

ANNUAL REPORT OF THE VIRGINIA DEPARTMENT FOR AGING AND REHABILITATIVE SERVICES (DARS)

Brain Injury & Spinal Cord Injury Services

For State Fiscal Year 2015-16

(July 1, 2015 to June 30, 2016)

HISTORY AND OVERVIEW

In 1989, the Department of Rehabilitative Services was designated in the Code of Virginia as the “lead agency to coordinate services” for individuals with physical and sensory disabilities, including people with traumatic brain injury. The General Assembly also appropriated the initial allocation of funding specifically designated for brain injury services in 1989: \$235,000 to Fairfax County for the development of a nonprofit organization to provide a continuum of state-contracted brain injury services in Northern Virginia (primarily case management). This resulted in the establishment of Head Injury Services Partnership (HISP), a nonprofit in Springfield, VA now called Brain Injury Services, Inc. DARS established the **Brain Injury Services Coordination (BISC) Unit**, which manages the agency’s specialized brain injury programs, services, and grants / contracts, in 1992, along with a full-time statewide brain injury coordinator position.

When the 2004 General Assembly appropriated new funding for brain injury services for State Fiscal Year (SFY) 2005 and 2006 in Item 327.4 of the Appropriations Act, it also directed that

“...the Department of Rehabilitative Services shall submit an annual report to the Chairmen of the Senate Finance and House Appropriations Committees documenting the number of individuals served, services provided, and success in attracting non-state resources.”

The information contained herein constitutes the **2016 Annual Report of State-Funded Brain Injury Services Programs** from the Department for Aging and Rehabilitative Services (DARS) to the Chairmen of the Senate Finance and House Appropriations Committees. The State Fiscal Year (SFY) 2016 allocation of state general funding for the statewide network of DARS-contracted Brain Injury Services (BIS) Programs was \$4,776,342, and provided direct services to approximately 4,270 individuals. The nine (9) organizations that contract with the Commonwealth of Virginia to operate 13 community-based programs for Virginians with brain injury brought in \$2.5 million in non-state resources, including cash and donated goods/services.

The brain injury advocacy community successfully garnered **\$750,000** in new funding for SFY 2016 (and a restoration of a FY '15 reduction). The new funding was allocated among three of DARS’ BISC Unit’s programs: *Personal Assistance Services for People with Brain Injury (PAS/BI)* program (↑ \$30,000 to \$107,639); the *Brain Injury Direct Services (BIDS) Fund* (↑ \$19,657 to \$175,000); and the balance was allocated to the statewide network of contracted *Brain Injury Services (BIS) Programs* (↑ \$700,343 to \$4,878,112) to facilitate expansion of core brain injury services, as well as enhance infrastructure.

LEGISLATIVE STUDIES

During this reporting year, the **Joint Commission on Health Care (JCHC)** completed its 2015 study on barriers and options to placement [treatment] for individuals with brain injury...and other conditions that can cause challenging and aggressive behaviors. This was in response to **Senate Joint Resolution 80**, which directed the Joint Legislative Audit and Review Commission to “*study the progress made by the Commonwealth in expanding access to brain injury services.*” DARS staff met with JCHC personnel throughout the process, provided requested information and data, and facilitated the access of JCHC to the Virginia Brain Injury Council, DARS’ network of state-funded BIS Programs, and other stakeholders such as survivors, family members, and caregivers. The JCHC recommendation most likely to be implemented is for relevant state agencies to enter into an agreement to coordinate statewide efforts; identify service gaps; develop priorities, an implementation plan, and a timeline for addressing service needs at all levels of care. DARS is committed to keeping stakeholders abreast of the study and invited JCHC to present periodically to the Virginia Brain Injury Council throughout the process.

In addition to the JCHC study noted above, the **Department of Medical Assistance Services (DMAS)** was directed via a 2015 legislative study to convene a state-level work group that addresses sharing data for the purpose of service provision, policy and program planning, especially in regard to neurobehavioral services:

Item 310 #5c: [DMAS], in collaboration with the departments of Behavioral Health and Developmental Services, Aging and Rehabilitative Services, and Health, shall convene a work group with community stakeholders to: (i) recommend methods to improve data capture on the annual incidence of brain injury, (ii) review expenditure data on Virginians with brain injury receiving care outside of the state, and (iii) evaluate options for providing for their care in the Commonwealth. [DMAS] shall report... recommendations to the Chairmen of the House Appropriations and Senate Finance Committees by December 1, 2016."

Advocates will likely recommend that the work group be continued, with a goal of developing a detailed implementation plan for meeting the neurobehavioral needs of people with brain injury.

In 2007, the **Joint Legislative and Audit Review Commission (JLARC)** completed a study of “access to brain injury services in the Commonwealth” <http://jlarc.virginia.gov/pdfs/reports/Rpt360.pdf>. DARS continues to adhere to the findings of this October 2007 report, which confirmed an ongoing need for specialized services for people with brain injury in the Commonwealth, particularly for those with significant impairments living in unserved and underserved areas. JLARC’s recommendations reinforce many of the ongoing policy agenda items of the Brain Injury Association of Virginia and the Virginia Alliance of Brain Injury Service Providers. The 2007 report also reflects concerns similar to those expressed by the Virginia Brain Injury Council, the statewide advisory body to the DARS Commissioner. Several of the JLARC recommendations were addressed and reported to JLARC in May 2008 (see <http://jlarc.virginia.gov/pdfs/reports/Rpt389.pdf> for the agency’s progress report on meeting the JLARC recommendations).

As the result of a JLARC recommendation, a Code of Virginia amendment eliminated the DARS Central Registry for Brain Injury and Spinal Cord Injury, effective July 1, 2008. The Code mandated that DRS work collaboratively with the Virginia Department of Health (VDH) to obtain information

from the **Virginia Statewide Trauma Registry** on patients treated for brain injury, for the purpose of conducting outreach. VDH has been extremely cooperative in working with DARS to achieve a consistent transfer of data for outreach and research purposes, but there have been ongoing challenges in assuring the accuracy of the data download. One of the major challenges this year was VDH's upgrading of the Trauma Registry from ICD-9 to ICD-10, a massive undertaking. Along with staff turnover issues at VDH, the upgrade to ICD-10 understandably caused a delay in addressing the bugs in DARS' data download. The agencies are currently working to resolve these issues and, in the meantime, DARS has been able to start addressing the backlog in the outreach efforts from the past year. DARS continues to work with VDH to enhance access to all of the brain injury related records in the Registry so that the agency can use the information to analyze data, anticipate trends, etc. DARS previously had access that was more comprehensive and is trying to get it re-established.

In its 2007 report, JLARC identified as a priority - and these remain a priority to date - the needs of returning soldiers and veterans living with brain injury; the incidence and needs of people with brain injury in the correctional system; and the enhancement of program monitoring and evaluation of DARS' state-funded BIS Programs. DARS' BISC Unit strives to comply with JLARC's recommendations to conduct a minimum of two program evaluations per year. During this reporting period, the BISC Unit was not fully staffed for nearly a year, which made it difficult to complete monitoring visits. DARS staff conducted an evaluation (programmatic and fiscal) of Brain Injury Services of Southwest Virginia (BISSWVA) in March 2016. This was not a comprehensive evaluation, as DARS had conducted one in 2014. However, since BISSWVA was recently awarded state funding to expand its services to Martinsville/Danville areas, DARS conducted a "soft audit" of the activities and funding related to services only in that area. No exceptions were noted.

NEUROBEHAVIORAL ISSUES

A critical issue highlighted in the 2007 JLARC report, and endorsed by all of the state-funded BIS Programs, as well as the Virginia Brain Injury Council and the Virginia Alliance for Brain Injury Services Providers every year (including 2016), is the need for specialized residential and community-based neurobehavioral treatment services for people with brain injury and challenging behaviors. Neurobehavioral issues often cause an individual to end up in the criminal justice and mental health systems, where effective, appropriate support is typically not available. As a last placement resort, sometimes individuals are placed in out of state facilities that have trained staff and environmental safeguards to deal with extremely challenging situations. (It is estimated that approximately 10+ individuals are housed in such facilities out of state, paid for with Virginia Medicaid dollars). When individuals with brain injury and behavioral health issues are in crisis (i.e., at risk of harm to themselves or others), they may be admitted to psychiatric hospitals if they can gain admission. Unfortunately, they are often stabilized with sedating medications and discharged back home or to a nursing facility, both of which are ill-equipped to handle the recurring behavioral and mental health challenges, creating a never-ending and disturbing cycle.

The Commonwealth Neurotrauma Initiative (CNI) Trust Fund awarded a one-year grant in SFY 2014 to James Madison University to develop a comprehensive reference document, "*Access to Neurobehavioral Services in Virginia*." This document, completed in late 2015, updated the Virginia Brain Injury Council's 2007 White Paper on Neurobehavioral Services. The report is a thorough look at neurobehavioral services in Virginia, including types of services, available funding, and potential

models implemented successful in other states. The report has been widely disseminated, was well-received, and has been cited by other professionals in Virginia and elsewhere. The authors have presented the results of the study, along with their recommendations, at three national / state conferences during SFY 2015 and 2016.

