



Cynthia O'Donoghue, Ph.D., and Cara Meixner, Ph.D., principal investigators

Elizabeth Roth Hawk Sanchez, M.A., co-author

Research Team

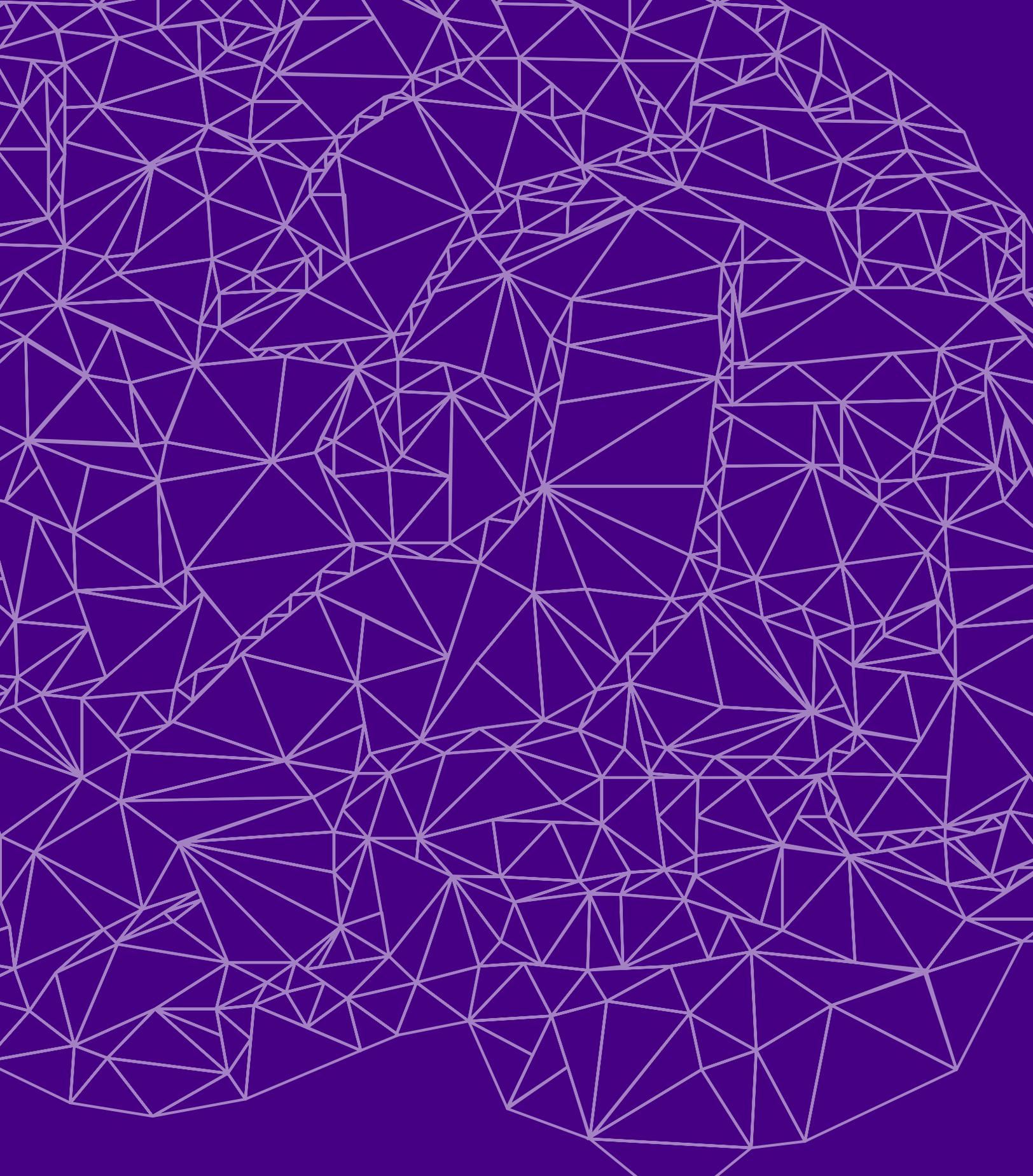
Janice Dean

Rachel Galloway

Caroline Barlow

Julia Teague





**Executive Summary:**

## Executive Summary:

This paper details the history, current state of affairs, and proposed initiatives for the Commonwealth of Virginia relative to neurobehavioral care for individuals following acquired brain injury. This work was supported through a Commonwealth Neurotrauma Initiative Trust Fund grant (CNI) with the charge to deliver a comprehensive, authoritative report on “Access to Neurobehavioral Services in Virginia.” The active grant period spanned from June 2014 through October 2015. The principal investigators utilized a mixed-methods research trajectory (i.e., both quantitative and qualitative approaches) to address this multifaceted issue.

