disABILITY LAW CENTER OF VIRGINIA

Protection & Advocacy for Virginians with Disabilities

Snapshot:
The State of Services for Virginians with Traumatic Brain Injury

Prepared by The disAbility Law Center of Virginia

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Executive Summary

Virginia fails to serve individuals with traumatic brain injuries and their families. In spite of years of studies and recommendations to create more robust community based services, Virginians with TBI cannot access needed services.

Core Community-Based Services are Insufficient

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

Despite three decades of brain injury systems advocacy in Virginia, comprehensive community based services are still lacking. Medicaid has yet to embrace this population, and people with complex behaviors must obtain rehabilitation outside of Virginia. If not obtained these individuals are at risk of ending up in nursing homes, psychiatric hospitals, jails or the streets which will potentially subject them to abuse and neglect common in these settings. The strain on these individuals, their families, and communities is enormous. The needs of war veterans with brain injury are also at stake. There is an abundance of needs assessments and reports that outline these complex issues. However, the statistics are a call to action not a mere assessment of the problem.

> There are likely 166,525 Virginians with long term disabilities resulting from a traumatic brain injury.
> (Based on CDC prevalence Rate of TBI in the United States)

The Department for Aging and Rehabilitative Services, the lead state agency and primary funder for brain injury services in the community, has consistently identified the following areas of community-based need for this population[2]:

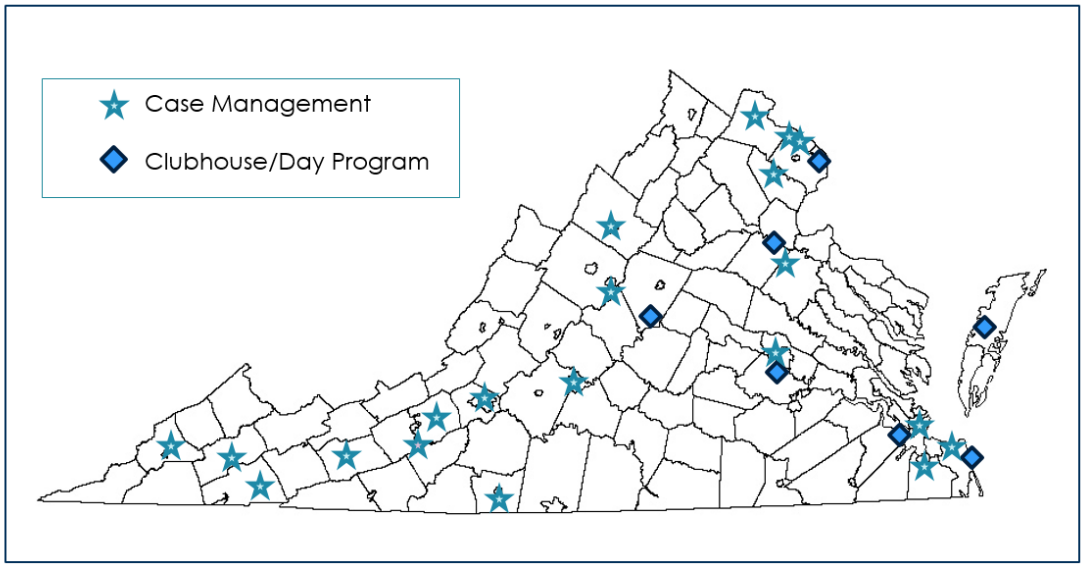
Information/Referral/Advocacy
Case Management
Individual/Family Supports
Education/Awareness
Social/Recreational/Peer Support
Residential Treatment
Community Living Services
Employment
Transportation, Day Programs

[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*

[2] *Brain Injury in Virginia State Action Plan 2009-2013: Full Report http://www.vadrs.org/cbs/biscis.htm*

In 2007 JLARC published an extensive report entitled ACCESS TO STATE-FUNDED BRAIN INJURY SERVICES[3]. This study found that, though community-based brain injury services have increased, the demand still far exceeds the availability.

> "Geography and service availability still limit access, and some needed services are not available. For example, Richmond area, Northern Virginia, and Roanoke have case management programs, clubhouse/day programs, and other services for persons with brain injury in the community. By contrast, individuals in Southside, the Northern Neck, and large parts of the Interstate 81 corridor from Winchester to Lexington have little or no access to community-based services a concern made more pressing by the number of military service members returning with TBIs." JLARC, SENATE DOCUMENT NO. 15



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

THE DARS 2014 ANNUAL REPORT OF STATE-FUNDED BRAIN INJURY SERVICES shows that in FY 2014:

Approximately 2,500 individuals received direct services such as case management, clubhouse or day programs, resource coordination, supported living, and support groups. About 1,500 individuals received consultation or information and referral.