The urgent need for a range of specialized residential and community-based neurobehavioral treatment and services was again identified during SFY 2016 as a top priority by the Virginia Brain Injury Council in its annual “Priorities Letter” to DARS Commissioner James Rothrock. Appropriate short and long-term services to stabilize and support Virginians in their efforts to re-integrate into society are needed by many individuals across the Commonwealth. More data are needed to evaluate the effectiveness of residential treatment options, as well as short-term community-based life skills training and applied behavior analysis / positive behavior supports, when working with individuals with neurobehavioral concerns. One alternative discussed by advocates was to pursue funding for a 2-4 year pilot program offering residential treatment to a specified number of individuals with neurobehavioral issues, followed by long-term case management services that include specialized community-based behavioral intervention and supports. This would allow Virginia to make informed, cost-effective policy decisions based on empirical, qualitative data.

HISTORY OF FUNDING

In 1989, the General Assembly appropriated an initial allocation of \$235,000 in funding designated for brain injury services. Although funding for brain injury services has increased slowly since then, the most dramatic increase occurred during SFY 2005: a total appropriation of \$1.9 remains the single largest allocation of dedicated state funding for brain injury services in Virginia. No additional funding was allocated until SFY 2009, when \$200,000 was appropriated to strengthen the statewide infrastructure of the state-funded BIS Programs, enhancing their ability to operate on a daily basis. The next budget change occurred in SFY 2011 when a 5% reduction (\$191,050) was taken, and then restored in SFY 2012 via budget amendment, which added \$194,931 to the General Fund the second year to restore funding. No new funding was allocated for brain injury services in SFY 2013; in SFY 2014, the General Assembly appropriated \$105,000 to address existing wait lists.

In the latter part of SFY '15, DARS' BIS Programs were reduced by a total of \$122,124, necessitating minor cost cutting measures (e.g., reduced hours for staff, not filling a vacancy, limit travel). To their credit, the BIS Programs have all been creative in managing these periodic contract reductions, thus mitigating any harmful effects on service provision.

As noted earlier, the brain injury community was successful in requesting additional funding in SFY 2016: **\$750,000** in new funding was allocated for brain injury services (including restoration of FY '15 reduction). Of that amount, an additional \$700,343 (to \$4,776,342) was designated for the statewide network of contracted BIS Programs. Due to a late notification of the exact amount of the new funding allocation, along with lengthy delays in implementing revised state contracts (caused by staff turnover, multiple contract modifications which had to be done in a linear fashion, issuing a new Request For Proposals, etc.), DARS realized that the programs would not be able to expend \$300,000 (six months' worth) of state funds before June 30th, the end of the state fiscal year. To maximize the appropriate and expedient use of these state general dollars, DARS solicited input from all of the programs on any outstanding needs or wish lists for their programs. DARS staff then developed a dissemination plan

which was approved by Commissioner Rothrock and the 9 programs. DARS staff worked closely with the BIS Programs over a period of months to purchase needed supplies and equipment; to enhance physical accessibility of programs (i.e., installing an automatic door opener, replacing worn carpeting, a fall hazard, with linoleum); and to facilitate the purchase of three (3) accessible vans for clubhouse / day programs.

Since the *initial* allocation of state funding in 1989 (\$235,000) to the *current* level in 2016 (\$4,776,342), brain injury services funding has increased an average of only \$168,191 per year. A crucial attribute of the BIS Programs is that they have been very successful in bringing in non-state funding and resources: in SFY '16, the programs successfully brought in **\$2.5 million in non-state funding and resources**. As directed in the 2005 Appropriations Act, and as documented in this report, state-funded BIS Programs work hard to attract non-state resources that supplement state general funds which do not fully support operating costs. The additional non-state funding helps to relieve, but does not eliminate, wait lists and an inability to expand types of services or geographic areas served. As the cost of doing business continues to rise against a backdrop of level and decreased funding, several programs have reduced, or delayed filling, a number of staff positions.

Maintaining adequate funding to support the infrastructure of existing programs remains an ongoing challenge, and funds to create new programs that serve Virginians with brain injury remains a significant challenge. When companies are unable to offer cost of living boosts to staff over a period of many years, the result is that employees begin to look for better opportunities elsewhere. To that end, the Virginia Alliance of Brain Injury Services Providers (VABISP) is exploring a legislative option to grant a special designation to the BIS Programs; this allows full-time staff to receive cost of living increases whenever the state does. However, the Alliance recognizes that such legislation would likely not be passed given the state's current budget situation; therefore, further exploration will be deferred until budget is more stable.