The challenge of caring for individuals with acquired brain injuries has been a topic of concern for decades. This is not a situation unique to Virginia; it spans the nation. In order to examine this complex problem systematically, the research team conducted a comprehensive review of the literature, considered influential factors (e.g., the political landscape), attended to regulatory guidelines (e.g., funding, legal, etc.), inventoried model systems of care within the United States, surveyed care providers to assess statewide needs, and conducted interviews to expand upon survey findings.

An analysis of key data points serves to inform the recommendations for consideration provided in this report. Specifically, the factors include service provision in model states, cost data determined via a Freedom of Information Request (FOIA) to the Department of Medical Assistance Services (DMAS), and analyses of potential funding mechanisms (e.g., General Assembly appropriations, Medicaid waivers, etc.).

## Definitions

As directed for the scope of this work, *neurobehavioral and neurobehavioral needs* are defined as:

**Neurobehavioral:** the way the brain affects emotion, behavior, or learning (CDC, 2014a).

**Neurobehavioral needs [issues]:** the compromising cognitive, behavioral, and social changes that result from an acquired brain injury (ABI). Although neurobehavioral issues vary in duration depending on the severity of the injury, persons with both mild and severe ABI may experience changes in their thoughts and personalities and find everyday problem-solving difficult. Persistent neurobehavioral issues often lead to compromised functional abilities that limit an individual’s capability to engage in professional, social, and educational activities. These persistent compromises may increase risks of unemployment, government financial assistance, and incarceration. In addition, co-morbid mental health diagnoses that further complicate functional abilities and societal contributions are not uncommon for individuals with brain injury (Baddeley, 1986; DeGuise et al., 2008; Evans, 2001; Johnstone, Mount, & Schopp, 2003; Wood, 2001; Zasler, Martelli, & Jacobs, 2013).

## Incidence and Prevalence of ABI

The incidence and prevalence of acquired brain injury (ABI) in the United States is difficult to estimate, which complicates projecting numbers for neurobehavioral issues.

**Through an analysis of CDC and United States Census Bureau data, an estimated 106,000 Virginians, ages 18 to 65, are thought to have experienced a traumatic brain injury. In addition, 148,800 are estimated to have experienced a stroke. These data suggest that at least 254,400 adult Virginians live with an acquired brain injury.**

## Model States

There are many differences in how each state approaches the provision of neurobehavioral care. These variances are related to both the targeted point of care in the service continuum (i.e., acute, rehabilitative, community-based) and the financial mechanisms used to fund these programs. For this reason, this paper provides a detailed review of five states that serve as exemplars of care for individuals with physical, cognitive, behavioral, and psychiatric challenges following brain injury. No one program is considered to be the definitive course of action for Virginia; however, aspects from each of these programs inform recommendations and considerations.

---

## Current Costs

Expanding services through a more systematic approach for individuals with neurobehavioral needs will require financial resources. The issues of cost are mediated by the demonstrated cost of care evidenced in the data furnished through a Freedom of Information Act (FOIA) request. These data indicate that while costs per day are relatively stable when compared across years, the *percentage* of persons with brain injury served in Virginia skilled nursing facilities increased by 394% from 2011 to 2014. Furthermore, the data reveal that out-of-state placements are up to four times the cost of in-state placements though this may be attributed in part to differences in individual care needs. It is projected that as the system of care within the Commonwealth is improved, efficiencies that are gained will decrease both in- and out-of-state expenses.

