THE NEUROBEHAVIORAL IMPASSE IN VIRGINIA

In two separate studies in 2007, the Joint Legislative and Audit Review Commission discussed the abysmal access to services faced by persons with brain injury who are experiencing cognitive, behavioral and psychiatric issues.

Their report, **Access to State Funded Brain Injury Services in Virginia** (Senate Document #15, 2007), stated "*Given limited resources, the State may want to consider addressing the needs of those with severe behavioral issues first if additional resources are allocated to this population. This segment of the population with brain injury is most likely to be at risk of placement in a skilled nursing home, local jail, local licensed hospital, or State prison or to not receive any services at all. There is virtually no system of care in the community for people with behavioral problems who do not have the financial resources to pay for private care.*"

The report entitled **Availability and Cost of Psychiatric Services in Virginia** (Senate Document #19, 2007), confirmed a general shortage of appropriate community based treatment options for persons with traumatic brain injury and that this population often faces difficulty accessing services. "*Licensed hospital staff reports that State hospitals will not accept these individuals...Some persons served by State mental hospitals in previous years are now deemed inappropriate for admission, although statutorily required regulations on State hospital admission have not been issued. As a result, local departments of social services, jails, and community services boards are responsible for these persons.*"

AGENCY ISSUES

Department of Medical Assistance Services:
There is no publically funded instate neurobehavioral treatment program, so the agency is routinely sending Virginians out of state to receive the treatment they need, fracturing families and spending twice the money that would be needed to treat them in state. DMAS estimates it would take $500,000 per year to operate a program similar to Brain Tree Manor (in Massachusetts) in a nursing home in Virginia, yet they (and the Department of Behavioral Health and Developmental Services) continue to send patients out of state. The agency has pursued but failed to secure implementation of a brain injury waiver; additionally, they have not relaxed licensure requirements that might provide funding to private in-state programs that can provide an appropriate level of care.

Department of Behavioral Health and Developmental Services:
Commissioner Jim Rothrock corresponded with Commissioner James Reinhard about the desire of the Virginia Brain Injury Council to establish a dialogue between the agencies about the challenges faced by persons with brain injury and psychiatric and substance abuse co-morbidities as they attempt to access agency and affiliated organizations' services. Commissioner Reinhard responded by requesting his agency

initiate a workteam, this was initiated June 2009, and we've had one face to face meeting and one phone conference since then. Recent changes at the Department have created new opportunities and Commissioner Stewart has delegated responsibility for this workgroup to John Pizzoli, Assistant Commissioner for the Behavioral Health Services Division.; it remains to be seen what actions are taken and created to address the discrimination individuals with brain injury face when trying to access services through the CSB's.

While it is understood that each CSB is governed by its local government and not the Department for Behavioral Health and Disability Services, DBHDS contracts, licenses, evaluates, and provides funds, guidance, and direction to the CSBs (obtained from the DBHDS website: http://www.dbhds.virginia.gov/documents/reports/OCC-CSB-Overview2007.pdf). Our hope is that DBHDS would use its role to acknowledge the discrepancy in services to individuals with brain injury and provide direction to remedy the inconsistent policies among the CSBs.

The Brain Injury Association of Virginia feels strongly that DBHDS needs to put in writing what they will and will not do for persons with brain injury, and disseminate that to DRS and BIAV, prepare written directives and disseminate them to all CSB staff reminding them of their mandate to serve any Virginian in crisis or with substance abuse issues, regardless of whether they do or do not have brain injury, and create more effective avenues for redress if those services are denied.

Community Services Boards:

The Brain Injury Association of Virginia and other brain injury service providers in Virginia have experienced several instances of brain injury survivors being refused evaluation and/or treatment from their local Community Services Board. This discovery is disturbing because 1) survivors of brain injury are not receiving proper support from the local professionals who are supposed to serve them, and 2) it highlights disability discrimination on the part of some local CSBs. The word "some" is used because a few CSBs are appropriately accommodating to brain injury survivors. However, the lack of a uniform policy leads the directive open to interpretation by local CSB directors and staff.