While system capacity in existing programs has increased from about 1,000 individuals in 2007 to 4000 individuals in 2014, ***no new programs, particularly in the unserved areas of Virginia, have been created since the JLARC Study in 2007.***

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

This data suggests that, as of 2014, only a small percentage of Virginia's estimated 166,526 individuals with disabilities resulting from a brain injury are receiving community based services. Funding for core brain injury community-based services needs to be increased dramatically.

Reasons the System Fails for Individuals with Severe Brain Injuries

Often cognitive and behavioral complications result from severe TBI and require specialized treatment. A position paper on TBI titled NEUROBEHAVIORAL TREATMENT FOR VIRGINIANS WITH BRAIN INJURY (2010)[4] focuses on these unmet behavioral needs of Virginians with brain injuries. This report stresses the need to move away from skilled nursing facilities (SNF) or psychiatric hospitals to respond to the neurobehavioral needs related to brain injury. In addition to being restrictive environments these facilities lack physicians and personnel with expertise in brain injury rehabilitation. This report also outlined that the best practice in neurobehavioral care includes in-state residential treatment followed by the option of community-integrated group homes and community based supported living programs and services. This method supports the requirement of *Olmstead* and the Americans with Disabilities Act (ADA). However, what happened to one of dLCV's clients, John, is more common:

> John survived a brain injury from a car crash only to find himself in the middle of giant gap in TBI service in Virginia. He was prematurely discharged from the hospital despite persisting complex behaviors. Upon leaving the hospital he 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. His journey highlights the lack of a seamless service system so necessary for these individuals.

In 2014, the **Joint Commission on Health Care (JCHC)** reviewed progress in implementing recommendations from the 2007 JLARC STUDY. **Portia Cole, PhD, Senior Policy Analyst with the JCHC** reviewed the interim report's preliminary findings at the Virginia Brain Injury Council's October 2014 meeting and stated:

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

[4] NEUROBEHAVIORAL TREATMENT FOR VIRGINIANS WITH BRAIN INJURY, 2010 http://www.vadrs.org/cbs/biscu.htm

The report continued:

> "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."
> (Portia Cole, Ph.D., JCHC Senior Policy Analyst)

According to the Americans with Disabilities Act (ADA) on which Olmstead is based, services for individuals with disabilities should be provided in the most integrated and least restrictive setting. Virginia is out of compliance with Olmstead, and the ADA. This leaves Virginia open to legal action by the federal government and by private parties.

These concerns demand a rapid response to the 2015 Virginia General Assembly's mandate to require DBHDS to provide persons with TBI access to waiver services making services in the community possible. In addition, the 2015 General Assembly requirement for DBHDS to "allow individuals with acquired brain injury access to services for substance abuse disorders and drop-off centers" must be implemented soon. Additionally, restrictive Medicaid policies need to be addressed immediately to prevent more out-of-state placements.

THE 2012 VIRGINIA COLLABORATIVE POLICY SUMMIT ON BRAIN INJURY AND JUVENILE JUSTICE[5] addressed a long held assumption that there is a possible correlation between offender populations and undiagnosed brain injury[6]. The Summit report identified numerous studies to support this idea. In Virginia's study of 867 juveniles, over half of their participants (52.5%), reported a history of hitting or hurting their head. Timonen and colleagues (2002)[7] found in their study that TBI during childhood or adolescence increased the risk of developing mental disorders two-fold.

These disorders, in combination with cognitive impairment, can result in impaired impulse control and poor judgment often leading to criminal behavior, especially if these youth remain unidentified or untreated. The same is true for adults. Even mild injuries, which often go undiagnosed, can have long term cognitive and emotional deficits that require aggressive intervention.