---

## Potential Funding Mechanisms

Excluding Virginia, nearly half of the States fund services for individuals with brain injury through a Medicaid Home and Community-Based Services (HCBS) waiver (National Association of State Head Injury Administrators [NASHIA], 2015). In short, this allows for a waiver of federal law such that certain eligibility groups (i.e., persons with brain injury) can receive a combination of medical, rehabilitative, and other services in home and community-based settings under prescribed criteria. Some states use a HCBS waiver specific to traumatic or acquired brain injury while others combine multiple diagnostic groups into a single waiver. Waivers are funded through both federal and state dollars, providing economies of scale while maintaining cost neutrality against what would otherwise be spent on institutionalized care. Further, some waivers provide residential treatment options, or may be combined with exceptions to policy (ETP).

In addition to waivers, 23 states, including Virginia, have trust funds dedicated to funding necessary programs of care for individuals with brain injury (National Association of State Head Injury Administrators [NASHIA], 2014a). Many states have appropriations directed by the General Legislature to support these programs. The levels of states' appropriations are highly variable with an array of specified uses for the monies allocated.

---

## Survey Findings

In order to provide evidence-based recommendations that address statewide needs, a mixed-methods survey of organizations and agencies that provide services in Virginia was conducted via *Qualtrics*, an online survey tool. The participants were a non-random sample of brain injury professionals who were identified as individuals who could respond on behalf of their organization or agency. The participant list was compiled from organizations in Virginia that provide services to individuals with brain injury and whose contact information was either available or accessible (e.g., BIAV, DARS) via snowball sampling.

Organizational or agency representatives completed the survey with a robust 44% response rate. More than half (37/72) of the respondents indicated that their organization offers programs or services that are specific to individuals with neurobehavioral needs. Twenty-seven respondents estimated the number of annual *neurobehavioral needs* cases for which they provide service. Although the range varied greatly, responders reported serving an average of 158 cases to 161 cases annually.

Based on comprehensive findings from this investigation, the approaches to improving access to neurobehavioral services for individuals following acquired brain injury are grounded in a systemic change that emphasizes a continuum of care reliant upon interagency collaboration (the Department for Aging and Rehabilitative Services [DARS], the Department of Behavioral Health and Developmental Services [DBHDS], and the Department of Medical Assistance Services [DMAS]).

To address the unmet need for community-based and intensive neurobehavioral services for Virginians living with brain injury, it is necessary to coordinate an integrative system of care that addresses three primary areas on the continuum. Each component of the system should be considered when developing or expanding services. For instance, it is unreasonable to implement a 24-hour security unit for individuals in high-need neurobehavioral cases without also considering the role of education and prevention, transitional and supportive living, and crisis stabilization.

### 1. Prevention, education, and screening/identification

Lack of provider training and education is among the most critical barriers to individuals seeking appropriate care (Meixner, O'Donoghue, & Witt, 2013). Screening and identification are linked to the successes of prevention and education. The creation of a statewide diagnostic resource team comprised of representatives from the medical, mental health, and rehabilitative communities is necessary to serve these purposes. Models of screening and identification services already exist in Virginia. For example, DBHDS's *Regional Education Assessment Crisis Services Habilitation* [REACH] program is in existence to help provide crisis support services for individuals with intellectual and/or developmental disability.

Convenient, accessible, and cost-effective education may be offered through a variety of means. Mobile and virtual education are vital in strengthening individual and multi-agency systems of care. So as not to reinvent educational modules, it is recommended that the Commonwealth explore states that have implemented successful evidence-based practices.

Another CNI grant, the *Community Based Brain Injury Screening Initiative*, may prove instrumental in advancing screening measures. Having just commenced, this three-year scope of work entails the development of a brain injury questionnaire with educational materials and oversight of brain injury screening and training initiatives at eight service sites.

#### *Funding considerations for prevention, education, and screening/identification*

- Pursue allocation of General Assembly monies in addition to the ability to bill for services (i.e., REACH model).
- Seek external funding augmenting provision of Commonwealth monies (e.g., Health Resources and Services Administration grants).

### 2. Crisis stabilization in a 24-hour, secured unit

It is recommended that the Commonwealth pilot a small neurobehavioral crisis unit (i.e., 5-8 beds) in a public acute care adult psychiatric facility (e.g., Western State Hospital). Over time, the number of beds needed should be reevaluated based on accurate bed utilization statistics. A state psychiatric hospital appears the optimal choice for individuals at risk of harm to self or others. Such facilities are comprised of highly competent multidisciplinary teams that routinely diagnosis and treat severe behavioral issues.

This is a priority issue necessitating the support and collaboration of multiple state agencies, legislators, and providers. Individuals needing this high level of short-term care will have been referred by providers or through the work of an integrative crisis response system. Persons placed in a crisis prevention unit may or may not meet Temporary Detention Order (TDO) criteria – but will require step-down into a stabilization residence or re-entry into the community.

### *Funding models for crisis stabilization units*

- In a joint effort between DARS, DBHDS, and DMAS, pursue allocation of General Assembly monies in addition to the ability to bill for services.
- DARS, DBHDS, and DMAS need to collaborate to assess the feasibility of a waiver, either through a demonstration waiver, a supplement to a community-based neurobehavioral waiver, or an exception to policy (ETP).

### 3. Provision of short- and long-term residential and community-based supports

Model states employ a robust system of care for persons with brain injury that offer an array of residential and community-based supports – generally funded by a Medicaid waiver. This is advised for the Commonwealth of Virginia and ties to the previous two recommendations given the need for a system of supports that meets varied neurobehavioral presentations.

#### Residential Supports

While return to the community is ideal and coheres with federal legislation, some persons with neurobehavioral needs exist in a state of persistent crisis that necessitates long-term residential care. Those individuals in the Commonwealth who do not have access to long-term self-pay options or workers compensation are often placed in skilled nursing homes, where they remain vulnerable to neurobehavioral problems given the lack of coordinated, multidisciplinary supports. More often than not, persons with more severe neurobehavioral presentations are moved from one facility to the next, ultimately facing discharge, potential placement in out-of-state-facilities, incarceration, or death.

It is projected that a minimum of 25 neurobehavioral cases annually will require more long-term residential supports. This specialized care likely encompasses 24/7 supervision for safety and intervention for medications and therapies. Many complex, chronic neurobehavioral cases are managed in other states through contractual agreements with private providers; costs are wide-ranging.

#### Community-Based Supports

Persons with neurobehavioral issues often require supports beyond what is offered through case management and clubhouse programs, especially as they transition to the home from residential treatment. Likewise, their caregivers may need respite and in-home assistance services. As indicated in the literature, pharmacological, medical, rehabilitative, mental health and psychiatric, neuropsychological and psychological (e.g., behavioral analysis), vocational, educational, and other community-based supports are needed to care for those with brain injury. In particular, interdisciplinary approaches coordinated through intensive case management are optimal for individuals and their families both across the lifespan and through a recovery process that is typically non-linear.

States with robust community-based neurobehavioral programs are funded through waivers, which offer preventative care for persons with brain injury who are *at risk* for crisis and assure services for those individuals no longer in need of residential crisis mitigation or stabilization.

A waiver uses a person-centered case management approach to organize and fulfill needs in a cost-effective manner. Although the waiver application, approval, and vetting processes are lengthy, the Commonwealth should recognize its additional benefits – namely, the opportunity for seamless integration of services and an opportunity for federal matching funds.

*Funding model for the provision of short- and long-term residential and community-based supports*

- Establish a neurobehavioral brain injury waiver, exploring which type of waiver (e.g., 1115, 1915) best suits the needs of the Commonwealth. To develop a systems based model of care, DARS, DBHDS, and DMAS must be integrally involved.

Conclusions

Appropriately serving individuals in the Commonwealth of Virginia requires a holistic system that is designed to educate the community, mitigate crises, and offer crisis intervention services. Given the complexity of neurobehavioral symptoms, collaboration between the medical, rehabilitative, and mental health communities is required.

As first suggested by Virginia Senate Document Number 15, *Access to State-Funded Brain Injury Services in Virginia* (Joint Legislative Audit and Review Commission [JLARC], 2007), and the Virginia Brain Injury Council's 2010 report, *Neurobehavioral Treatment for Virginians with Brain Injury*, this level of system change is significant and therefore, complex. It will require financial commitment, labor resources, interagency involvement, legislative support and advocacy at all levels. The proposed approach merits consideration of the most viable components to effect improvements in accessing appropriate services, addressing issues in both accessibility and quality of care. **All findings of this study stress a compelling need for multi-agency, interdisciplinary neurobehavioral services provided across a system of care with responsiveness to individualized needs.**