

# **COMMONWEALTH OF VIRGINIA** DEPARTMENT FOR AGING AND REHABILITATIVE SERVICES

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#### **MEMORANDUM**

TO:	The Honorable Janet D. Howell The Honorable George L. Barker Co-Chairs, Finance and Appropriations Committee
	The Honorable Barry D. Knight Chair, House Appropriations Committee
FROM:	Kathryn A. HayfieldKAHCommissioner, Department for Aging and Rehabilitative Services
RE:	DARS Brain Injury Services 2022 Annual Report

As the lead state agency for brain injury in the Commonwealth, the Virginia Department for Aging and Rehabilitative Services (DARS) is pleased to submit this 2022 annual report. When the 2004 General Assembly appropriated new funding for brain injury services for State Fiscal Years (SFY) 2005-06 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."

Please let me know if you have any questions regarding the report.



# **Brain Injury Services**

**Report to** 

Chairman of the House Appropriations Committee Co-Chairwoman and Co-Chairman of the Senate Finance and Appropriations Committee

> Virginia Department for Aging and Rehabilitative Services

Commonwealth of Virginia Richmond December 1, 2022

# **EXECUTIVE SUMMARY**

As the lead state agency for brain injury in the Commonwealth, the Virginia Department for Aging and Rehabilitative Services (DARS) is required to provide an annual report per Item 327.4 of the 2004 Appropriations Act documenting *"the number of individuals served, services provided, and success in attracting non-state resources."* 

In SFY 2022 nine state funded community based organizations provided support to 2279 individuals living with brain injury. This is a small increase over the previous fiscal year which saw a growth of 68%, despite the COVID pandemic. In addition to providing services to people living with a brain injury, these nine organizations have also seen a dramatic growth in the number of family members looking for information, resources, and their own support.

Currently 19% of Virginia counties and cities do not have any brain injury services at all. But in 2022 the General Assembly included three key budget items that will significantly expand services across the entire Commonwealth including:

- \$570,000 per year in new funding to expand brain injury case management to unserved areas of the Commonwealth.
- Medicaid reimbursement for brain injury case management as part of the State Plan for Medical Assistance beginning in SFY 2024.
- \$250,000 for DMAS to convene a workgroup to develop a plan for a neurobehavioral science unit and a waiver program for individuals with brain injury and neuro-cognitive disorders.

DARS is an active participant in the DMAS Workgroup designing Case Management and waiver services. DARS staff on the Workgroup include: Carolyn Turner, Director of Disability Services in the Division for Community Living; Chris Miller, Brain Injury Services Coordination Unit Director; and Joani Latimer, State Long-Term Care Ombudsman. Seven of the nine state funded brain injury services providers also participate in the workgroup. Chair of the Brain Injury Council Dr. Cara Meixner (Brain Injury Researcher/JMU Professor) and Council Secretary Dr. Kara Beatty (Brain Injury Survivor/Neuropsychiatrist) are also Workgroup members.

The Brain Injury Services Annual report includes additional detail on services provided, activities of the Virginia Brain Injury Council, and the focus of the most recent federal traumatic brain injury grant. Advances are being made in screening for brain injury across service providers including community service boards, domestic violence programs, and housing/homelessness agencies. Efforts are being made to improve the use and reliability of data to direct brain injury resources. Using the resources of Virginia's No Wrong Door/Virginia Navigator, more people with brain injury and their families can access online screening for brain injury and connect directly to local services.

#### **Program Background**

In 1989, the Code of Virginia (§51.5-9.1) designated the Department for Aging and Rehabilitative Services (DARS) "as the lead state agency for coordinating rehabilitative services to persons with functional and central nervous system disabilities [to include]... traumatic brain injury..." The Code further states that DARS shall provide for the assessment of the need for rehabilitative and support services for such persons, identify gaps in services, promote interagency coordination, develop models for case management, and advise the Secretary of Health and Human Resources, the Governor, and the General Assembly on programmatic, fiscal, and service delivery policies.

In 1989, the General Assembly made the first appropriation of \$235,000 in dedicated funding for brain injury services to Fairfax County. That funding has grown to \$9,538,487 in SFY 2023 and is distributed across nine community- based organizations around the Commonwealth.

Virginia has been a leader in supporting the needs of people living with brain injury and their families. The Commonwealth was:

- The first state to establish a brain injury state registry in legislation (1984).
- One of the first states to establish a state brain injury advisory board (1986).
- One of the first states to designate a "lead agency" (DARS) to coordinate services for people with traumatic brain injury (1989).
- Home to one of the longest standing Traumatic Brain Injury Model Systems program in the country which is based at Virginia Commonwealth University.
- Identified as one of the "Core 16" state traumatic brain injury grantees by the Federal Administration for Community Living (2016).