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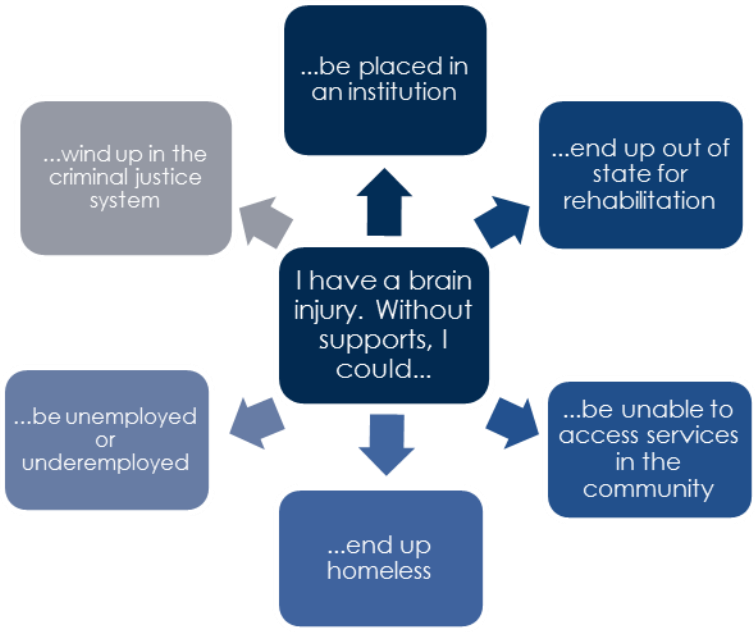
[5] *Virginia Collaborative Policy Summit on Brain Injury and Juvenile Justice: Proceedings Report (January 2013) Supported by Grant #H21MC06763-04-00 from the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB).*
[6] *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*
[7] *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.*

Another unacceptable outcome of TBI is homelessness. Increasingly studies are pointing to a high rate of TBI among persons who are homeless as compared to the general population.

Consider the possible outcomes for people with a TBI without appropriate supports:



Some Good News?

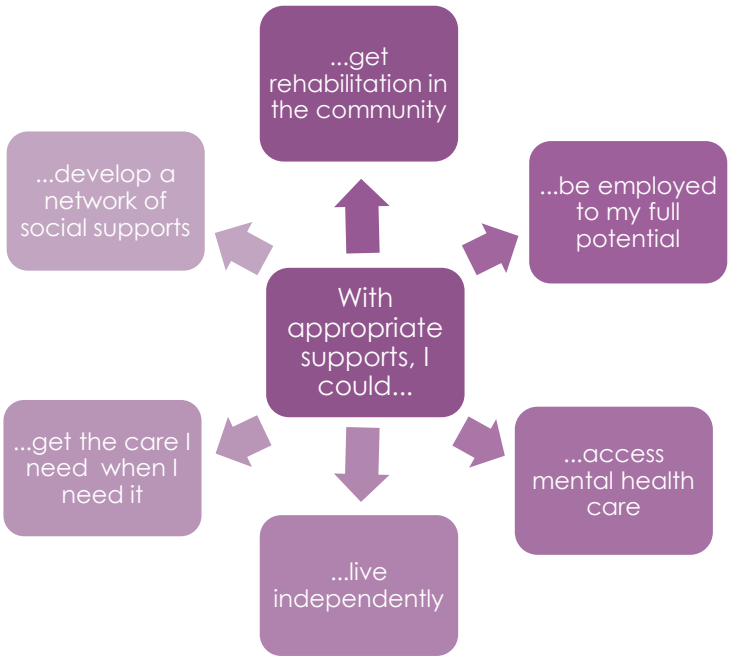
A positive outcome in Virginia's effort with juveniles has been the development of a Brain Injury Screening Tool by the Virginia Commonwealth University to reliably evaluate juveniles entering the DJJ system. Screening for TBI among youth in jails is important, but by this time it is too late. Systems change should be focused on early detection of TBI at all ages to initiate treatment with an aim toward preventing crime and time in jail, and other inappropriate institutional settings.

Failure to Provide Services has Consequences

Best practices in public policy, and compliance with federal law, call for fully funded services for Virginians with brain injury (who lack private funds) and that these services be provided in the least restrictive environment. The outcome for the individual, their family and the community is far more positive, far less expensive and in line with the Americans with Disabilities Act. The alternative is placement in expensive, ill-equipped institutions; greater long term dependence on public funding; possible homelessness, and a host of other social costs that have yet to be fully calculated. In addition, if changes are not made, then Virginia is placed at risk for ADA non-compliance.

Better Services Means Better Outcomes

Consider the possible outcomes for people with a TBI with appropriate supports:



In Summary

The three continuing unmet needs in serving adults with brain injury are: