaid waiver redesign, the department shall include as stakeholders and eligible participants, individuals with acquired brain injury regardless of age in which the injury was sustained, who have serious physical, cognitive, and/or behavioral health issues who are at risk for institutionalization or who are institutionalized but could live in the community with adequate supports. (307#1c)

It remains to be seen how many individuals will be served or how long it will take for waivers to be fully funded to the extent necessary to meet the enormous demand.

C. Individuals with challenging TBI Behaviors Face Ill-Equipped System

APPROPRIATE IN-STATE PUBLICALLY FUNDED PROGRAMS ARE UNAVAILABLE

THE JCHC INTERIM REPORT also reinforced the JLARC findings in 2007 that showed there is still an absence of publicly-funded in-state neurobehavioral treatment. As a result, some individuals receiving Medicaid have been placed in out-of-state neurobehavioral facilities. Consider the story of one client of the dLCV:

> John survived a brain injury from a car crash only to find himself in the middle of a giant gap in TBI service in Virginia. He was prematurely discharged from the hospital despite persisting complex behaviors and had no plan of care in place. His wife struggled to arrange home rehabilitation until this was no longer an option because he began wandering the streets late at night. He was temporarily detained at a State Hospital where he stayed until Medicaid could arrange for a comprehensive rehabilitation program out of state, since current policies prevent use of in-state placements. After appropriate treatment at this facility, John successfully transitioned back to his home community, however, his journey there highlights the lack of a seamless service system in Virginia.

THE JLARC AND JCHC INTERIM REPORTS acknowledge that the absence of publicly-funded neurobehavioral programs in Virginia may be due to several factors, including the lack of a Medicaid waiver for brain injury, licensing/reimbursement restrictions, and policy variations within state agencies.

Access to Mental Health is Limited

Individuals with brain injury also have difficulty accessing programs due to lack of space or insufficient insurance coverage. For many years, these individuals have attempted to access Virginia's mental health system through Community Service Boards (CSB), but were often turned away even if they had a co-occurring mental health diagnosis.

As an additional step forward, the **2015 Virginia General Assembly** authorized the DBHDS to allow persons with brain injury to access DBHDS's crisis services, substance abuse services, and drop-off centers. DBHDS will also be required to report the number, types, and costs of services for individuals with acquired brain injury who are served through state facilities and CSB's. Realistically, it will take time for CSB staff to be trained in brain injury service provision but it is imperative that the system move rapidly to achieve this goal. Appropriate CSB services can encourage successful community integration.

War veterans with TBI have also had difficulty accessing mental health services in Virginia. The **Virginia Wounded Warrior Program (VWWP)**, soon to be known as **Virginia Veteran and Family Support** was statutorily established in 2008 to provide a mental health and rehabilitative program for veterans within the Virginia Department of Veteran Services in cooperation with DARS and DBHDS. This program attempts to link veterans with TBIs within the existing systems that serve persons with vocational and mental health issues in the community. Still, much work needs to be

done to ensure access to appropriate services by all individuals with TBI who have mental health and behavior challenges.

Individuals Are at Risk of Becoming Institutionalized

The 2010 report titled NEUROBEHAVIORAL TREATMENT FOR VIRGINIANS WITH BRAIN INJURY 2010[3] stresses the need to move away from using skilled nursing facilities (SNF) or psychiatric hospitals to respond to the neurobehavioral needs related to brain injury. These facilities typically do not have physicians and personnel who are skilled in brain injury, nor do they offer brain injury rehabilitation.

> 500 individuals with brain injury were institutionalized in state facilities and nursing homes. (JCHC 2014, SJR 80)

dLCV is particularly concerned that most individuals who sustain a brain injury lack resources to pay for private programs. These individuals are at risk of placement in public psychiatric settings that may use highly intensive and invasive practices such as seclusion and restraint. Again, the 1999 OLMSTEAD decision, requiring a least-restrictive environment, must be considered as more appropriate options are developed. The Neurobehavioral Treatment report carefully outlined the best practice which consists of in-state intensive residential treatment, followed by the option of community-integrated group homes and community based supported living programs and related services.