# **Understanding Brain Injury**

Acquired brain injury is the umbrella term for all brain injuries. Traumatic brain injury (TBI) is caused by an external force. TBI's are caused by falls, car and sports accidents, assault (shaken, abuse) gunshot, stabbing, or military actions. Non traumatic brain injuries are caused by internal factors like stroke/aneurysm, infection, seizure disorder, opioids and brain tumors.

Whatever the cause, brain injury affects the functional ability of the brain. The Centers for Disease Control (CDC) estimates that about 2% of the population has a disability due to a brain injury. However, it is believe that many brain injuries, especially those associated with repeated trauma or concussions may go undiagnosed. The Brain Injury Association of Virginia estimates that as many as 300,000 Virginians have a disability related to a brain injury.

Many people consider a brain injury as the accident which caused harm to the brain. It is often thought of as an "invisible disability" since brain injury survivors appear "normal" in appearance.

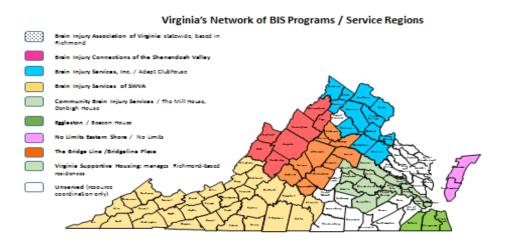
In reality, a brain injury is a chronic condition that has long lasting impact on the lives of the survivor and their family.

Living with a brain injury brings poorer health outcomes, decreased lifespan, and additional complications. For example:

- People 65 years and older die or are hospitalized for traumatic brain injuries more often than younger people in Virginia each year.
- Homeless individuals are more likely to have a brain injury than the general population.
- The rate of brain injury among incarcerated individuals is greater than the general population.
- Survivors of domestic violence often are undiagnosed for brain injuries incurred during their abuse.
- Ten percent of individuals in Virginia's trauma registry with a TBI had a co-occurring mental health issue at the time of hospital discharge.

#### **Brain Injury Services**

DARS manages a network of nine Brain Injury Services Programs across Virginia. The programs offer one or a combination of three "core services"; resource coordination, clubhouse / day program models, and specialized adult and pediatric case management. The map below reflects the areas of Virginia currently served by DARS' state-funded Brain Injury Services (BIS) Programs, as well as regions of the state which remain unserved. Currently nineteen percent of Virginia counties and cities do not have any brain injury services at all.



- *Case Management (adults and children):* determine individual / family needs, develop individualized service plans with personal goals, and identify supports and resources. Services may include in-home consultation and intervention, education planning, life skills training, and oversight of outsourced services.
- *Clubhouse/Day Program:* work-related and socialization activities in a supportive, therapeutic environment. Members / participants may receive limited case management with an individualized service plan that identifies personal goals and resources. These programs provide a venue for survivors to participate meaningfully while benefiting from an educational, vocational, and therapeutic social environment.
- *Resource Coordination:* outreach to Virginians hospitalized due to brain injury; information and referral; education / training; public awareness; and consultation and technical assistance for survivors, family members / caregivers, and professionals. DARS contracts with the Brain Injury Association of Virginia to provide this service statewide.
- *Consultation/Information & Referral:* Short term assistance provided to individuals with brain injury and/or their families seeking services and assistance without admission to one of Virginia's core services above.

Service	Number Served
Case Management	1258
ClubHouse and Day Support	305
Resource Coordination	980
Information & Referral	951
New Referrals	541

In SFY 2022, 2279 unduplicated individuals received brain injury services.

In the 2022 General Assembly special session, legislators approved amending the Medicaid State Plan to add Targeted Case Management for individuals with severe traumatic brain injury (HB 680) and appropriated \$1,718,823 in state general funds for the program. In August 2022 the Department for Medical Assistance Services (DMAS) convened a workgroup of stakeholders, including DARS and seven of the nine state funded brain injury service providers, to begin development of the program. Information on the activities of this workgroup can be found at <a href="https://www.dmas.virginia.gov/for-providers/long-term-care/programs-and-initiatives/brain-injury-services/">https://www.dmas.virginia.gov/for-providers/long-term-care/programs-and-initiatives/brain-injury-services/</a>.

Targeted Case Management will allow for Medicaid reimbursement of Case Management for individuals with severe traumatic brain injury when the service is provided by approved providers and appropriately trained and accredited staff. Targeted Case Management must be available state wide and should result in an increase in the number of provider organizations across the state, ultimately serving many more brain injury survivors.