- A brain injury provider in Henrico attempted to get emergency services through the CSB for the client for nearly a year. Eventually they were able to get APS involved, who pulled some strings within the County to get a crisis worker out to do an assessment. Client was on the verge of death at this point and spent more than 2 months in the hospital as a result of her deteriorated physical and mental health. The provider argued quite vehemently with an emergency services worker with the Henrico CSB that they had a mandate to respond; CSB staff responded that the client's issues appeared to him to be the result of her brain injury, not mental illness, and that they didn't serve persons with brain injury.
- A brain injury provider in Wytheville was contacted by a client's mother and provided a copy of a letter she wrote outlining her plans to kill her son and herself. Staff contacted the CSB and met with two of the CSB staff who reviewed the letter, told the CM to go to the magistrate's office and initiate the TDO process, and then washed their hands of it.

- A brain injury provider in New River Valley told BIAV that St. Albans and the state hospital at Marion would not admit a client of theirs who was threatening himself and others; the CSB staff who worked with the client told the client he had two choices--go to jail or go home.

CROSS AGENCY INITIATIVES THAT ARE WORKING

Department of Education:
Activities focused on priorities identified during a strategic planning session in December 2009 are underway; they are to conduct a needs assessment to identify student needs and professional development needs; develop a guidance document about the appropriate conduct of evaluations by professionals trained in and/or specializing in traumatic brain injury; and to partner with PEATC, Parent-to-Parent and the Parent Resource Centers (PRCs) for development of information and training strategies for parents and families.

Department of Juvenile Justice:
DRS has, through the Commonwealth Neurotrauma Initiative Trust Fund, funded a study to investigate the incidence of brain injury among juvenile offenders; they have contracted with VCU's TBI Model Systems Program to work with Department of Juvenile Justice (DJJ) to address the needs of youth who are committed to the juvenile justice system, develop an effective screening tool for use by intake staff at DJJ, and provide staff training on appropriate treatment and intervention strategies.

Department of Veterans Services:
Representatives from DRS, BIAV and the Virginia Alliance of Brain Injury Services Providers serve as part of the Executive Strategy Committee for the Virginia Wounded Warrior Program. The focus of the committee is on strategic thinking and planning related to the care of our Commonwealth veterans and their family members, and the plan is to further expand and identify areas where we can strengthen partnerships on veteran issues. Specific attention is given to programs (coordination of programs serving veterans and families), resources (state, federal funding and grants), data (collection and sharing for data driven decisions, and research (joint funding of research projects, sharing of research findings for best practices).

CURRENT DISCHARGE OPTIONS FOR PERSONS WITH BRAIN INJURY EXPERIENCING NEUROBEHAVIORAL CHALLENGNES

Jail:
Helen Barbato's brother sustained a severe traumatic brain injury 2 years ago, and has been residing Norfolk area nursing homes since his discharge from acute care. In May, he was arrested at Sentara Nursing Home in Norfolk after threatening another patient. He was taken to the local jail, where he sat for over 3 weeks because the nursing home discharged him, there was no alternative placement available, and he could not return to his sister's home due to the increase in neurobehavioral issues and the vulnerability of

their elderly mother who lives with her daughter. The social worker at the Norfolk Jail told his sister it was likely that her brother would be released and basically be "on his own."

During the attempt to determine a discharge option, staff at DMAS suggested to Ms Barbato that Adult Protective Services APS be involved to assess the case and provide possible options. Eventually, he was seen by the pre-screener at the Norfolk Health Department and determined to still meet nursing home criteria. DMAS worked with the family and found another nursing home that would accept him. Luckily for Ms Barbato, this happened quickly; in some instances, case managers and/or family members must provide records to every nursing home in Virginia to find a placement, and if no facility will grant acceptance, then out-of state placement would be considered.

Out of State Placement:
Tommy was injured April 2007 in a car accident. After discharge, he lived at home for 7 months but the severe brain injury left him unable to care for himself and unable to control angry impulses. His mother was hurt several times as she attempted to care for him and everyone was affected by the strain. A nursing home placement worked in the beginning, but staff could not effectively deal with Tommy's agitation, even with medications that sedated him heavily; so they sought to move him and threatened to discharge him without any sort of discharge plan in June 2009. She was put her in touch with DMAS Long Term Care Unit, the long term care ombudsman for the facility, her State Senator and State Delegate, and after nine months managed to get him admitted to Brain Tree Manor, a nursing home in Massachusetts that specializes in neurobehavioral care for persons with brain injuries; he went there in March and as far as we know, he's still there.