CONCLUSION

The Centers for Disease Control estimate that anywhere from 2-10% of the population nationally is living with the effects of a brain injury. However, during a session at the annual conference of the National Association of State Head Injury Administrators (NASHIA), Dr. John Corrigan of Ohio State University / Ohio Valley Center on Traumatic Brain Injury presented research stating that current prevalence estimates should be closer to the upper end of 10%. It is estimated that over 300,000 people in Virginia have a need for some level of support and assistance due to disabilities caused by brain injury. Returning soldiers and veterans also continue to need long-term support services, as traumatic brain injury remains a "signature" wound of the Iraq/Afghanistan conflicts. In addition, the recent focus on sports concussions among former NFL players and in school sports means that more athletes and their families will be seeking information and services related to concussions and post-concussive syndrome.

The nine (9) BIS Programs reported approximately **200+** people on their wait lists during State Fiscal Year (SFY) 2016. The total amount of state funding for brain injury services in Virginia (\$4,776,342) – not including DARS' "in house" PAS/BI and BIDS Fund program - does not adequately meet the needs of a large number of unserved / underserved survivors and family members across the Commonwealth. In particular, there remains a critical need for an array of publically-funded residential

and neurobehavioral supports and services, as there are no options in Virginia that are affordable, accessible, and appropriate for the majority of individuals (no funding, do not meet eligibility criteria, etc.).

Nonetheless, DARS remains very pleased with how effectively and efficiently the contracted BIS Programs manage limited resources to provide quality services regardless of the economic climate - and even brought in significant amounts of non-state resources and funding. During FY '16, the BIS Programs brought in \$2.5 million in non-state resources which is reported in the following categories:

- Donations (*unsolicited*) / Contributions (*unsolicited*)
- Grants / Contracts (Federal / National, State, Local – public or private)
- Billable Services / Member Fees
- Annual Campaign (*solicited*) / Fundraising Activities (*solicited*)
- In-Kind Donation of Equipment/Supplies and Services (*reported as estimated dollar amount*)

DARS manages the **Brain Injury Direct Services (BIDS) Fund**, which was increased by \$30,000 in FY '16, bringing the total to **\$175,000**. Of that amount, **\$101,770** was provided to the nine BIS Programs for direct case services dollars. A total of **250+** individuals received specialized goods / services using BIDS funding, which includes people served through the individual BIS Programs, as well as those receiving BIDS support directly through DARS (which manages the balance of \$73,230). The BIDS Fund provides fiscal support for services and equipment that enhance an individual's ability to function more independently on a daily basis. BIDS, a "fund of last resort," is a critical resource for people with brain injury who have no other access to specialized services (e.g., neuropsychological evaluation, life skills training, emergency prescription assistance) or equipment (e.g., assistive technology, wheelchair repair/parts, adaptive computer tables).

DARS also administers a **Personal Assistance Services for People with Brain Injury (PAS/BI)**. In SFY 2016, the total amount of funding for this program was increased by \$30,000 to a total of **\$107,639** which now supports seven (7) individuals who require hands-on assistance to live successfully in community settings.

During FY '16, The BridgeLine organization, which operates BridgeLine Place clubhouse, was awarded accreditation by The Commission on the Accreditation of Rehabilitation Facilities (CARF). All BIS Programs, except two have achieved accreditation per contract requirements, and DARS is working with both programs toward this goal. Many programs, per DARS guidance, have been approved as vendors of "fee for services" such as Employee Development Services (EDS); Supported Employment Services (SES); and Community Support Services (CSS). This allows the programs to offer services to the larger community for a specified hourly reimbursement rate. Being a vendor of these community-based services also gives programs the opportunity to work with individuals who have Medicaid funding, thus expanding their revenue streams.

DARS looks forward to working with our community partners to continue improving services to Virginians with brain injury and their families in State Fiscal Year 2017.



TABLE A: NUMBER OF INDIVIDUALS SERVED / SERVICES PROVIDED

In SFY 2016, approximately **4,270** people received direct services (i.e., case management, clubhouse/day program, resource coordination, supported living, support groups and information / referral / consultation). Indirect services include number of people reached through public awareness / outreach activities, and media events (paper / on-line media, website hits, Facebook likes, Public Service Announcements, etc.) conducted by the programs. These events reach the general public; therefore, an exact number cannot be estimated.