Also in the 2022 special session, the General Assembly approved "... \$570,000 each year from the general fund to expand brain injury case management to unserved areas of the Commonwealth." The 2022 Appropriations Act in Item 330 L.5. requires when "allocating additional funds for brain injury services, the Department for Aging and Rehabilitative Services shall consider recommendations from the Virginia Brain Injury Council (VBIC)." In keeping with this requirement, the Virginia Brain Injury Council convened a Funds Dissemination Committee at their July 22, 2022 meeting. The Committee met August 25, 2022 and reviewed the budget amendment, the 2022 Virginia Brain Injury Council Priorities shared with the DARS Commissioner, and the recommendations of the nine state funded brain injury providers. Their recommendation was approved by the Virginia Brain Injury Council October 28, 2022 and was forwarded to Commissioner Hayfield. In accordance with recommendations of Funds Dissemination Committee these new funds will help to establish new brain injury case management providers in the latter half of SFY 2023 in the unserved areas of the Commonwealth which include the Northern Neck and Middle Peninsula, Rappahannock County, and Southern Virginia.

Together, these two appropriations will allow Virginia to take a huge step forward in providing service to those with the most severe disabilities caused by traumatic brain injury.

# **Funding & Resources**

State funded providers contributed 30% of total funding for community based brain injury services. In SFY 2022 state general funds totaled \$6,231,179 and providers secured an additional \$2,661,243 through fundraising, donations and other sources. The percentage of provider budgets coming from state funds ranges from 43% to 93% with larger organizations having more fundraising and other sources of revenue and therefore less reliance on state funds.

Brain injury service providers also used volunteers as a program resource. In SFY 2022 the state funded brain injury providers used 2989 volunteer hours valued at \$226,816. They also helped to develop the next generation of brain injury professional by hosting 25 interns for a total of 4728 hours. Interns generally are pursuing advanced degrees in social work, physical therapy or occupational therapy.

This year the General Assembly increased the appropriation for existing state funded brain injury providers by \$1.2 million for workforce retention, recruitment and capacity building. Providers used these funds in the following ways:

57%

- Increased salaries/wages
- Added new positions 12%
- Staff training 2%
- Other (Benefits, Equipment, Outreach) 29%

#### Virginia Brain Injury Council

The Virginia Brain Injury Council (VBIC) was established in 1986. Twenty eight members are appointed by the DARS Commissioner and include individuals with brain injury, family caregivers, service providers, other professionals, and citizen advocates. The purpose of the Council is to promote accessible, affordable, and appropriate services for Virginians with brain injury and their families by advising DARS, the lead state agency for brain injury in Virginia.

The Council is staffed by one of the three positions within the Brain Injury Services Coordination Unit which is part of the DARS Division for Community Living.

Council meetings are held quarterly on the fourth Friday of the month (January, April, July, October) and are open to the public.

**Establishing Priorities:** Annually the Brain Injury Council submits a letter to the Commissioner of the Department for Aging and Rehabilitative Services outlining priority areas for consideration by DARS.

The Priorities Committee identified three priority areas for the upcoming year:

#### 1. Assure brain injury services are available throughout Virginia.

The Council requested that DARS submit a budget request to expand Case Management to every area of Virginia.

The addition of new funding, Targeted Case Management, and a potential brain injury waiver by the General Assembly will achieve this objective

# 2. Coordinate data to consistently and accurately measure the availability of brain injury services throughout Virginia.

The Council requested that DARS engage partners, including the Brain Injury Association of Virginia, the Virginia Alliance of Brain Injury Service Providers, Virginia Commonwealth University's TBI Model Systems, and other external organizations, to share information and establish a system for consistently and accurately identifying areas underserved by case

management and other critical community-based services. The metrics established also should take into consideration diversity, equity, and social determinants of health. This process should be used to identify the availability of services to direct planning, program development, and to allocate future funding.

The Council is in the process of develop a Committee focusing on brain injury related data as follow up to a data sharing summit held in April, 2022. More information on the summit is available in the section regarding the Federal TBI Grant from the Administration on Community Living (ACL).

# 3. Continue support for the Council's Housing Workgroup.

The Council requested that DARS continue its support for and staffing of the Council's Housing Workgroup. The Committee has just begun its important work of exploring the complex network of housing and supportive services that we strongly believe are critical for individuals living with brain injury throughout Virginia.

The Council's Housing Workgroup is continuing its work and will present initial findings and recommendations to the Council in April, 2023.

**Council Membership:** Over the past year the Council has been working to establish a new membership structure that has at least 50% representation from individuals living with a brain injury. In part this is in response to a requirement from the Administration on Community Living (ACL) for all federal TBI grantees. But it also represents an ongoing goal of the Council to increase the engagement and voices of individuals with lived experience of brain injury.