Nursing Home:
In 2004, Richard had a horrible car accident. He was left with a severe traumatic brain injury and paralysis on his left side, but the issues that followed were much more involved than his wife Sharon ever could have imagined. He has bounced from one nursing home to another in an attempt to find the best treatment and care. Sharon reports he is currently in his ninth location because of a lack of appropriate, affordable, accessible and available treatment and long term living options for those with brain in jury in Virginia. An initial placement at a facility in Annandale was short lived because of behavioral issues. A stay in a King George County nursing home ended after Richard fell and broke his hip, an injury that went undetected for 6 weeks because he was unable to communicate his pain to staff members and they decided it was just a change in his mental status that did not warrant a work-up. A brief stay at a rehabilitation hospital in Richmond was followed by a new placement in a nursing home in Charlottesville. However, the staff at the facility was unequipped to handle the specific issues of a brain injury patient, and tried to have him arrested. Sharon worked with DMAS, who sent him to Brain Tree Manor. She states "Richard was there for two years. We had a hard time seeing him of course, and we estimate the state spent at least $1,000,000 on his case alone. At one point while he was there, there were at least 9 other Virginians receiving care at the same facility for the same reasons." Currently he is at a nursing home close to his family; while the nursing home does struggle at times to provide his

care, Richard and his family received treatment and nursing home staff received training that has improved the situation.

TWO DEATHS SINCE JANUARY 2010

Assisted Living:
Bobby sustained a TBI in 6/30/04 when he fell cleaning gutters. A quiet gentle person, he and his wife both taught at the local high school and were respected and active members of the community. After the injury, she cared for him at home for 5 years, despite exhibiting significant behavioral issues, that culminated in an attempt to choke their teenage daughter. Tammy had Bobby admitted to a local psych hospital and for a short time Discharge Assistance Program funding from DBHDS paid for a brief stint at the Lakeview program in Blacksburg. Upon discharge from Lakeview, he was transferred to an Assisted Living Facility about 1½ hours from their home. Tammy was deeply concerned about the care he received (or more accurately, did not receive). He was isolated from others – because his behavior was challenging, they left him in his room, only going in his room when they needed to. She often found him soiled from not having assistance with toileting, and questioned how often he was fed. Bobby died from neglect in this assisted living facility early this year.

Nursing Home:
On August 15, 2004, Elvin was 37 years old, working as a plant supervisor for a company in the Shenandoah Valley; he had employer provided health insurance, was paying his bills, and living his life like most of us do. On August 16, he was in a car accident, and sustained multiple fractures and a punctured lung; no cognitive or behavioral deficits were observed by his family at that time. One week later, he underwent surgery to repair his right lung, and ended up with an anoxic brain injury.

He was eventually discharged to a nursing home, because of the extent of his care needs and three years later, he was discharged to UVA because of an alleged infection, and the nursing home refused to take him back, saying they could no longer manage his behavioral issues. He was at UVA over 6 months because they couldn't find any placement for him; his treating physician at UVA called Lee Price at DMHMRSAS and was told he could not be admitted to a state institution because he had a brain injury. When they did find a discharge option, his niece was pressured to sign a release to send him to a nursing home 3 hours away with no experience treating brain injury (UVA staff threatened her with dropping him off on her doorstep). Once at the nursing home, numerous pleas to the nursing home staff from the family, APS and the long term care ombudsman for the facility to investigate his medical complaints were ignored. His behavior continued to escalate and his physical and mental condition continued to decline. DMAS finally agreed to send him to Brain Tree Manor; he arrived malnourished with aspiration pneumonia, and was immediately admitted to the hospital where he spent three weeks, eventually dying from inappropriate and negligent care from a nursing home in Chase City that lacked the capacity and had no business providing care to this man. Unbelievably, DMAS, having paid to send him there and agreed to pay for his treatment, would not pay the cost to return his body to his home.