Individuals Are at Risk for Legal Problems or Homelessness

Another risk resulting from inappropriate intervention for brain injury-related behaviors is involvement with the legal system. A long held assumption is that a correlation exists between offender populations and undiagnosed brain injury[4]. THE 2012 VIRGINIA COLLABORATIVE POLICY SUMMIT ON BRAIN INJURY AND JUVENILE JUSTICE[5] report reviewed the literature on this and found numerous studies to support this assumption. In a Virginia study of 867 juveniles, over half of the participants (52.5%) reported a history of hitting or hurting their head. In their 2002 study, Timonen[6] and colleagues found that TBI during childhood or adolescence increased the risk of developing

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[3] *http://www.vadrs.org/cbs/biscis.htm; Neurobehavioral Treatment for Virginians with Brain Injury, 2010*

[4] *Wald, Halgeson, & Langlois (2008). Traumatic Brain Injury Prisoners, Brain Injury Professional, 5(1), 22-25. Available from: http:www.brainline.org/content/2008/11/traumatic-brain-injury-among-prisoners_pageall.html*

[5] *Virginia Collaborative Policy Summit on Brain Injury and Juvenile Justice: Proceedings Report (January 2013) Supported by Grant #H21MC06763-04-00 from the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), and Maternal and Child Health Bureau (MCHB).*

[6] *Timomen M., Miettunen J., Hakko H., Zitting P., Veijola J, von Wendt L., Rasanen P., (2002). The association of preceding traumatic brain injury with mental disorders, alcoholism and criminality: The Northern Finland 1966 birth cohort study. Psychiatry Res., 113 (3), 217-26.*

mental disorders two-fold. These disorders in combination with cognitive impairment at any age, can result in impaired judgment and impulse control, often leading to criminal behaviors. Notably, even physical issues from TBI such as slurred speech or an awkward gait can be confused as intoxication and cognitive difficulties can inadvertently result in non-compliance. Either can result in arrest.

One method of counteracting this risk is the Virginia Commonwealth University's **Brain Injury Screening Tool** used to reliably evaluate juveniles entering the DJJ system. Next steps include establishing procedures to screen for TBI, as well as developing training materials for DJJ personnel related to screening, evaluation and intervention protocols. This model should be considered for adults with TBI who are incarcerated. However, it goes without saying, that a better system to screen for and treat TBI well before the crime is committed is a far more compassionate and economically sound approach.

Many individuals with TBI are also placed in homeless shelters or end up on the street. Increasingly, studies point to a high rate of TBI among persons who are homeless as compared to the general population. For instance, cities that have done studies on how many homeless individuals suffer from TBI, report numbers that are scattered but all statistically significant: 98 percent (Hamilton, Ontario 2008-2010), 53 percent (Toronto, Ontario 2008), 67 percent (Boston, Mass. 2006-2007), 48 percent (Milwaukie, Wis. 2004), 24 percent (Fort Lauderdale, Fla. 2003) and at least 50 percent (National Healthcare for the Homeless Council). Of those, 70 percent occurred prior to becoming homeless in (Toronto), more than half occurred prior to age 20 (Boston), and the average age for the first TBI was 17 (Hamilton)[7].

VCU's Most Recent Study Highlights Additional Deficiencies

Finally, in January 2014, the **Virginia Commonwealth University Survey Evaluation and Research Laboratory (SERL)** published the VIRGINIA STATEWIDE ACQUIRED BRAIN INJURY NEEDS AND RESOURCES ASSESSMENT[8]. Approximately 600 brain injury survivors, family members/caregivers, and professionals/providers participated in a survey which documented current needs across the spectrum of care. The study found that providers were still more focused on the initial medical and acute rehabilitation needs of individuals, as opposed to creating treatment options in the community.

One concern uncovered by the study was that aging parents and relatives will become unable to provide supports to their disabled family member. For many individuals with TBI, there will be no fully formed system of community-based supports in place when this occurs. Highlights of the study include:

> Only 21% of brain injury survivors report working full time following their brain injury; 65 % were employed at the time of injury.

[7] *http://www.ipsnews.net/2011/06/us-brain-injuries-especially-invisible-among-homeless-part-ii/*

[8] *http://www.vadrs.org/cbs/downloads/SERLABIPresentationJan242014.pptx*

51% of caregivers reported that their family member needed help with daily living.

75% of caregivers were 50 or older, suggesting that, as the care givers age, there will be an increasing need for assistance to fill this gap.

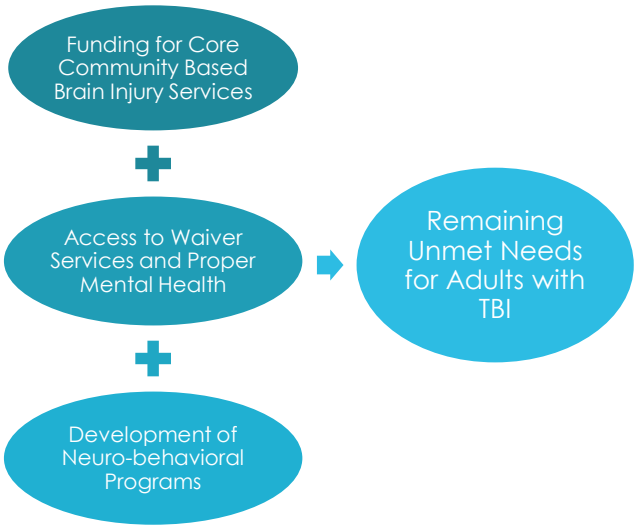
The majority of respondents had persistent problems with cognition (86%), behaviors and emotions (70%), physical (69%) as well as medical (66%), and communication disorders (55%).