A Committee made up of current Council representatives living with a brain injury reviewed many different structures that increase Council representation from 18% brain injury survivors to at least 50%. At their October 28, 2022 meeting the Council approved a revised membership structure.

The table below shows the changes from the current to the new membership structure. There are two key changes. First is the addition of new survivor members. Over the next three years the Council will add nine new members with brain injury to reach a total of 15. The other is transition of state agency representatives from full members without term limits to Advisors who will act as subject matter experts for the Council.

All potential new members are vetted by a Committee of the Council. Recommendations for new members are put before the Council in January of each year. Once approved, the slate of new member recommendations are presented to the DARS Commissioner for her approval. New members are inducted onto the Council in April of each year.

# Council Membership Comparison

Representative	Current #	Proposed #
Person who has sustained a brain injury/survivor of a brain injury	At least 2	At least 15
Family members/caregivers		At least 3
Licensed, registered, or certified healthcare professionals	At least 1	1
Individual currently affiliated with a hospital or healthcare system	At least 1	1
An individual who is not an employee or current member of the Board of Directors of an organization or program that receives state general funds appropriated by the Virginia General Assembly and administered through DARS for brain injury services		0
An individual who is an employee or current member of the Board of Directors of an organization or program that receives state general funds appropriated by the Virginia General Assembly and administered through DARS for brain injury services		0
<ul> <li>State Agency or Disability/Advocacy Providers</li> <li>Traditionally these have been state agency or community program</li> <li>representatives without term limits including:</li> <li>State agency representatives</li> <li>Other disability/advocacy providers</li> </ul>		0
<ul> <li>Other Representatives including:</li> <li>Individuals with a significant interest in the mission of the Council</li> <li>Individuals who work for State agencies and/or other disability/advocacy providers interested in the mission of the Brain Injury Council may apply but are not expected to represent the interests of their employer.</li> </ul>		7
<ul> <li>Standing Member Positions (permanent members/no term limit)</li> <li>Brain Injury Association of Virginia (BIAV)</li> <li>Virginia Alliance of Brain Injury Service Providers (VABISP)</li> <li>DARS Brain Injury Services Coordination Unit Director</li> </ul>		3
Commissioner Special Appointees (appointed by the Commissioner/have term limits)		0
Council Advisors (professionals working in state agencies appointed by the leadership at their agencies/serve to advise the Council as subject matter experts but are not members of Council)		As invited by Council

# Administration on Community Living TBI State Partnership Grant (2021 – 2026)

The Department for Aging and Rehabilitative Services (DARS) received initial federal funding under the national Traumatic Brain Injury (TBI) Act when the State Grant Program was established in 1998. DARS has since received five subsequent federal grants, most recently for the period August 2021 through July 2026.

The goal of the most recent grant is that Virginia achieve *A Comprehensive Coordinated Entry to Services and Supports* (ACCESS) for individuals with TBI and their caregivers through innovative practices and partnerships. Primary objectives include individuals with TBI will: 1) receive appropriate behavioral health treatment; 2) have a more direct route to person centered services and resources; 3) provide input into the direction of Virginia's brain injury services as the leading voices of the Virginia Brain Injury Council; 4) caregivers will have access to an expanded system of supports and; 5) have service development driven by accurate data and progress measured through data-based evaluation.

In implementing this grant DARS will partner with Virginia No Wrong Door/Virginia Navigator, the Department of Behavioral Health and Developmental Services, the Virginia Association of Community Services Boards, the Brain Injury Association of Virginia, and James Madison University.

Outcomes of the grant include:

- Pilot screening for brain injury in at least one Community Services Board and one DBHDS mental health facility.
- Increase Brain Injury Council members to at least 50% individuals living with brain injury.
- Increase resources related to brain injury for survivors and their families in Virginia Navigator including screening for risk of brain injury with links to brain injury resources for those who screen positive.
- Pilot a peer mentor program for caregivers of individuals living with a brain injury.
- Conduct a comprehensive needs and resources assessment to provide input into a state plan for aging and the next federal grant application.

Federal grant funding is \$200,179 annually which is matched by DARS funding of \$130,000 for a total of \$330,179 per year and a total of \$1,650,895 over the five year period.

# Virginia Brain Injury Data Sharing Summit

DARS continues work to develop an accurate and meaningful set of data to drive planning for brain injury services. Using data effectively to plan for and increase access to brain injury services is an important goal given that individuals with brain injury and their families access a

wide variety of services across state and community-based organizations. Data drives policy, funding, and services.