NAME OF PROGRAM / SERVICE AREA	SERVICES PROVIDED	NUMBER SERVED
BRAIN INJURY ASSOCIATION OF VIRGINIA (BIAV) - <i>Statewide</i>	Information & Referral (I&R)	1450
	Professional Training	300
	Caregiver Services	515
	Camp (adult / adolescent overnight)	75
BRAIN INJURY SERVICES, INC. (BIS INC) <i>Northern Virginia, Fredericksburg, and Winchester Metropolitan Areas</i>	Case Management	435
	Clubhouse / Day Program	73
	Educational / Training / Conferences	60
	Caregiver Services	40
	I&R / Consultation	150
	Mental Health / Specialty Programs	140
BRAIN INJURY SERVICES OF SOUTHWEST VIRGINIA (BISSWVA) <i>Roanoke, Far Southwest, Martinsville/Danville</i>	Case Management	375
	Life Skills Training	10
	CLiC (on-line support program)	60
COMMUNITY BRAIN INJURY SERVICES (CBIS) <i>Richmond, Newport News</i>	Case Management	105
	Case Management: I&R	15
	The Mill House: Clubhouse	75
	The Mill House: I&R	15
	Denbigh House: Clubhouse	105
	Denbigh House: I&R	15
CROSSROADS TO BRAIN INJURY RECOVERY (CBIR) <i>Harrisonburg</i>	Case Management	50
EGGLESTON / BEACON HOUSE <i>Virginia Beach Metropolitan Area</i>	Beacon House: Clubhouse	45
	Support Group	30
NO LIMITS EASTERN SHORE (NLES) <i>Eastern Shore</i>	No Limits: Day Program	32
THE BRIDGELINE (TBL) <i>Charlottesville Metropolitan Area</i>	BridgeLine Place: Clubhouse	25
	Case Management	20
	I&R / Consultations	30
VIRGINIA SUPPORTIVE HOUSING (VSH) <i>Richmond Metropolitan Area</i>	Case Management	25
TOTAL NUMBER SERVED:		4,270

TABLE B: NONSTATE RESOURCES

During SFY 2016, the nine (9) state-contracted BIS Programs brought in an estimated \$2.5 million in nonstate resources and funding. This may include cash in the form of donations / contributions, grant funding, awards, etc., as well as in-kind contributions of volunteers. The table below shows the total amount of nonstate resources for each program in the following categories:

- Donations / Contributions (*unsolicited*);
- Grants / Contracts (Federal / State / Local, public/private);
- Billable Services / Member Fees;
- Annual Campaign / Fundraising Activities (*solicited*); and
- In-Kind Donation of Equipment/Supplies and Services/Personnel (*reported as estimated dollar amount*).

DONATION / CONTRIBUTION CATEGORIES →							
NAME OF PROGRAM / SERVICE AREA ↓	Donations and Contributions	Grants and Contracts	Billable Services and Member Fees	Annual Campaign and	In-Kind Donation: Equipment / Supplies Services / Personnel	CASH AMOUNT OR ESTIMATED VALUE	
BRAIN INJURY ASSOCIATION OF VIRGINIA (BIAV) - <i>Statewide</i>	31,899	170,500	91,989	58,634	33,297	\$386,318	
BRAIN INJURY SERVICES, INC. (BIS INC) <i>Northern Virginia, Fredericksburg, Winchester</i>		666,539	122,572	152,993	125,695	\$1,067,799	
BRAIN INJURY SERVICES OF SOUTHWEST VIRGINIA (BISSWVA) <i>Roanoke, Far Southwest, Martinsville/Danville</i>	27,057	262,774		57,821		\$347,652	
COMMUNITY BRAIN INJURY SERVICES (CBIS)	The Mill House <i>(Richmond)</i>	14,196	109,178	63,641	26,489	23,200	\$236,704
	Case Management <i>(Richmond)</i>	11,031	1,666		16,556	10,150	\$39,403
	Denbigh House <i>(Newport News)</i>	13,011	68,403	2,924	20,969	20,200	\$125,507

CROSSROADS TO BRAIN INJURY RECOVERY (CBIR) <i>Harrisonburg, Fishersville</i>	18,010	44,988	5,128	3,090	37,307	\$108,523
EGGLESTON / BEACON HOUSE <i>Virginia Beach</i>				51,555		\$51,555
NO LIMITS EASTERN SHORE (NLES) <i>Eastern Shore</i>	2,117			6,172	2,355	\$10,644
THE BRIDGELINE (TBL) <i>Charlottesville</i>	30,170		33,383	3,306	766	\$67,622
VIRGINIA SUPPORTIVE HOUSING (VSH) <i>Richmond</i>			107,448		6,114	\$113,562
TOTAL NONSTATE RESOURCES: \$2,555,289						