In Summary

Over the last three decades, a vast amount of attention has been paid to identify and track the unmet needs of Virginians with brain injury and their families. Special attention has been paid to veterans with TBI, youth offenders with possible TBI, and those with neurobehavioral problems resulting from TBI. Lack of access to established services such as Medicaid waivers and local mental health services have prevented many from living successfully in their communities.

While the 2015 General Assembly session made modest but meaningful advances in addressing some of the key persisting issues outlined in this report (such as Medicaid reform, access to the DBHDS system, and increased services) no progress was made in addressing the large, urgent gap involving TBI neurobehavioral care. As seen in this report, addressing this significant problem will go a long way in avoiding the worst-case scenarios that often include placement in institutional settings, incarceration and homelessness.

Remaining deficiencies in the TBI service system were recently outlined in the annual PRIORITIES LETTER (ISSUED APRIL 15, 2015) prepared by the Virginia Brain Injury Council and submitted to the Commissioner of the Department of Aging and Rehabilitation Services. These needs are echoed throughout this report and are defined as follows:



In 1996 Congress passed the Traumatic Brain Injury (TBI) Act recognizing the vast array of services needed by individuals who survive a brain injury. The program is operated by the U.S. Department of Health Resources and Services Administration (HRSA) which funds Implementation Partnership Grants which focus on systems change, and since 2000, Protection and Advocacy Grants to facilitate the rights and entitlements of people with brain injury. Under the Protection and Advocacy for TBI (PATBI) grant all states have received allotments ranging from $50,000 to $117,000. States can use these grants to provide information and referral services, legal representation, training, and advocacy for individuals with brain injury and their families. The disABILITY Law Center of Virginia (dLCV) has been Virginia's recipient of these funds since 2003.

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Addendum

DARS Programs and Services for Persons with Brain Injury

Commonwealth Neurotrauma Initiative Trust Fund (CNITF) was established in 1997 to make available funds to Virginia-based organizations, institutions and researchers to address the need to improve the treatment and care of Virginians with traumatic spinal cord and brain injuries. http://www.vacni.org/historyandstatus.htm

The Brain Injury Services Coordination Unit (BISCU) serves as a point of contact for customers seeking general or agency-specific information about brain injury resources. BISCU manages over $6 million in programs, contracts, and federal grants involving brain injury services throughout the Commonwealth. http://www.vadrs.org/cbs/biscis.htm

Nine **State-Funded Brain Injury Programs** are located throughout Virginia that offer a wide variety of direct services including information and referral, pediatric and adult case management, life skills training, and club house programs that develop work skills and behaviors that support community and vocational re-entry. http://www.dars.virginia.gov/cbs/apps/outcomes/

Brain Injury Direct Services Fund (BIDS) provides short-term specialized services, assistive technology, and other equipment/goods to help individuals live more independently and move forward in their recovery from an acquired brain injury. The BIDS Fund does *not* pay for inpatient medical rehabilitation or any type of residential services. *BIDS funding is currently suspended.*

Community Rehabilitation Case Management Services (CRCMS) Program assists people with severe physical and sensory disabilities to build a quality of life of their choosing through self-direction, support, and community resources. CRCMS Rehabilitation Specialists provide individualized long-term case management to people across the Commonwealth, as well as outreach and support services to residents of nursing facilities. Many individuals with severe TBI make use of this important program. http://www.dars.virginia.gov/cbs/ltcrm.htm

Consumer-Directed Personal Assistance Services (PAS) Program for People with Brain Injuries is consumer-directed in nature and may be available to eligible individuals with brain injury who do not qualify for PAS from any other source. Individuals must have a representative to assist in management of the program. http://www.dars.virginia.gov/cbs/pas.htm

Wilson Workforce Rehabilitation Services/Brain Injury Services (WWRC) The Brain Injury Clinic at WWRC is a one-day outpatient service consisting of neuropsychological and physical medicine evaluations. Individualized service plans are developed that reflect findings and recommendations of these evaluations. http://www.wwrc.net/BrainInjuryClinic.htm