Research completed by Virginia Commonwealth University TBI Model Systems funded through the previous federal TBI grant confirmed the lack of comprehensive and connected data systems that can provide a full picture of brain injury in Virginia. Much of what exists is segmented by source. This trend exists nationally as well, as DARS staff have learned from other states while participating in the Administration for Community Living (ACL) TBI State Partnership Program workgroups.

To begin to address this issue, DARS convened a data summit to engage state agency partners to plan for data sharing on April 8, 2022. Twenty-three people from eleven different agencies participated.

Following small group discussions and share-out several themes emerged that will help focus DARS efforts moving forward.

Several themes came from the group discussions along with potential actions for addressing them.

- 1. To facilitate connections we need to know more about where people with brain injury are receiving services. Screening can be a key. Relationships have been developing among state and community agencies that can provide early successes with screening that may lead to further expansion in collaboration and data sharing. Two projects will be expanded or initiated that test the value of screening in identifying individuals with brain injury and connecting them to services:
  - The Brain Injury Association of Virginia (BIAV) Screen and Intervene Initiative with the Virginia Department of Health.
  - New funding for a screening initiative with Central Intake of Housing and Homelessness programs in collaboration with the Department for Housing and Community Development.
- 2. Finding intersections, connections, and commonalities will require understanding that individuals with brain injury do not "belong" to any one system. They are not "yours" or "ours" and in thinking of them this way we maintain fractures in the system and disrupt services to those we support. It also requires us all to learn the system that individuals with brain injury navigate. This will require a great deal of work as each state agency and system has high caseloads and pressures. Data gives us powerful information but sometimes we may need to rally around individuals one at a time to show what can be achieved through effective collaboration and/or to see things through their perspective.
  - Use the project ECHO model of case presentation and discussion to provide education and show opportunities for collaboration.

- Create a mechanism for interagency collaboration around individuals with brain injury facing system challenges that might be overcome through direct conversation/brainstorming.
- Map the service journey for individuals with brain injury. What do we learn? Where are the gaps, the dead ends, and the barriers?
- Use data to provide a clear picture of co-morbidities of individuals with brain injury and mental illness, substance use disorder, intellectual and developmental disabilities, housing insecurity, employment needs, and the impact of aging with brain injury and the risks of brain injury among older adults.
- 3. The work needs to be focused on specified outcomes. We cannot expect partners to participate in work that will not lead somewhere valuable. Once outcomes are defined, we will know what data we need. It will be difficult to do this because everything is important access to services, housing, transportation, quality of life. We now consider social determinants of health as a critical factor in assessing health quality, along with trauma, new technology, and other new trends that we have not yet even anticipated.

There is so much information available in the world today it is easy to become overwhelmed and miss what is important or to spend all our time filtering it that we do not get anywhere. We also need analysis experts in our midst to make sure that the conclusions we are drawing are accurate. Ultimately, this requires a plan that includes what we want to achieve and how to get there. Data for data's sake will not move us forward and could leave us stuck in one place.

- Identify specific goals and objectives for using data. This will drive what data we need to find and use.
- Use the recommendations from the data plan to identify worthwhile data sources.
- There are new sources of data that will be available through the statewide Information & Referral organization BIAV, through the developing partnership with Virginia's No Wrong Door which is expanding its brain injury resources, along with work across states, and through NASHIA to develop national initiatives.
- The VCU data plan recommends use of an "honest broker" to assist in collecting and analyzing data.
- Once we know what we want to do, use the data to tell compelling stores, both quantitatively and qualitatively.
- 4. The work that is done needs to be sustainable. With turnover in positions and leadership, a clear plan will help to assure that efforts continue. Partnerships and formal agreements need to be in place between organizations to assure they continue regardless of staff changes. What incentives or investments will be needed to make the work last through to fruition? We need to specifically plan for sustainability and anticipate barriers.

#### Conclusion

Virginia has been a leader in developing brain injury services and in SFY 2022 has taken positive steps to improve services for individuals living with brain injury and their families. The nine state funded brain injury service providers worked diligently during the COVID pandemic to maintain consistent and flexible supports for their constituents and have incorporated what they learned during this time into the services they currently provide. The pandemic brought to the forefront the needs of family caregivers, lack of affordable housing and supportive services for brain injury survivors, and the behavioral support needs that often lead people to have to seek services outside of Virginia. The General Assembly responded with Targeted Case Management and an evaluation of the costs and value of a brain injury waiver.

DARS continues to convene state agencies and community-based organizations that are realizing the prevalence of individuals with brain injury among their clientele. Increased screening, training for these service providers, and ready access to information and resources is helping them and the people they support.